



# Breast Cancer **PATIENT GUIDE**

 **WVUCancerInstitute**

## Important Phone Numbers

Betty Puskas Breast Care Center	304-293-7521 option 2
Emergency	911
J.W. Ruby Memorial Hospital	304-598-4000
Mary Babb Randolph Cancer Center	304-598-4500
Medical Center Pharmacy	304-598-4848
Medical Records (Ruby)	304-598-4110
Oncology Center (Ruby/9-West)	304-598-4091
Plastic and Reconstructive Surgery	304-293-3311
Radiation Oncology	304-598-4706
Surgery	304-293-1022
Triage	304-598-4500 or 1-877-427-2894
<i>(This line is NOT for emergencies. If you are having an emergency, please call 911, or go to your nearest emergency department.)</i>	
WVU Healthline	800-982-8242

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## INTRODUCTION

Designed to help you through your unique cancer experience, each section of this guide provides information, resources, and space to write down questions and notes. Please bring this guide with you to your appointments.

Each patient's treatment plan looks different to meet their individual needs, including pre-operative imaging, biopsy, consultations, and meetings. As a result, some of the sections may not apply to your care.

If you have questions about your health or the care you are receiving, please ask. The staff at the WVU Cancer Institute wants to make sure you understand your cancer diagnosis and treatment.

**Chemotherapy** - Treatment that uses medication to stop the growth of cancer cells by destroying the cells or by stopping them from dividing.

**Consultation** - A meeting to talk things over.

**Diagnosis** - The way a disease, condition, or injury is identified from its signs and symptoms.

**Endocrine** - Tissues that make and release hormones that travel in blood to control the actions of other cells or organs.

**Immunotherapy** - A type of therapy that uses substances to stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases.

**Pre-operative** - Happens before an operation or surgery.

**Radiation** - Energy used to treat some types of cancer.

## Your Healthcare Team

Over the course of your breast cancer experience, you will meet different members of your care team. Below you will find information about their role in your care. Depending on your treatment plan, you may also work with other types of healthcare professionals that are not listed here.

### **ANESTHESIOLOGIST**

An anesthesiologist provides medicine or other treatments to prevent or relieve pain during surgery and procedures.

### **ATTENDING PHYSICIAN**

The attending physician is responsible for your overall care in a hospital or clinic setting.

### **CARE MANAGER/SOCIAL WORKER**

A care manager (or social worker) serves as an advocate to help manage potential barriers to care and to connect patients with resources.

### **CLINICAL PHARMACIST**

Clinical pharmacists, specially trained in oncology, ensure safety in compounding, preparing, and dispensing chemotherapy and all other medications.

### **CLINICAL TRIALS RESEARCH NURSE AND SPECIALIST**

Many of our physicians are involved in clinical trials that assess new cancer treatments and therapies that advance cancer care. Clinical trials research nurses and specialists work with oncologists to assess eligibility, coordinate clinical trial protocols, and report outcomes.

### **DIAGNOSTIC RADIOLOGICAL TECHNOLOGIST (RT)**

An RT has advanced training to operate diagnostic equipment, such as magnetic resonance imaging (MRI), computed tomography (CT), or positron emission tomography (PET) scanners and mammography equipment.

### **DIETITIAN/NUTRITIONIST**

A dietitian (or nutritionist) helps a patient form healthy eating habits to improve health and prevent disease.

### **FELLOW**

A fellow has finished medical school and residency training in a general area of medicine and is currently training to learn more about a specific area of medicine, like oncology.

### **HEMATOLOGIST**

A doctor with special training in diagnosing and treating blood disorders.

**INFUSION NURSE**

Infusion nurses are registered nurses who have specialized training in administering chemotherapy and other cancer treatments.

**LICENSED PRACTICAL NURSE (LPN) AND MEDICAL ASSISTANT**

LPNs and medical assistants draw lab specimens; obtain temperature, blood pressure, pulse, height, and weight; update medical records; complete insurance forms; schedule appointments; and assist with admissions.

**MEDICAL ONCOLOGIST**

Medical oncologists are the primary healthcare provider for people with cancer. They coordinate your care and treatment, such as chemotherapy, hormone therapy, immunotherapy, and targeted therapy. They may also provide supportive care and coordinate treatment with other specialties, like radiation and surgical oncologists.

**NURSE PRACTITIONER (NP)**

An NP is a nurse with additional education and training in how to diagnose and treat disease. In cancer care, an NP may manage the primary care of patients based on a practice agreement with a doctor.

**OCCUPATIONAL THERAPIST (OT)**

An OT is trained to help people who are ill or disabled learn to manage their daily activities.

**ONCOLOGY NURSE NAVIGATOR**

Oncology nurse navigators are registered nurses who are specifically trained in cancer care. They work closely with your oncology team to coordinate and navigate your personalized care plan. They are available to answer any questions or concerns and ensure delivery of care.

**PATHOLOGIST**

A pathologist is a doctor who has special training in identifying diseases by studying cells and tissues under a microscope.

**PHARMACY SPECIALIST**

Oncology pharmacy specialists are Doctors of Pharmacy who have completed specialized residency training in clinical oncology pharmacy. These pharmacists work closely with each patient, the patient's oncology provider, and the clinical care team to ensure you receive the safest and most effective medication therapy.

**PHYSICAL THERAPIST (PT)**

A PT is trained to evaluate and treat people who have conditions or injuries that limit their ability to move and do physical activities. They also teach exercises and activities to help prevent injury and increase motion.

**PHYSICIAN ASSISTANT (PA)**

A PA is licensed to do certain medical procedures under the guidance of a doctor. They may take medical histories, complete physical exams, take blood and urine samples, care for wounds, and give injections.

**PRIMARY CARE DOCTOR**

A primary care doctor provides general healthcare and refers you to an oncologist for your cancer care. You may still see them for general healthcare while being treated for cancer.

**PSYCHIATRIST, PSYCHOTHERAPIST, AND PSYCHOLOGIST**

These are medical providers who treat patients with mental or emotional concerns.

**RADIATION ONCOLOGIST**

A radiation oncologist is a doctor who has special training in using radiation to treat cancer.

**REGISTERED NURSE (RN)**

An RN can give a patient their medication and provide care that has been ordered by a physician, nurse practitioner, or physician assistant.

**RESIDENT**

A resident works with an attending physician to receive more training in a specific area of medicine. They have completed medical school and their internship.

**SURGEON**

A surgeon is a doctor who removes or repairs a part of the body by operating on the patient.





## NOTES

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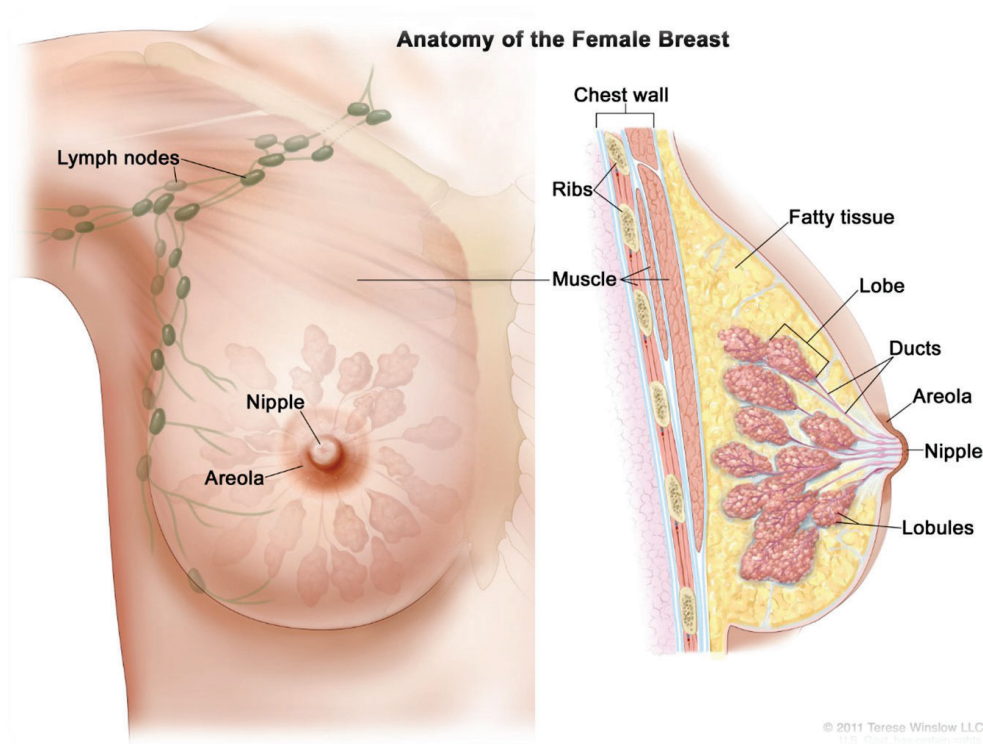
# What is breast cancer?

Breast cancer is a disease in which healthy breast cells change into malignant cells and grow out of control. These cells often form a mass called a tumor or cause deposits of calcium in the breast tissue called calcifications. The breast is made up of parts called lobes and ducts, which are surrounded by connective tissue and fatty tissue and include blood vessels, lymphatic channels, and sensory nerves. Each breast has 15 to 20 sections called lobes. Each lobe has many smaller sections called lobules. Lobules end in dozens of tiny bulbs that can make milk. The lobes, lobules, and bulbs are linked by thin tubes called ducts.

The nipple and areola are shown on the outside of the breast. The lymph nodes, lobes, lobules, ducts, and other parts of the breast are also shown.

Each breast also has blood vessels and lymph vessels. The lymph vessels carry an almost colorless, watery fluid called lymph. Lymph vessels carry lymph out of tissues and through lymph nodes. Lymph nodes are small, bean-shaped structures found throughout the body. They filter lymph and store white blood cells that help fight infection and disease. Groups of lymph nodes are found in the breast, in the axilla (armpit), above and below the collarbone, and in the chest.

The most common type of breast cancer is ductal carcinoma, which begins in the cells of the ducts. Cancer that begins in the lobes or lobules is called lobular carcinoma. Inflammatory breast cancer is an uncommon and aggressive type of breast cancer that causes the breast to appear warm, red, and swollen.



## Risk Factors

Anything that increases your chance of getting a disease is called a risk factor. Having a risk factor does not mean that you will get cancer; not having a risk factor does not mean that you will not get cancer. Risk factors for breast cancer include:

- A personal history of invasive breast cancer, ductal carcinoma in situ (DCIS), or lobular carcinoma in situ (LCIS)
- A personal history of benign (non-cancer) breast disease
- A family history of breast cancer in a first-degree relative (mother, daughter, or sister)
- Inherited changes in the BRCA1 or BRCA2 genes or in other genes that increase the risk of breast cancer
- Breast tissue that is extremely or moderately dense on a mammogram
- Exposure of breast tissue to estrogen made by the body, which may be caused by:
  - Menstruating at an early age
  - Older age at first birth or never having given birth
  - Starting menopause at a later age
- Taking hormones, such as estrogen, combined with progestin for symptoms of menopause
- Treatment with radiation therapy to the breast/chest
- Drinking alcohol
- Obesity

**Areola** - the area of dark-colored skin on the breast that surrounds the nipple

**Axilla** - the underarm or armpit

**Malignant** - cancerous

**Carcinoma** - cancer that begins in the skin or in tissues that line or cover internal organs

**Ductal** - beginning in the lining of the milk ducts

**Estrogen** - a type of hormone made by the body that helps develop and maintain female sex characteristics and the growth of long bones

**In situ** - in its original place; found only in the place where they first formed

**Progestin** - a female hormone

## Hereditary Factors

Genes in cells carry hereditary information that is received from a person's parents. Hereditary breast cancer makes up about 5-10 percent of all breast cancers. The majority (90 percent) of women with breast cancer do not carry a known mutation. The most common mutations that place patients at risk for breast cancer are BRCA1 or BRCA2, and these place women at a significantly increased lifetime risk of breast cancer.

Women with BRCA mutations also have an increased risk for ovarian cancer and possibly other cancers. Men who have a mutated gene related to breast cancer also have an increased risk of breast and other cancers.

There are tests that can find mutated genes. These are called genetic tests and are offered to patients with breast and other types of cancers. If a genetic mutation is discovered, then other members of the family can be offered testing to determine if they also have an elevated risk for cancer. In many cases, these tests are considered covered procedures by insurance companies. There is a law that prohibits discrimination in healthcare coverage and employment for people who are found to have a mutation that raises the risk for cancer.

## Testing Cancer Cells

Decisions about the best treatment are guided by results from testing cancer cells. The tests give information that suggest:

- How quickly the cancer may grow
- How likely it is that the cancer will spread through the body
- How well certain treatments might work
- How likely the cancer is to recur

You may hear your care team mention that they are waiting for results from the following tests:

- Estrogen receptor (ER) and progesterone receptor (PR)
- Human epidermal growth factor type 2 receptor (HER2/neu)
- Oncotype DX (genomic test or genetic testing of the tumor)

Based on these tests, breast cancer is described as one of the following types:

- Hormone receptor positive (estrogen and/or progesterone receptor positive) or hormone receptor negative (estrogen and/or progesterone receptor negative)
- HER2/neu positive or HER2/neu negative
- Triple negative (estrogen receptor, progesterone receptor, and HER2/neu are all negative)

**Genetic** - related to genes; genes are pieces of DNA, and most genes have the information for making a specific protein

**Hereditary** - passing of genetic information from parent to child through the genes

**Recur** - come back

## Factors Affecting Treatment Options and Recovery

The treatment options and chance of recovery depend on many different things, including:

- The stage of the cancer (the size of the tumor and whether or not it is in the breast only or has spread to lymph nodes or other places in the body)
- The type of breast cancer
- Estrogen receptor and progesterone receptor levels in the tumor tissue
- Human epidermal growth factor type 2 receptor (HER2/neu) on the tumor tissue
- Whether the tumor tissue is triple negative
- How fast the tumor is growing
- How likely the tumor is to come back
- A woman's age, general health, and menopausal status (whether a woman is still having menstrual periods)
- Whether the cancer has just been diagnosed or has recurred

## Stages of Breast Cancer

In breast cancer, stage is based on the size and location of the primary tumor, the spread of cancer to nearby lymph nodes or other parts of the body, tumor grade, and whether or not certain biomarkers are present.

There are three types of breast cancer stage groups:

**Clinical prognostic stage** - used first to assign a stage for all patients based on health history, physical exam, imaging tests (if done), and biopsies. It is described by the TNM system, tumor grade, and biomarker status (ER, PR, HER2). In clinical staging mammography or ultrasound, it is used to check the lymph nodes for signs of cancer.

**Pathological prognostic stage** - used for patients who have surgery as their first treatment. The pathological prognostic stage is based on all clinical information, biomarker status, and laboratory test results from breast tissue and lymph nodes removed during surgery.

**Anatomic stage** - based on the size and the spread of cancer as described by the TNM.

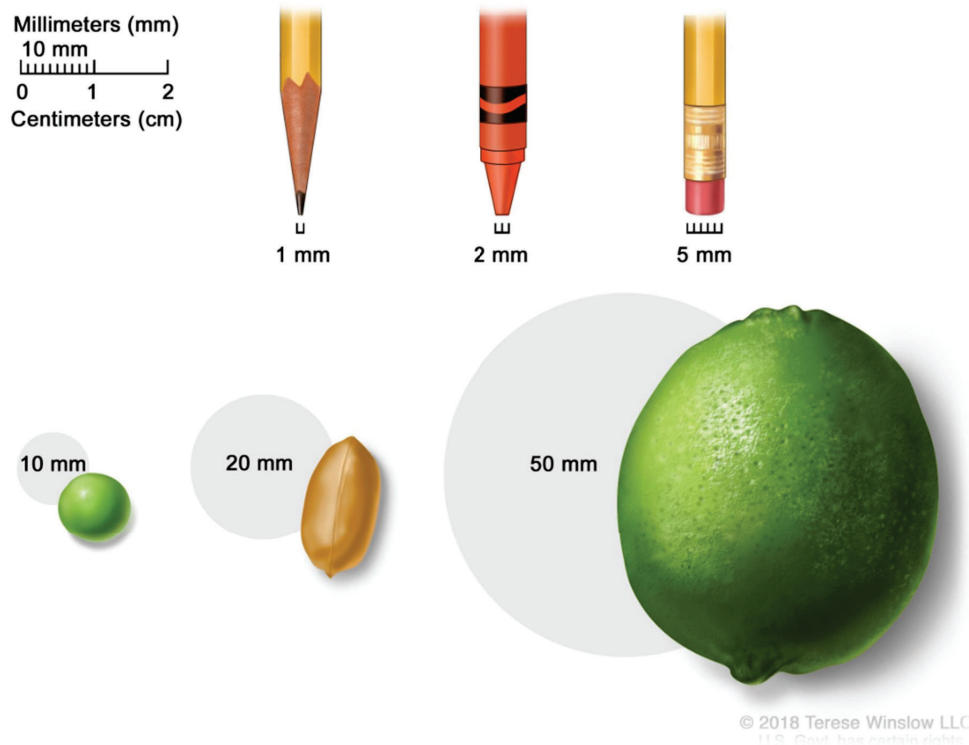
**Pathological** - based on how different cancer cells look from normal cells under a microscope

**Prognostic** - something that forecasts the likely outcome based on known information

## TNM (Tumor, Lymph Node, Metastasis) System

This system is used to describe the size of the primary tumor and the spread of cancer to nearby lymph nodes or other parts of the body. For breast cancer, the TNM system describes the tumor as follows

**Tumor (T)** - The size and location of the tumor is often measured in millimeters (mm) or centimeters (cm). Common items that can be used to show tumor size are shown in the picture below.



**Lymph Node (N)** - The size and location of lymph nodes where cancer has spread. When the lymph nodes are checked using mammography or ultrasound, it is called clinical staging.

**Metastasis (M)** - The spread of cancer to other parts of the body.

**Anatomic** - referring to the structure of the body system; used in parts of the world where biomarker testing is not available (not used in the United States).

**Metastasis** - the spread of cancer cells from the place where they first formed to another part of the body

## Grading System for Breast Cancer

The grading system describes a tumor based on how abnormal the cancer cells and tissue look under a microscope and how quickly the cancer cells are likely to grow and spread. To describe how abnormal the cancer cells and tissue are, the pathologist will assess the following three features:

- How much of the tumor tissue has normal breast ducts
- The size and shape of the nuclei in the tumor cells
- How many dividing cells are present, which is a measure of how fast the tumor cells are growing and dividing

## Biomarker Testing for Breast Cancer Receptors

Healthy breast cells and some breast cancer cells have receptors (biomarkers) that attach to the hormones, estrogen, and progesterone. To check for these biomarkers, samples of tissue containing breast cancer cells are removed during a biopsy or surgery. The samples are tested to see whether or not the breast cancer cells have estrogen or progesterone receptors. Another type of receptor found on the surface of all breast cancer cells is called HER2. HER2 receptors are needed for the breast cancer cells to grow and divide.

For breast cancer, biomarker testing includes the following:

- Estrogen receptor (ER): Breast cancer cells that have estrogen receptors are called ER positive (ER+). Breast cancer cells that do not have estrogen receptors are called ER negative (ER-).
- Progesterone receptor (PR): Breast cancer cells that have progesterone receptors are called PR positive (PR+). Breast cancer cells that do not have progesterone receptors are called PR negative (PR-).
- Human epidermal growth factor type 2 receptor (HER2/neu or HER2): Breast cancer cells that have higher than normal amounts of HER2 receptors are called HER2 positive (HER2+). Breast cancer cells that have a normal amount of HER2 are called HER2 negative (HER2-).

Sometimes the breast cancer cells will be described as triple negative or triple positive.

- Triple negative: If the breast cancer cells do not have estrogen receptors, progesterone receptors, and are HER2-, the cancer cells are called triple negative.
- Triple positive: If the breast cancer cells do have estrogen receptors, progesterone receptors, and are HER2+, the cancer cells are called triple positive.

# Finding the Stage of Breast Cancer

The staging of breast cancer can be complex because of all of the factors that need to be considered. Talk with your doctor about your stage of cancer and what it means for you.

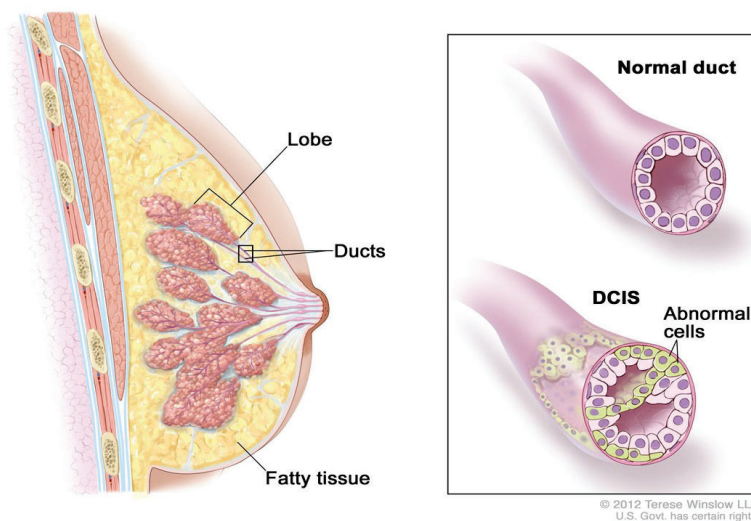
## Types of Breast Cancer

### Non-invasive breast cancer:

#### Ductal Carcinoma In Situ (DCIS)

Ductal carcinoma in situ (DCIS) is a noninvasive type of breast cancer and is found in the lining of a breast duct. The cancer cells have not spread beyond the duct to other tissues in and around the breast. In some cases, DCIS may evolve and become an invasive cancer and spread to other tissue. There is no way to know which cases of DCIS may become invasive.

#### Ductal Carcinoma In Situ (DCIS)



### Invasive breast cancer:

#### Ductal Carcinoma

Ductal carcinoma is the most common type of breast cancer. It begins in the lining of the milk ducts. In this type of ductal carcinoma, cancer cells have moved through the walls and outside of the breast duct to the surrounding normal tissue. It can spread through the lymph system to other parts of the body.



### **Lobular Carcinoma**

Lobular carcinoma is a type of invasive breast cancer that begins in the lobules of the breast and spreads to surrounding normal tissue. It can spread through the lymph system to other parts of the body. Lobular carcinoma-in-situ (LCIS), however, is not a malignancy but is a marker of elevated risk for developing breast cancer.



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### **Inflammatory Breast Cancer**

Inflammatory breast cancer is a rare form of invasive breast cancer. In inflammatory breast cancer, the cancer involves the lymphatic channels of the skin of the breast, which makes it appear red and swollen and feel warm. The skin of the breast may also show the dimpled appearance called “peau d’orange” (like the skin of an orange). There may not be any lumps in the breast that can be felt.

### **Recurrent Breast Cancer**

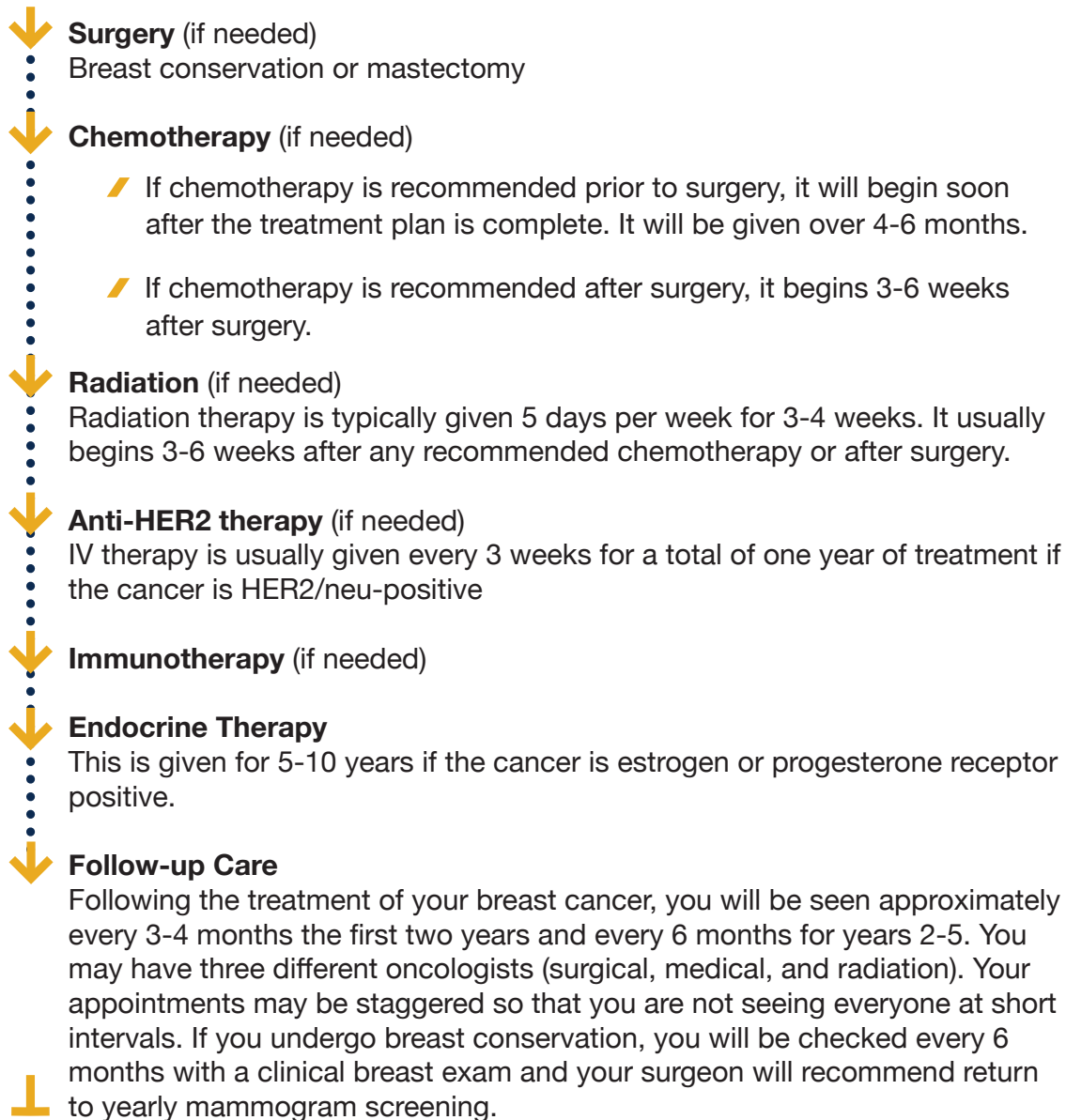
Recurrent breast cancer is cancer that has recurred, or come back, after it has been treated. The cancer may come back in the breast tissue or skin of the breast (local recurrence), chest wall, nearby lymph nodes (regional recurrence), or other sites in the body (distant recurrence or metastatic).

### **Metastatic Breast Cancer**

Metastatic breast cancer is breast cancer that started in the breast and has spread to other parts of the body. This type of breast cancer most commonly spreads to the bones, lung, liver, and occasionally the brain. It is not curable, but treatments are given to control disease. Some patients are able to live several years with metastatic breast cancer.

## General Timeline

Pre-operative imaging, biopsy, consultations, and development of a treatment plan.



Breast cancer is not a medical emergency, but it is often a psychological emergency. You will have time to gather all necessary information, obtain a complete breast imaging evaluation, and seek second opinions, if you wish. You need to make sure that you are comfortable with your physicians and your decisions before proceeding.

# Breast Cancer Treatment Worksheet

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Age: \_\_\_\_

## Diagnosis:

Invasive cancer	Invasive ductal	Invasive lobular	Other
Non-invasive cancer:	DCIS (Ductal Carcinoma In-Situ)		
Grade	1	2	3
Estrogen receptor (ER):	Positive	Negative	Pending
Progesterone receptor (PR):	Positive	Negative	Pending
Her-2.neu status (HER2):	Positive	Negative	Pending
Tumor (T):	Tx T4	T0	Tis T1 T2 T3
Lymph node (N):	Nx	N0	N1 N2 N3
Metastasis (M):	M0	M1	
Stage:	Pending		



## NOTES

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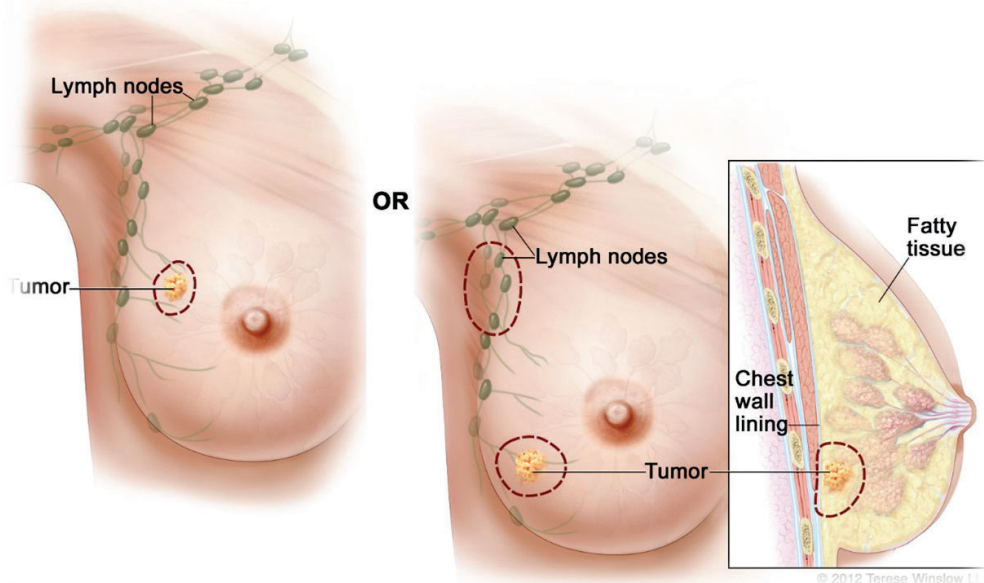
# SURGERY

Surgery is an operation to remove or repair a part of the body or to find out if a disease is present. It is also called an operation. Most patients with breast cancer have surgery to remove their cancer. There are different types of surgery.

## Types of Breast Cancer Surgery

### Breast-conserving surgery

This involves an operation to remove the cancer and some normal tissue around it, but not the entire breast. It is also known as lumpectomy, partial mastectomy, segmental mastectomy, quadrantectomy, or breast-sparing surgery. To be a candidate for breast conservation (“lumpectomy”), the cancer generally needs to be localized to one area of the breast and small enough to be completely removed and still maintain a reasonable breast shape and appearance. The components of breast conservation include the following:



### Lumpectomy

This procedure refers to the removal of the tumor with a margin of normal tissue (with pre-operative radioactive seed or wire localization, if not palpable). About 10-30 percent of the time, the margins are found to be positive on their final pathologic review and a second surgery is necessary to remove more tissue to clear the margins. The surgery is typically an outpatient (or same-day) surgery.

### Radiation therapy

Lumpectomy patients generally require post-operative radiation therapy (5 days per week for 3-4 weeks). This usually starts 4-6 weeks after your surgery, but if chemotherapy is needed, radiation will start after chemotherapy is finished. A consultation with a radiation oncologist will be arranged to discuss post-operative radiation therapy.

## Mastectomy

This is an operation to remove the whole breast that has cancer. Patients who have large cancers or cancer cells scattered over a large portion of the breast (in multiple quadrants) are not candidates for breast conservation. Radiation may not be necessary after a mastectomy unless certain tumor characteristics exist that require further local treatment (such as positive lymph nodes, very large tumors, or positive margins). Mastectomy options include:

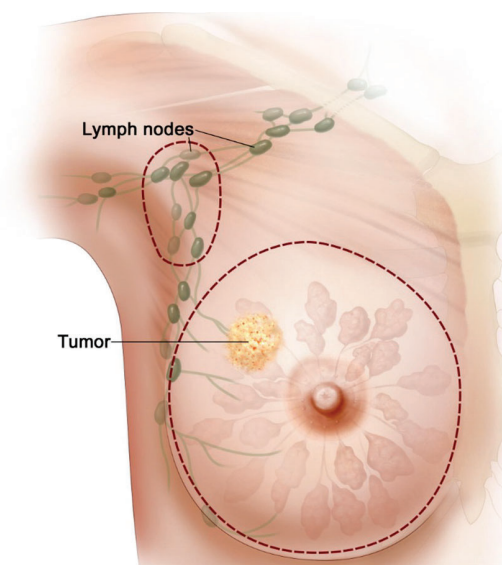
### **Skin-sparing mastectomy with immediate reconstruction**

The breast surgeon removes the breast (mastectomy) and usually some lymph nodes, and the majority of the breast skin envelope is preserved for reconstruction. The plastic surgery team then comes into the operating room and begins an immediate reconstruction. Options include inserting a temporary tissue expander into the space where the breast was, and this is followed by a permanent implant or an autologous tissue transfer (using skin or tissue from another area on your body) at a later time. If a tissue expander reconstruction is done, the patient usually stays in the hospital one night and goes home with 1-3 drains for 10-14 days. Your hospital length of stay is dependent on the type of procedure you have and will be discussed at the time of plastic surgery consultation. You will have a consultation with the plastic surgeon well before your surgery to hear information on your options and to decide the best plan.

### **Traditional mastectomy without reconstruction**

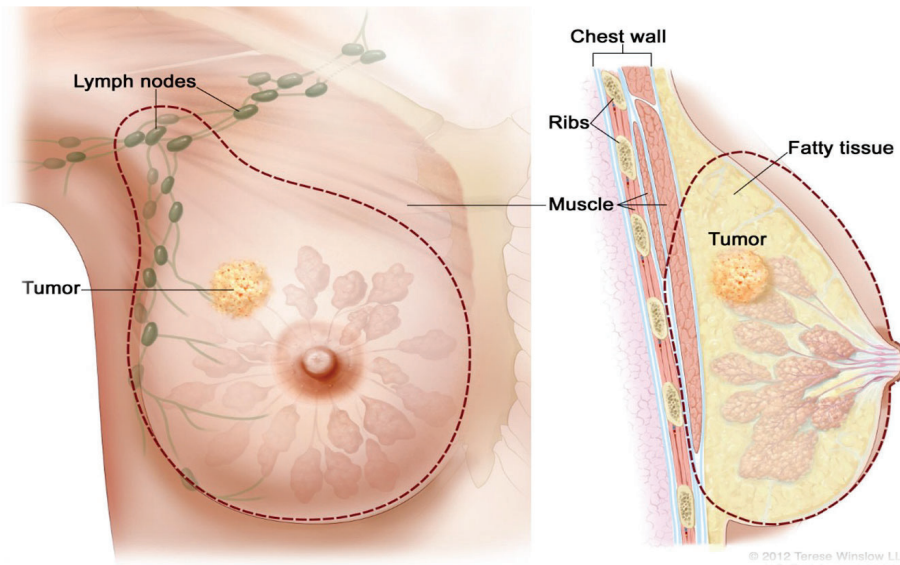
If a patient chooses this, the breast and most of the surrounding skin is removed, and the surgeon tries to make a flat chest on the side of the mastectomy. A prescription can be written for a prosthesis that fits inside a bra.

Reconstruction can be undertaken at a later date if the patient changes her mind, although a larger amount of breast skin will have been removed at the time of the original surgery and is no longer available for reconstruction. Patients usually spend one night in the hospital and go home with 1-2 drains in place for 10-14 days



## Modified radical mastectomy

This is an operation to remove the whole breast (mastectomy) that contains cancer and many of the lymph nodes under the arm (axillary dissection). The underlying muscle is not removed unless the cancer directly invades the muscle.



## Axillary staging surgery

### Sentinel lymph node biopsy (using blue and/or radioactive dye)

Sentinel lymph node biopsy is a procedure that removes the first draining lymph nodes in the armpit on the cancer side. This procedure is not necessary for most noninvasive cancers (DCIS) unless patients undergo a mastectomy. Typically, 1-3 sentinel nodes are removed from the armpit at the time of the breast operation. In many cases, the result on the lymph nodes is not known at the time of surgery, although sometimes the surgeon sends them to the pathologist for a rapid assessment. If the nodes are negative for cancer, no further surgery under the arm is necessary. If the nodes are positive for cancer cells, the patient may need a second operation (axillary dissection). The blue dye will turn the urine blue for approximately 24 hours after surgery and the patient's skin will appear paler than normal. This procedure carries a long-term risk of arm swelling (lymphedema) on that side of 5-10 percent.

**Autologous** [aw-tol-uh-guh s] - using the patient's own skin, fat, tissue, or muscle

**Axillary dissection**

This is the removal of the fatty tissue in the armpit region that contains additional lymph nodes. This operation is usually only done only if the sentinel lymph nodes are involved with cancer cells or if the patient has enlarged nodes at the time of diagnosis and surgery.

A drain is left in place under the arm to collect the fluid that is normal after surgery; the drain can be removed when the fluid output falls below 30 ml (1 ounce) in a 24-hour period. This procedure carries a long-term risk of arm swelling (lymphedema) on that side of up to 20-25 percent. The risk of motor nerve damage that could cause arm weakness occurs in less than 1 percent of patients.



## Pre-Operative Instructions

- Surgery will be scheduled by the surgical oncology scheduler. They can be reached at 304-293-1022. You will be contacted with details once a surgery date is confirmed.
- You will have a pre-anesthesia evaluation appointment made once your surgery is scheduled. Depending on your general health and age, you will meet either in-person or virtually with an anesthesia team member, who may coordinate additional studies – lab work, EKG, or chest X-ray may be needed. This is done in the days/weeks before your surgery to allow time to identify any problems that might raise your risk during surgery.
- Ruby Day Surgery Center staff will contact you the afternoon/evening before your surgery with your arrival time and any additional instructions regarding your surgery. The staff begins to make these calls to patients around 2pm. The staff will leave a message if you are not available.
- You are to have nothing to eat or drink as directed by anesthesia prior to your procedure. This includes the use of tobacco, candy, or gum.
- If you need to stop aspirin, Motrin, Advil, Coumadin, and Plavix or other anticoagulants seven days prior to surgery, please follow the instructions from your cardiologist or primary care physician.
- STOP all vitamins, herbs, and fish oil seven days before surgery.
- The day of surgery, report to the first floor of J.W. Ruby Memorial Hospital to register for surgery.
- Family members may wait with you until you go into the operating room. They will then be directed to the family waiting rooms until after surgery. Once your family arrives in the waiting area, have them check in with the volunteer. After your surgery, your doctor will come to the waiting area or call your family to discuss your condition.
- Call the Ruby Day Surgery Center (304-598-6200) and/or the Surgery Office (304-293-1022) if you are unable to report for surgery. Please let us know as soon as possible so that modifications can be made.
- You must have a responsible adult drive you home and stay with you for 24 hours in case there are any post-operative complications.
- If you have questions, please call 304-293-1022.



## Post-Operative Instructions

These instructions apply to patients undergoing breast biopsies, lumpectomies, mastectomies, and axillary lymph node surgery:

The following information is to help guide you in recovering from surgery. Everyone recovers differently, and other health conditions can affect this. Please use this as a guide, and speak with a healthcare provider about your questions and concerns.

### Activity

- You will need someone to drive you home after surgery.
- You will need someone to stay with you for 24 hours after surgery.
- If you only had a lumpectomy, you can drive 24 hours after surgery. If you had surgery to your armpit or mastectomy, you may drive after 2 weeks.
- The day after your surgery you can do most of your normal activities of the day. For one month, you should not do vigorous activity that might cause your breast to move too much or stretch the incision.
- After lumpectomy alone, you may return to normal activities, such as light housekeeping, walking, and stationary bicycling. After armpit surgery or mastectomy, for 3-6 weeks, you should not perform yardwork and housework, jog, push/pull, or participate in vigorous exercise. Examples of activities that are not recommended for one month are jogging, aerobics, horseback riding, heavy lifting, and repetitive pushing/pulling with your arm.
- You may begin your arm exercises after your post-operative appointment (typically 2 weeks after surgery).

### Wound Care

- A surgical bra will be placed at the end of your surgery to help minimize movement, swelling of the breast, and pain. You should wear this bra 24 hours a day (with the exception of showering) for 2 weeks or until your post-operative appointment. You may replace this bra with a compressive sports bra that clasps in the front if that provides better support.
- The gauze under the bra compressing your incisions should stay in place and be replaced when dirty with a dry washcloth or gauze for 2 weeks.
- Two days after surgery, you should remove the clear plastic dressing and white gauze that is over your incision. You should now be able to see your surgical incision, which will have either several narrow white steri-strips or purple glue overlying the incision. You may get the steri-strips or glue wet in the shower.
- Do not pick, peel, or remove the white tape or purple glue at any time. They will fall off after several weeks. You do not need any additional dressing over the incision.
- You may shower (not bathe in a tub or pool) as normal starting the first or second day after your surgery. Water may run over your incision. Do not

submerge your incision in water. Keep the incision clean and dry. You may pat your incision to dry; do not rub. Do not use any powder or lotion on your breast. Avoid deodorant under your arm for 2 weeks if you had armpit surgery.

- If you had axillary (armpit) surgery, you may have had blue dye injected into the breast. Your breast may appear blue, and you may have blue/ green urine for 24-48 hours, which will go away. Your skin tone may appear blue/ gray from the dye, which will also go away.

## **Pain**

- During surgery, the surgeon injected the breast with numbing medication, which will wear off.
- You should use ice (15 minutes on, 15 minutes off) on the surgical sites for the first 2 days after surgery and may continue after that if it helps with discomfort. Wrap the ice in a dry cloth, as your skin may still be numb. Do not use heat.
- Pain is usually mild enough that Tylenol (if you are not allergic) may be all that you need to take. You may take Tylenol as directed every 6x hours as needed for pain. Ibuprofen (Motrin, Advil) is also a good pain reliever after breast surgery (if you do not have ulcers or kidney problems).
- Your surgical team will use multiple modalities to help with postoperative pain. Many patients do not need prescription medication after breast surgery. Your surgeon will discuss with you whether or not you will need any additional medication.

## **Drain Care** (if applicable)

- The drainage is usually red when you first go home. This will change in color and become light cherry red, then amber, then yellow with clots or tissue sometimes in the tubing.
- You will see a black/blue stitch holding the drain tubing in your skin. Do not pull on the stitch. Keep the drain site/stitch at your skin covered, clean, and dry. You should strip the tubing from the drain and empty the drain bulb two to three times daily to prevent clogging. If the drain fills more than halfway, you may have to empty it more often.
- To strip the drain, start at the top of the tube next to your body and firmly pinch the tubing with your index finger and the thumb of one hand. With the other hand, also place the index finger and thumb on the tubing, slide your fingers down the tubing, and then release the hand. This will help move the drainage down the tubing.
- To empty the drain, wash your hands, uncap the pouring spout, and squeeze the contents of the bulb into the measuring cup. Do not touch the inside of the spout. Squeeze the bulb to create a vacuum and replace the cap while squeezing to maintain the vacuum.

- Measure and record the output and discard the drainage in the toilet. Record the amount each time you empty the bulb.
- When the drainage is less than 30 cc over 24 hours for 2 days, call 304-293-1022 to schedule an office visit to remove the drain.

**Signs and Symptoms of Infection**

Call if you experience any of these signs or symptoms:

- Increased redness or warmth at the incision
- Drainage from the incision that may be foul smelling, cloudy, yellow, or green
- Bulging or increased swelling at the incision
- Temperature of over 100.5 F
- Sudden increase in pain at the incision that is not relieved with pain medication

If you have questions or concerns, please call the Breast Surgery Office at 304-293- 1022. After hours, please call 800-982-8242 or 304-598-6100, or proceed to the closest emergency department.

**Please do NOT use MyWVUChart (patient portal) to message your surgeon about a wound problem**, as these messages may not go to the correct on-call surgeon and may not be seen in a timely manner. Any concerns about your surgical sites should be called in to the office during the day or the after-hours number listed on your discharge paperwork.

# Drainage Record

Name: \_\_\_\_\_ Date of Surgery: \_\_\_\_/\_\_\_\_/\_\_\_\_

[illegible]

## Breast Reconstructive Surgery

Many patients who have a mastectomy have the option of having the shape of the removed breast rebuilt. This is called breast reconstruction. There are several options for how this is done. Breast shape can be rebuilt using implants or using the patient's own tissue from somewhere else on their body. This process may be started at the time of the mastectomy or after the mastectomy incision has healed and breast cancer therapy has been completed. Sometimes, surgery on the remaining breast is offered ("symmetry procedure") so that the two breasts will look similar in shape and size. Breast reconstruction will not re-create how the breast felt or the exact look of your natural breast. However, the look of your new breast may restore a silhouette (appearance of a breast in clothing) that might be similar to what you had before your mastectomy.

### Things to consider for breast reconstruction

**Your emotional health** — Will losing part, one, or both breasts affect the way you view your body? Will it affect your sexual identity or body image? The way you feel about having breast reconstruction is unique to you.

**Your physical health** — Will your cancer treatment or other medical conditions affect your ability to heal after reconstruction? Do you have any medical conditions that may increase your risk of complications from surgery?

**Insurance** — The federal Women's Health and Cancer Rights Act of 1998 requires that insurance companies cover the cost of reconstructive breast and nipple surgery for women who have undergone a mastectomy. This law also covers a prosthesis for those who choose to delay or forego reconstruction. It also includes coverage for procedures on the uninvolved breast to improve symmetry. Be sure to ask your team about insurance coverage.

**The possibility of multiple appointments and surgeries** — Would you feel comfortable having to go through multiple surgeries in order to achieve the desired result? Reconstruction may require tissue expanders, revision after the initial surgery, nipple reconstruction, or other corrective surgeries.

**Scarring** — How will you feel about visible scars? Scars may be obvious on parts of the body where tissue was removed, as well as on the reconstructed breast(s).

**Future repair** — Many reconstruction options require revision over time. It is important to understand that reconstruction may take several surgeries to reach the desired result of a breast mound. There are limitations to reconstruction, and it is important to keep that in mind when evaluating the final result.

**Texture** — What will your reconstructed breast feel like? It can be helpful to talk to women who have had different types of reconstruction in order to understand what reconstruction options might feel like for you.

**Appearance** — If you have a single mastectomy, would you like to undergo more surgery to reshape the other breast to match the appearance of the

reconstructed breast with a lift, enlargement, or reduction? If you have a double mastectomy, would you want to have your breasts reconstructed to a new size and shape?

**Recovery** — Recovery from a mastectomy alone is often shorter than recovery from a mastectomy plus reconstruction. Would you be willing to go through the longer recovery time to have a reconstruction done at the same time as your mastectomy, or would you rather wait to have reconstruction at a later time?

**Loss of sensation** — Breast surgery alone will lead to change in sensation. Reconstruction will help restore the shape of your breast but not the sensation of a breast. Some sensation may return slowly over time, but sensation is greatly or completely diminished when the breast is removed.

### **Planning for reconstruction**

Based on your health and treatment plan, your breast surgeon may either suggest immediate or delayed reconstruction. Delaying reconstruction allows women to heal from cancer surgery before building a new breast.

Reconstruction may still be an option many years after breast cancer surgery.

**Immediate reconstruction** — The advantages of having breast reconstruction begun at the time of the mastectomy include the potential of having more breast skin to support reconstruction, because there is no surgical scarring or radiation damage in the area, unless radiation was given before surgery. It also means less surgery and exposure to general anesthesia and the ability to recover from the mastectomy and first phase of reconstruction at the same time. Additionally, changes to your physical appearance are not as dramatic if the breast reconstruction is started at the time of the mastectomy.

While immediate reconstruction can help alleviate the emotional impact of a mastectomy, it is not without risk. Even if you choose immediate reconstruction, it may require several surgical procedures to get the desired results. Immediate reconstruction also requires a longer surgery and recovery period. There is also the risk that you may need radiation after surgery, and this is likely to damage the new breast.

**Delayed reconstruction** — An advantage of delaying breast reconstruction is that it gives you the chance to focus on treatment. It also provides time to research reconstruction options. The disadvantage is living without a breast or breasts between your mastectomy and reconstruction surgeries. If this is a major concern, you should ask about a prescription for a temporary prosthetics.

While your surgeons may offer you breast reconstruction, you may choose to not have any reconstruction for your own personal reasons. It may be to get back to your life faster or because you feel it would be easier to live your life without a breast or breasts. This is a very personal choice and there is no wrong decision.

## Types of Reconstruction

There are four general types of surgery to reconstruct the shape of a breast. You may not be a candidate for all types of reconstruction. After you meet with the plastic surgeon, they can tailor your reconstruction depending on your desires and other medical conditions.

### 1. Use of an implant — a complex procedure performed by a plastic surgeon.

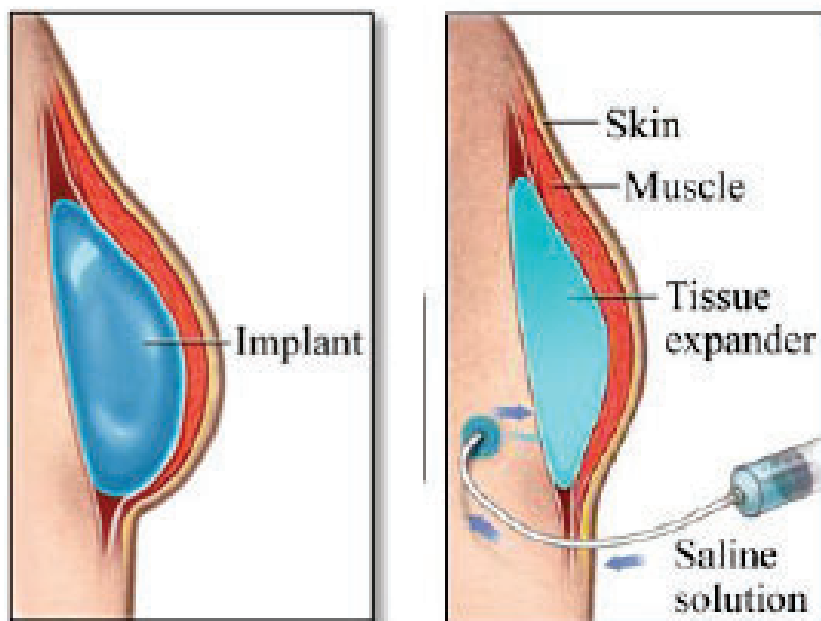
A direct implant is done in one stage. After the breast surgeon removes the breast, the plastic surgeon places an implant under or above the chest wall muscle depending on the type and location of the cancer and the judgement of the plastic surgeon.

An expander-to-implant procedure is done in two stages. First, a temporary tissue expander is placed under the skin and muscle into the space where the breast was removed. Saline is injected into the expander at the time of the procedure and gradually over the next few weeks to up to six months. The expander may feel tight or hard while it is being filled. When the breast area has stretched adequately, a second surgery is performed to remove the expander and replace it with a permanent implant.

Fears about silicone leakage has led the U.S. Food and Drug Administration (FDA) to evaluate breast implants. The FDA has determined that most silicone implants are safe for both reconstruction and cosmetic reasons.

You should feel free to ask your surgeon about any concerns you have about implants.

Implants will likely need to be replaced at some point in your lifetime. They can leak or tear, cause an infection, or develop scar tissue. Your plastic surgeon will help you manage these problems



Breast implant-associated anaplastic large cell lymphoma (BIA-ALCL) is a rare lymphoma that has been found in patients who have certain types of breast implants that have now been removed from use as mandated by the FDA. This is usually detected when a large amount of fluid accumulates around an implant, often years after it has been placed. The treatment is to remove the implant and its capsule.

Characteristic	Saline Implant	Silicone Implant
Components	Silicone shell filled with salt water	Silicone shell filled with silicone gel
Incision required	Shorter: implant is deflated when inserted	Longer: implant is full when inserted
Interior substance	Filled by surgeon during operation	Pre-filled by manufacturer
Rupture	Obvious	May be undetected
Follow-up recommended	MRI screening if a rupture is suspected	Periodic MRI screening

**2. Use of tissue from another part of your body** — may also be called reconstruction with a tissue flap or autologous tissue reconstruction.

This procedure uses tissue from your abdomen, back, thighs, or buttocks to rebuild the shape of a breast.

Tissue flaps behave more like your own body than implants, shrinking or expanding with changes in your weight.

This procedure results in two scars, one at the breast and the other where the tissue was removed, and longer recovery time.

While breast implants sometimes need to be replaced, this is not a concern with tissue flaps.

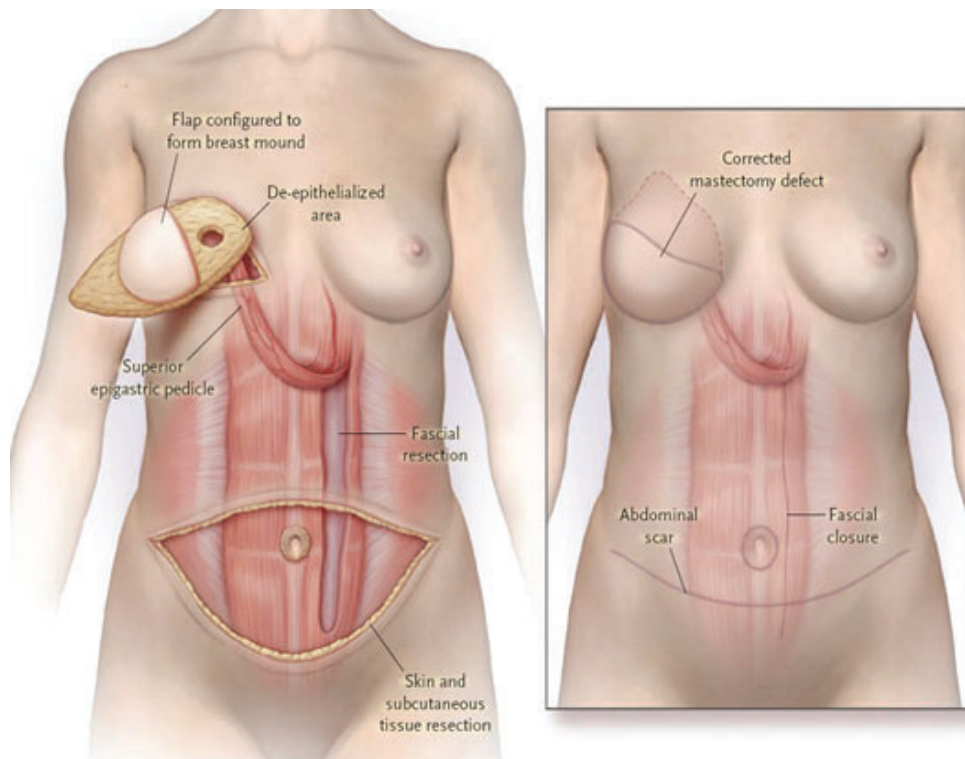
Tissue flaps are often used by themselves to reconstruct a breast, but some tissue flap procedures may additionally require a breast implant to achieve the desired shape or size.



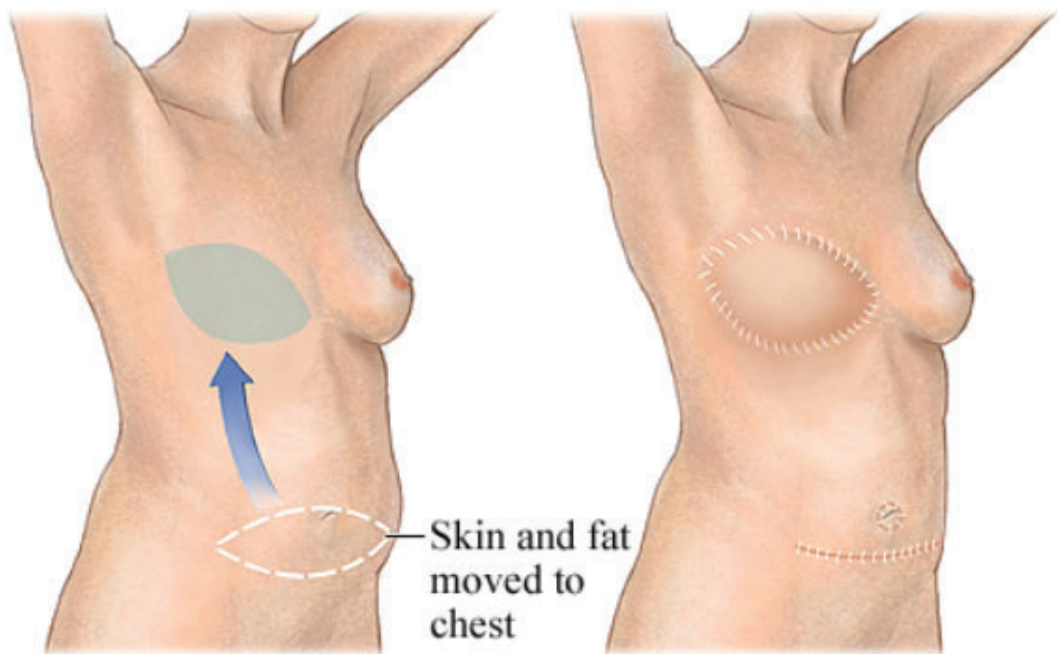
**3. Use of an implant and tissue from another part of your body** — There are several types of tissue flap procedures.

Name	Description
Lateral thoracic artery perforator flap	Uses excess tissue from your axillary area to help supplement the breast contour and give a better shape with an implant
Transverse rectus abdominis muscle (TRAM)	Flap uses tissue from the abdomen, including skin, fatty tissue, and muscle
Deep inferior epigastric perforator (DIEP)	Flap uses tissue from the abdomen, including skin and fatty tissue
Latissimus dorsi muscle	Flap uses tissue from the upper back abdomen, including skin, fatty tissue, and muscle
Gluteal artery perforator (GAP)	Also known as a gluteal free flap, uses tissue from the buttocks and abdomen, including skin and fatty tissue
Transverse upper gracilis (TUG)	Flap uses tissue from the inner thigh and abdomen, including skin and fatty tissue

## TRAM



## DIEP



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**4. Oncoplastic surgery** — rearrangement of your own breast tissue after a lumpectomy and a symmetry procedure on the unaffected breast (if needed).

This surgery is appropriate for women with large breasts who desire a decrease in size at the time they have a lumpectomy to remove the cancer.

Once the breast surgeon has performed the lumpectomy, a plastic surgeon can rearrange tissue to correct the defect remaining from the lumpectomy and, either at the same time or at a later date, perform a reduction or breast lift on the other side to make the breasts approximately the same volume.

Radiation can be performed after this type of reconstruction.

### **Fat Grafting**

Fat grafting is a method that may improve tissue damage after radiation and may improve breast reconstruction outcomes after radiation treatment. This technique takes fat from the buttocks, thighs, or abdomen and transfers it to the reconstructed breast to help improve any shape abnormalities after breast reconstruction surgery. The fat is obtained by liposuction and then injected into the areas where it is needed.

Although lumpectomy and partial mastectomy are breast-conserving surgeries, a scar is created. Dimpling or indentation of the breast might result from lumpectomy and radiation. Fat grafting can be used at the lumpectomy site in order to improve contour.

### **Nipple and Areola Reconstruction**

Nipple and areola reconstruction is a separate surgery and is usually the final step in breast reconstruction. Tissue from the reconstructed breast, opposite nipple, abdomen, eyelid, groin, inner thigh, or buttocks can be used to recreate a nipple. Because reconstructed nipples tend to shrink, they are initially made larger than the desired size. You may also opt for tattooing to give the nipple a natural color and to create an areola.

### **Concerns About Surgical Complications**

Like any major surgery, your surgeon should explain the risks, complications, and time commitments associated with your specific procedure, as well as ways to lower the risk of problems. Ask questions so you fully understand the risks before making your decision.

Surgery can pose risks, including infection, bleeding, blood clots, chronic pain, numbness, problems with healing, poor scar result, long-term wound problems, need for additional surgeries, or reactions to medications. Be sure to tell your surgeon about any changes you experience or if you have concerns that something doesn't look or feel right. Make sure you discuss your expectations with your surgeon. You should feel comfortable asking questions until you receive all of the information you need to make your decision.

### **You are in control**

Ask questions. Be sure to bring a list of questions to your appointment, and don't be afraid to ask your medical team to clarify anything you do not understand.

- Ask about your treatment and reconstruction options.
- Discuss how long it will take you to recover from the procedures and what to expect.
- Express how you feel.
- Find your own normal.
- Focus on taking everything one day at a time.



## NOTES

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**Questions you may want to ask about breast cancer surgery and reconstruction:**

What can I expect in terms of my recovery and rehabilitation?

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What physical, emotional, and behavioral challenges can I expect?  
How can I find support for these challenges?

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Do I need any special diet?

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Do I have any limitations to regular activities and exercise?

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When are my follow-up appointments?

Follow-up Appointment	Date/Time Health	Health Provider	Phone Number
Surgeon			
Oncologist			
Plastic Surgeon			

What changes to my daily routine can I expect while recovering?

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Can I drive after my surgery?

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Can I shower after my surgery?

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Will I need help with daily tasks? Can someone show my caregiver how to help me with these tasks?

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Who can I talk to about any unanswered questions I might have?

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When can I go back to work?

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Will I need to change bandages? How often?

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Will I need any supplies? What are they used for, and how do I order them?

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How can I determine my insurance coverage, and how much I will have to pay?  
Is there any assistance available?

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## Medications

Use this area to keep track of all of your medications.

Take this information to all medical appointments.

Medication	Dosage	Times per day



# RADIATION

Radiation therapy uses a high dose of radiation energy to shrink tumors, kill cancer cells, or to treat pain and other problems caused by the cancer tumor. About 60 percent of people with cancer will have radiation therapy, and sometimes, it is the only therapy needed. Treatment is personalized for each patient, tumor type, and medical situation.

## Types of Radiation Therapy

There are several different types of radiation therapy, including:

### **External beam radiation therapy**

- Whole Breast Radiation Therapy (WBRT)
- Post-mastectomy Radiation Therapy (PMRT)
- Partial Breast Irradiation (PBI)
- Regional Nodal Irradiation (RNI)

### **High-dose-rate (HDR) brachytherapy**

### **Image-guided radiation therapy (IGRT)**

### **Intensity modulated radiation therapy (IMRT)**

### **Intra-operative radiation therapy (IORT)**

### **Stereotactic body radiation therapy (SBRT)**

### **Stereotactic radiosurgery (SRS)**

### **External beam radiation therapy**

Therapy is given through the use of a machine that aims radiation at the cancer. The machine moves around your body to send radiation to the cancer from many different directions, but the machine does not touch you. It can be loud, and you may be given ear plugs to decrease the sound.

External beam radiation therapy is considered a local treatment, meaning that the radiation only goes to area of the body where the cancer is located.

#### **Whole Breast Radiation Therapy (WBRT)**

The entire breast is treated with radiation. Sometimes, the area where the tumors was before resection may be treated with additional radiation called a lumpectomy boost.

#### **Post-mastectomy Radiation Therapy (PMRT)**

In case of mastectomy, sometimes radiation to the chest-wall maybe indicated. Entire chest-wall is treated with radiation in PMRT. Sometimes, the mastectomy scar may be treated with additional radiation called a scar boost.

### **Partial Breast Irradiation (PBI)**

Only the area where the tumors was before resection is treated with radiotherapy. If given over a shorter time period, it is called Accelerated Partial Breast Irradiation (APBI).

### **Regional Nodal Irradiation (RNI)**

If indicated, the regional lymph nodes in the axilla (armpit), infraclavicular region (below the collar bone), supraclavicular (above the collar bone), intramammary (under the breastbone) on the side of the breast cancer maybe also be treated.

### **High-dose-rate brachytherapy**

- This therapy is given internally; seeds, ribbons, or capsules with a radiation source are placed in or near the tumor.
- It is a local treatment that only affects the area of the body with the cancer.
- The radiation source may be in your body for minutes, days, months, or for the rest of your life. It depends on your type of cancer, where the cancer is in your body, and your overall health.

### **Image-guided radiation therapy (IGRT)**

- IGRT uses imaging scans (e.g., CT, MRI, or PET) during the radiation therapy sessions to target the tumor. The scans are repeated at different times during treatment and used to detect changes in the tumor's size and location. This allows the radiation position and dose to be adjusted throughout treatment to improve accuracy of treatment and to spare normal tissue from damage.

### **Intensity modulated radiation therapy (IMRT)**

- IMRT uses many small beams of radiation. The strength of the beams can be changed to give different doses of radiation to different parts of the tumor.

### **Intra-operative radiation therapy (IORT)**

- IORT is used to give a single, large dose of radiation to the area where the tumor was removed in the operating room before the breast cancer surgery incision is closed. It is an advanced procedure that requires special equipment and is not widely available. The WVU Cancer Institute Department of Radiation Oncology is able to offer this treatment to patients who would benefit from it.

**Brachytherapy** - radioactive material sealed in needles, seeds, wires, or catheters placed directly into or near a tumor; also called implant radiation therapy, internal radiation therapy, or radiation brachytherapy

**Radiation** - energy used to treat some types of cancer

## Stereotactic radiosurgery (SRS)

- SRS uses focused, high-energy beams to treat small tumors with well-defined edges.
- It may be an option if surgery is too risky due to age, health problems, or the location of the tumor.
- Many small beams of radiation are aimed at the tumor from different directions. Each beam has very little effect on the tissue it passes through, but a precisely targeted dose of radiation is delivered to the site where all the beams come together.

Breast cancer may be treated with one or a combination of the above techniques depending on the specific type of the surgery performed and the final post-surgical pathology findings.

## What to expect

- Radiation therapy does not hurt while it is being given, but side effects can cause pain and discomfort.
- Some people are able to work full time during radiation therapy, while some can only work part time or not at all.
- You may feel fine when you first start radiation treatments, but as you receive more treatments, you may become tired, have less energy, or feel weak. Once you are done with treatment, it could take a few weeks or months to feel better.

## Side Effects

Side-effects are different for each person. Some people will have many, and others will have hardly any. Side-effects may be worse if you also receive chemotherapy before, during, or after your radiation therapy. Most side-effects will go away within a few months of finishing radiation therapy. Talk with your healthcare team about your chances of having side-effects and ways to manage them.

Common side-effects include:

- Fatigue
- Hair Loss
- Skin Changes
- Swelling
- Tenderness

Side-effect	Ways to manage
Fatigue	<ul style="list-style-type: none"> <li>• Try to sleep at least 8 hours each night</li> <li>• Plan time to rest</li> <li>• Try not to do too much exercise</li> <li>• Relax</li> <li>• Eat and drink well</li> <li>• Plan a work schedule that is right for you</li> <li>• Let others help you</li> <li>• Learn from others who have cancer</li> <li>• Keep track of how you feel each day</li> <li>• Talk with your doctor or nurse</li> </ul>
Hair loss	<ul style="list-style-type: none"> <li>• Decide whether or not to cut your hair or shave your head</li> <li>• If you plan to buy a wig, do so while you still have hair</li> <li>• Be gentle when you wash your hair</li> <li>• Do not use items that can hurt your scalp (e.g., straighteners or curling irons, brush rollers or curlers, hair bands and clips, hair dyes, perms)</li> <li>• Protect your scalp, stay warm</li> </ul>
Skin changes	<ul style="list-style-type: none"> <li>• Take extra care of your skin (do not rub, scrub, or scratch the treatment area)</li> <li>• Use only lotions, creams, or other skin products that your doctor or nurse suggest</li> <li>• Do not put anything on your skin that is very hot or cold</li> <li>• Be gentle when you shower or take a bath</li> </ul>
Swelling (edema)	<ul style="list-style-type: none"> <li>• Wear loose clothing and shoes that are not too tight</li> <li>• Raise your feet with a stool or pillows when you sit or lay down</li> <li>• Avoid crossing your legs when you sit</li> <li>• Talk to your doctor or nurse about special clothing that help with circulation</li> <li>• Exercise</li> <li>• Limit salt (sodium) in your diet</li> <li>• Take your medicine as directed</li> </ul>
Tenderness	<ul style="list-style-type: none"> <li>• Talk to your doctor or nurse about ways to handle tenderness or pain</li> </ul>

## **Late Reactions**

Radiation can also have long-term side-effects that can develop months to years after radiation. These may include, but are not limited to:

- Skin: Thickening, firmness, tanning, tenderness, discoloration
- Breast: Change in size or shape, firmness, tenderness
- Lung: Scarring, cough, shortness of breath
- Arm/Shoulder: Pain, stiffness, swelling; if lymph nodes are treated, lymphedema (arm swelling)
- Heart: Scarring of heart muscle or heart sac, causing heart failure
- Bone: Rib fracture
- Nerve: Brachial plexopathy (damage to nerve in shoulder/arm) causing pain, numbness, loss of strength
- Endocrine: Hypothyroidism (requiring thyroid replacement medication)
- Secondary Malignancy: In rare cases, radiation can lead to a second cancer in the area that is radiated, years after radiotherapy



## NOTES

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# CHEMOTHERAPY

Chemotherapy (chemo) is a mix of medications given to slow the growth of or kill cancer cells that may have moved to other parts of the body. A medical oncologist decides if a patient needs chemotherapy based on the patient's age, size of tumor, lymph node involvement, grade, estrogen receptor status, and other factors. Chemotherapy is a whole-body treatment, and the recommendation for chemotherapy is independent of the type of surgery that may be ordered.

## Types of Chemotherapy

Chemotherapy can be given in different ways:

**Injection** — given by a shot in a muscle in your arm, thigh, or hip, or right under the skin in the fatty part of your arm, leg, or belly

**Intravenous (IV)** — given directly into a vein

**Oral** — given through a pill, capsule, or liquid that you swallow

## Side-Effects

Side-effects are different for each person. Some people will have many, and others will have hardly any. How you feel can depend on how healthy you are before treatment, the type of cancer, how advanced it is, and your particular chemotherapy.

Short-term side-effects	Ways to manage
Constipation	<ul style="list-style-type: none"><li>• Drink at least 8 cups of water or other fluids every day</li><li>• Be active every day</li><li>• Keep a record of your bowel movements; show the record to your doctor or nurse and talk about what is normal for you</li><li>• Eat foods high in fiber</li></ul>
Diarrhea	<ul style="list-style-type: none"><li>• Eat 5-6 small meals and snacks a day instead of 3 large meals</li><li>• Drink 8-12 cups of clear liquids every day</li><li>• Eat foods low in fiber</li><li>• Let your doctor or nurse know if your diarrhea lasts for more than 24 hours or if you have pain and cramping with your diarrhea</li></ul>

<b>Short-term side-effects</b>	<b>Ways to manage</b>
Fatigue	<ul style="list-style-type: none"> <li>• Try to sleep at least 8 hours each night</li> <li>• Plan time to rest</li> <li>• Try not to do too much exercise</li> <li>• Relax</li> <li>• Eat and drink well</li> <li>• Plan a work schedule that is right for you</li> <li>• Let others help you</li> <li>• Learn from others who have cancer</li> <li>• Keep track of how you feel each day</li> <li>• Talk with your doctor or nurse</li> </ul>
Hair loss	<ul style="list-style-type: none"> <li>• Decide whether or not to cut your hair or shave your head</li> <li>• If you plan to buy a wig, do so while you still have hair</li> <li>• Be gentle when you wash your hair</li> <li>• Do not use items that can hurt your scalp (e.g., straighteners or curling irons, brush rollers or curlers, hair bands and clips, hair dyes, perms)</li> <li>• Protect your scalp, stay warm</li> </ul>
Increased risk of developing infection	<ul style="list-style-type: none"> <li>• Your healthcare team may adjust your chemotherapy dose or add medication to help your bone marrow recover more quickly so your body can make white blood cells that help fight infection</li> </ul>
Loss of appetite	<ul style="list-style-type: none"> <li>• Eat 5-6 small meals and snacks a day instead of 3 large meals</li> <li>• Plan to eat your meals and snacks at the same time every day</li> <li>• Drink milkshakes, smoothies, juice, or soup if you do not feel like eating solid foods</li> </ul>
Mouth sores	<ul style="list-style-type: none"> <li>• Visit a dentist at least 2 weeks before you start chemotherapy</li> <li>• Keep your mouth moist by sipping water throughout the day, sucking on ice chips or sugar-free hard candy, or chew sugar-free gum</li> <li>• Avoid foods or drinks that can hurt your mouth (e.g., sharp or crunchy foods, spicy foods, and hot foods and drinks)</li> <li>• Your doctor or nurse may recommend other options</li> </ul>



<b>Short-term side-effects</b>	<b>Ways to manage</b>
Nausea and vomiting	<ul style="list-style-type: none"> <li>• Eat small meals and snacks</li> <li>• Avoid strong smells</li> <li>• Suck on sugar-free hard candy, mints, or tart candy</li> <li>• Suck on small pieces of popsicles or fruit ices</li> <li>• Take deep, slow breaths or get fresh air</li> <li>• Your healthcare provider can prescribe medication to help reduce nausea and vomiting</li> </ul>
Nerve damage (neuropathy)	<ul style="list-style-type: none"> <li>• Be careful when working with sharp or dangerous objects</li> <li>• Avoid falling by holding onto handrails and using non-slip mats in your bathtub or shower</li> <li>• Be careful when using hot water, and use a thermometer to check the that the temperature of your shower or water for washing dishes is not hot enough to burn you</li> </ul>
Problems with cognitive function (“chemo brain”)	<ul style="list-style-type: none"> <li>• Keep a record of the signs and symptoms you notice and how it is affecting your daily life</li> <li>• Talk to your doctor or nurse about any concerns</li> </ul>
Heart damage	<ul style="list-style-type: none"> <li>• Wear loose clothing and shoes that are not too tight</li> <li>• Raise your feet with a stool or pillows when you sit or lay down</li> <li>• Avoid crossing your legs when you sit</li> <li>• Talk to your doctor or nurse about special clothing that help with circulation</li> <li>• Exercise</li> <li>• Limit salt (sodium) in your diet</li> <li>• Take your medicine as directed</li> </ul>
Infertility	<ul style="list-style-type: none"> <li>• Talk to your doctor or nurse about fertility options before you begin treatment</li> </ul>
Leukemia	<ul style="list-style-type: none"> <li>• This is a rare side-effect that occurs in some patients</li> <li>• Talk to your doctor or nurse about your concerns</li> </ul>
Osteopenia and Osteoporosis	<ul style="list-style-type: none"> <li>• Your healthcare team may complete bone density tests to monitor bone loss and offer treatment options if bone loss is noticed</li> </ul>

## Chemotherapy at Home

Some patients receive their chemotherapy at home. If you are able to do this, you need to take precautions to avoid unnecessary exposure to you, your family, and your pets from the medication. There is no danger to others from normal contact with you from hugging, kissing, or sharing food. It is exposure or contact with the medication or your body waste that may be dangerous. Here are a few ways to be safe while receiving your chemotherapy.

### Storing medication

- Keep medications in a safe place away from children or pets. Follow the instructions on the medication label for storage.
- If medication needs to be refrigerated, do not place it on the shelf nearest the freezer; place it in a zip-lock bag in the crisper bin.
- Do not keep medication in your bathroom because humidity can damage the medication.

### Medicine taken by mouth

- Wash your hands after handling medications.
- Caretakers should wear protective gloves to handle medications and not touch them with their bare hands.
- Take the medicine at the same time every day.

### Removal of chemotherapy materials

- A disconnection kit and instructions will be provided to patients using home infusion chemotherapy.

### Handling medication spills

- For spills on a hard surface, like a table or floor, wear 2 pairs of protective (latex) gloves, and wear glasses or other protective eye wear.
- Clean the spill with paper towels, wash the area 3 times with soap and water, and throw away all of the clean-up materials in your plastic chemotherapy waste container.
- For spills on a soft surface, like clothing or bedding, wash the items as soon as possible. If you cannot wash them immediately, place them in a plastic bag and dispose of the bag in the chemotherapy waste container when you do wash the item.
- The soiled items should be washed separately from other laundry twice before being used again. They can be washed with other items during the next washing.
- If the medication splashes in someone's eye, flush the eye with water for 15 minutes. Call the doctor who prescribed the medicine immediately. If possible, have someone call the doctor while the eye is being flushed and ask for further instructions.

### **Creams or pastes**

- Wear latex gloves when using the chemotherapy cream or paste.
- Put used gloves and any other waste in the plastic chemotherapy container. If you don't have a container, place the waste in a zip-lock bag, and take it to your doctor's office on your next visit.
- Wash your hands with soap and water after you remove the gloves.

### **Pregnant women**

- Women who are pregnant or breastfeeding should not handle chemotherapy medications or clean up spills.

### **Sexual intercourse**

- The use of condoms is recommended for 3-7 days after therapy to protect your partner from exposure to chemotherapy drugs in your bodily fluids.

## **Handling Chemotherapy Waste Materials Safely**

Chemotherapy can remain in the body for 3-7 days after treatment. It leaves the body through urine, stool, vomit, semen, and vaginal secretions. You need to take precautions during this time, whether you receive chemotherapy in the clinic, hospital, or at home. Caretakers should wear latex gloves when handling waste materials.

### **Bedpan, urinal, or emesis (vomit) basin**

- After each use, empty and rinse the container thoroughly with water. At least once a day, put on latex gloves and wash the item with soap and water. Discard the gloves after each use, then wash your hands with soap and water.

### **Disposable underwear or bed pads**

- For sanitary reasons and the containment of odor, it is recommended that you double-bag the soiled underwear or bed pad by placing it in a plastic bag, tie the bag, place the tied bag in a plastic trash bag, tie the trash bag, and dispose of the double-bagged item in the trash.

### **Linens and clothing**

- Wash soiled items as soon as possible. If you cannot wash them immediately, place them in a plastic bag and dispose of the bag in the chemotherapy waste container when you do wash the item. The soiled items should be washed separately from other laundry twice before being used again. They can be washed with other items during the second washing.
- If urine, stool, or vomit comes in contact with your hands or other body parts, wash the area immediately with soap and water. Caretakers should wear latex gloves when handling your bodily waste.

### **Toilet**

- Flush the toilet immediately after use. If you have younger children or pets in the home that may have contact with the toilet, flush it twice after each use.

## **OTHER TYPES OF THERAPY**

There are a few other types of therapy that your healthcare team may use to treat or manage your cancer. These therapies include targeted therapy, immunotherapy, and hormone therapy.

### **Targeted Therapy**

Targeted therapy is a type of treatment that uses medications or other substances to identify and attack (target) cancer cells without harming normal cells.

**Monoclonal antibodies** — uses antibodies made in a laboratory from a single type of immune system cells. The antibodies can identify substances on cancer cells or normal substances that may help cancer grow. The antibodies attach to those substances and kill the cancer cells, block their growth, or keep them from spreading.

- Given by infusion or injection
- May be used alone or in combination with chemotherapy
- Examples of monoclonal antibodies are trastuzumab, pertuzumab, and margetuximab

**Antibody drug conjugates** — a single medication that is made up of a monoclonal antibody attached to a chemotherapy. The antibody can identify substances on cancer cells that may help cancer grow. The antibody attaches to those substances on the cancer cell and releases the chemotherapy into the cell to kill the cancer cells.

- Given by infusion
- Examples of antibody drug conjugates are ado-trastuzumab emtansine, fam-trastuzumab deruxtecan, sacituzumab govitecan, and datopotamab deruxtecan

**Tyrosine kinase inhibitors** — block signals needed for tumors to grow.

- Oral medications
- May be used alone or with other anticancer medications
- Examples of tyrosine kinase inhibitors are lapatinib, tucatinib, and neratinib

**Cyclin-dependent kinase (CDK) inhibitors** — block the proteins, cyclin-dependent kinases, that cause cancer cells to grow.

- Examples of cyclin-dependent kinase inhibitors are palbociclib, ribociclib, and abemaciclib

**Phosphatidylinositol 3-kinase (PI3K) and AKT inhibitors** – block the protein called PI3K that cause cancer cells to grow.

- Examples of PI3K inhibitors are alpelisib and inavolisib and an example of an AKT inhibitor is capivasertib

**Mammalian target of rapamycin (mTOR) inhibitors** — block the protein called mTOR and may keep cancer cells from growing and prevent the growth of new blood vessels to the tumor.

- Example of mammalian target of rapamycin inhibitor is everolimus

**PARP inhibitors** — block DNA repair that may cause cancer cells to die.

- Examples of PARP inhibitors are olaparib and talazoparib

## **SIDE-EFFECTS**

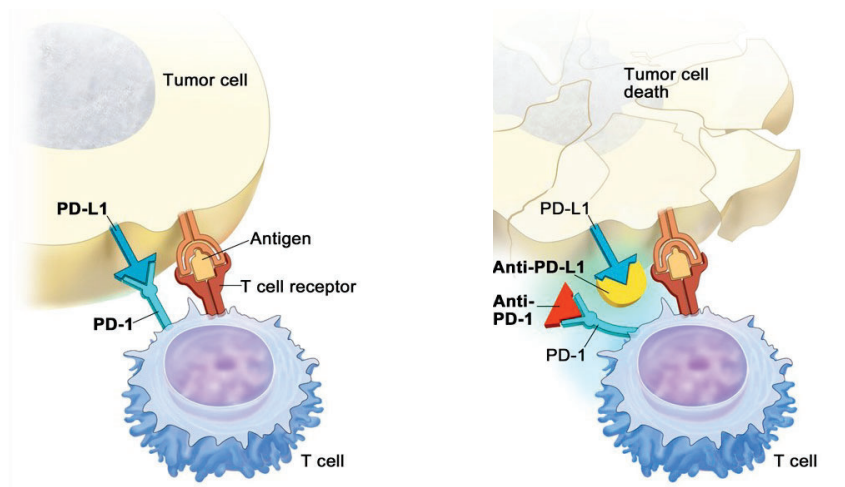
Side-effects are different for each person. Some people will have many, and others will have hardly any. How you feel can depend on how healthy you are before treatment, the type of cancer, how advanced it is, and your chemotherapy.

# Immunotherapy

Immunotherapy uses the patient's own immune system to fight cancer. Substances made by the body or made in a laboratory are used to boost, direct, or restore the body's natural defense against cancer. This is also called biotherapy or biologic therapy.

**Immune checkpoint inhibitor therapy:** PD-1 is a protein on the surface of T cells that helps to keep the body's immune system in check. When PD-1 attaches to the protein PD-L1 on a cancer cell, it stops the T cell from killing the cancer cell. PD-1 inhibitors attach to PD-1 and allow the T cells to kill cancer cells.

Pembrolizumab is a PD-1 inhibitor used in combination with chemotherapy to treat metastatic breast cancer. It is also used with neoadjuvant chemotherapy to treat early-stage triple negative breast cancer.



## Hormone Therapy

Hormones are made by glands in the body and are moved through the blood. Some hormones can cause certain cancers to grow. Hormone therapy removes or blocks their action and stops cancer cells from growing. Some cancer cells have places where hormones can attach known as receptors. Medications, surgery, or radiation can be used to reduce the production of hormones or block them from working.

**Tamoxifen** — hormone therapy given to patients with early, localized breast cancer that can be removed with surgery and those with metastatic breast cancer.

- Along with estrogens, tamoxifen can work on cells all over the body and may increase the chance of developing endometrial cancer.
- Women taking tamoxifen should have a pelvic exam and pap smear every year.
- Any vaginal bleeding, other than menstrual bleeding, should be reported to your doctor as soon as possible.

**Luteinizing hormone-releasing hormone (LHRH) agonist** — given to some premenopausal women who are diagnosed with hormone receptor positive breast cancer.

- LHRH agonists decrease the body's estrogen and progesterone.
- Examples of LHRH agonists are leuprolide and goserelin.

**Aromatase inhibitor** — given to some postmenopausal women with hormone receptor positive breast cancer.

- Aromatase inhibitors decrease the body's estrogen by blocking an enzyme called aromatase from turning androgen into estrogen.
- Examples of aromatase inhibitors are anastrozole, letrozole, and exemestane.

**Estrogen receptor antagonists** — given to some postmenopausal women with hormone receptor positive breast cancer.

- Estrogen receptor antagonists bind to estrogen receptors to block estrogen from binding – preventing estrogen activity – and decrease the number of estrogen receptors.
- Examples of estrogen receptor antagonists are fulvestrant (given by injection) and elecestrant (oral).

# SERVICES AND RESOURCES

## Sexuality and Intimacy

Our certified sex therapist at WVU Medicine uses open communication in a welcoming environment to educate and develop individualized treatment plans for every patient. Get help with a variety of symptoms, including but not limited to:

- Anxiety
- Depression
- General sexual trauma
- Trauma related to cancer diagnosis and treatment
- Sexual dysfunction
- Body image/self-esteem issues

If you are experiencing difficulties with sex, ask your doctor for a referral to the Sexual Therapy Clinic, a branch of the WVU Department of Obstetrics and Gynecology, or call 304-598-4880 and ask to make an appointment with the sex therapist.

## Fertility Preservation

The WVU Medicine Center for Reproductive Medicine offers consultation on fertility preservation for cancer patients facing radiation or chemotherapy.

How does it work?

- You or your doctor can contact the Center for Reproductive Medicine to discuss your unique case.
- You should start this process as soon as possible, especially if you are going to have radiation, chemotherapy, or surgery.

Who is eligible?

- Every patient is different, and options may exist for all ages to preserve fertility.

How long does it take?

- The process can often be completed within a few weeks after initial contact.
- The Center for Reproductive Medicine will work with your cancer care team to minimize disruption to your cancer treatment.

How much does it cost?

- Fees vary based on the procedure and are assessed for the initial preparation and freezing, annual storage, and any necessary physician visits.

### Contact information:

**WVU Center for Reproductive Medicine**

**1322 Pineview Drive, Suite 2, Morgantown, WV 26505**

**Phone: 304-598-3100 • Fax: 304-598-8301**



## **Tattooing**

Many breast cancer patients seek to have the physical appearance they had prior to surgery. One way this can be done is through nipple and areola restorative tattooing.

### **Contact information:**

**Marnie Rustemeyer, Certified Areola Tattoo Artist**

**Email:** [marnie@mediinkllc.com](mailto:marnie@mediinkllc.com)

**Phone:** 646-346-3211

**Location:** Charleston and Huntington area

**Artist Portfolio:** [bit.ly/3qgMNUK](https://bit.ly/3qgMNUK)

## **Wellness Boutique**

Located in the Mary Babb Randolph Cancer Center on the ground floor, wigs and head coverings are available in the Wellness Boutique. Patients may receive one wig or three comfort items (e.g., hats, scarves, beanies, turbans) free of charge per year. Staff are available to measure for wigs and hats.

A certified orthotic and mastectomy fitter is available to measure for lymphedema compression garments and post-mastectomy bras. See more details below.

## **Post-Mastectomy Supplies**

There are three types of post-mastectomy products patients might consider to help regain the look and feel of their body before surgery. The foam breast form and silicone prosthesis are inserted in the mastectomy bra on the side or sides of the mastectomy.



*Left to right: Mastectomy bra, Foam breast form, Silicone prosthesis*

How do I get one?

- Discuss mastectomy supplies with your physician.
- Ask your breast surgeon for a prescription for mastectomy supplies.
- Discuss mastectomy supplies with your insurance company.

This is a personal preference, and some patients do not use any of these supplies.

## Communities, Support Groups, and Online Resources

**Living Beyond Breast Cancer** focuses on connecting people with updated breast cancer information and providing a community of support. The group offers multiple programs, including free webinars hosted by leading health experts and conferences for those living with advanced or metastatic cancer.

**Learn more:** [lbbc.org](https://lbbc.org)

**Make Your Dialogue Count** is a community focused on the specific needs and concerns of people diagnosed with advanced or metastatic breast cancer. Their mission is to recognize and provide supportive resources for those living with an advanced diagnosis. This includes the patient, their caregivers, friends, and family members.

**Learn more:** [mbcalliance.org/project/make-your-dialogue-count](https://mbcalliance.org/project/make-your-dialogue-count)

**Metastatic Breast Cancer (MBC) Alliance** is an online community for those living with MBC that includes blogs and chat rooms, information on clinical trials, networking, a support group, and referrals to organizations that may offer financial assistance.

**Learn more:** [mbcalliance.org](https://mbcalliance.org)

**Metastatic Breast Cancer Network** is a non-profit advocacy group that provides up-to-date information and resources for those with metastatic breast cancer. This includes educational resources and a list of in-person support groups by state. They also champion clinical trials and research initiatives.

**Learn more:** [mbcn.org](https://mbcn.org)

**METAvivor** is a non-profit and volunteer-led organization dedicated to the fight of those people diagnosed with Stage 4 (metastatic) breast cancer. They fund research through a scientific peer-to-peer process, and aim to provide awareness and support to anyone living with metastatic disease.

**Learn more:** [metavivor.org](https://metavivor.org)

**Living Beyond Cancer** is a free, closed online support group that offers information for people currently receiving cancer treatment, those who have completed cancer treatment, and their caregivers.

[Facebook.com/Groups/LivingBeyondCancer](https://www.facebook.com/Groups/LivingBeyondCancer)

**The Caregiver Support Group** is geared to caregivers of cancer patients. More information: 304-285-1731.

**The Survivors Club** offers patients of any cancer diagnosis and their caregiver in-person social support. More information: 304-285-1731.

**American Cancer Society**

[Cancer.org](https://www.cancer.org)

**Centers for Disease Control and Prevention**

[CDC.gov/Cancer](https://www.cdc.gov/Cancer)

**National Cancer Institute Patient Education**

[Cancer.gov/Publications/Patient-Education](https://www.cancer.gov/Publications/Patient-Education)

# YOUR INFORMATION AND APPOINTMENTS

## **MyWVUChart**

WVU Medicine offers patients the ability to view their medical information and interact with physicians' offices online by using MyWVUChart.

With a MyWVUChart account, you can request an appointment with your provider, view and download a copy of your Patient Health Summary, view test results, refill prescriptions, and communicate electronically and securely with your medical care team.

You can obtain a MyWVUChart activation code for yourself at any WVU Medicine clinic location during checkout or online at [MyWVUChart.com](https://MyWVUChart.com).

The MyWVUChart patient support line is 1-866-98-CHART. The line is open Monday through Friday, 8 am to 5 pm.

Individuals seeking proxy access to a family member's (including children up to age 18) MyWVUChart account must visit an activation site in person with the family member to obtain necessary signatures.

### **MyWVUChart mobile app**

Access your WVU Medicine information when you are away from your computer. This free mobile app is available for Apple and Android devices. Download the MyChart app and configure with our WVU Medicine location zip code 26506.

### **Urgent medical matters**

MyWVUChart is not intended for sending messages requiring urgent attention. For urgent medical matters, contact your doctor's office by phone. If you have a medical emergency, dial 911.

### **Privacy and security**

WVU Medicine is committed to providing quality healthcare and respecting the privacy and confidentiality of your medical information. Our policies regarding access to and release of medical records conform to state and federal laws, and are designed to safeguard your privacy.

### **Technical support**

[MyWVUChart@WVUMedicine.org](mailto:MyWVUChart@WVUMedicine.org)

Toll-free support line: 866-982-4278

For complete terms and conditions, please visit [MyWVUChart.com](https://MyWVUChart.com).

### **Appointment alerts**

WVU Medicine offers a text messaging service to remind you of your upcoming appointments with us. You will receive a text message seven days before your scheduled visit. You can opt-out at any time.

### To sign up:

1. Provide your cell phone number at registration
2. Text WVUHC to 622622

Message and data rates may apply. Text HELP to 622622 to receive help. STOP to 622622 to opt-out. Visit [txt.tvox.com](http://txt.tvox.com) for more information.

### Appointments and rescheduling

- To schedule or reschedule appointments at the Mary Babb Randolph Cancer Center, please call 304-598-4500.
- Once you have received a cancer diagnosis and a treatment plan, it is highly recommended that you avoid missing appointments and any scheduled treatment appointments.
- To speak with a member of your healthcare team to discuss medical issues requiring you to reschedule, please call and ask to speak with the triage nurse. Depending upon symptoms you are experiencing, your provider may recommend that you keep your appointment.
- If you need to cancel an appointment, please call as soon as possible to ensure timely rescheduling for clinic and treatment appointments.
- If you need to reschedule an appointment, please call and a scheduler will assist you.
- If you are having an emergent medical issue, call 911.

*Materials in this patient guide were adapted from:*  
[Cancer.gov/Publications/Dictionaries/Cancer-Terms](http://Cancer.gov/Publications/Dictionaries/Cancer-Terms)  
[Cancer.gov](http://Cancer.gov)  
[Cancer.org](http://Cancer.org)  
[MayoClinic.org](http://MayoClinic.org)

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# NOTES

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