

Breast Cancer Treatment

What You Should Know

New York State Department of Health

Cancer Services Program

Your partner for cancer screening, support and information



■ Table of Contents

1	Introduction	1
2	Taking Care of Yourself After Your Breast Cancer Diagnosis	3
3	Working with Your Doctor or Health Care Provider	5
4	What Are the Stages of Breast Cancer?	7
5	Your Treatment Options	11
6	Breast Reconstruction	19
7	Will Insurance Pay for Surgery?	23
8	If You Don't Have Health Insurance	24
9	Life After Breast Cancer Treatment	25
10	Questions to Ask Your Health Care Team	27
11	Breast Cancer Hotlines, Support Groups, and Other Resources	31
12	Definitions	37

1 Introduction

You are not alone. There are more than two million breast cancer survivors living in the United States today. Great improvements have been made in breast cancer treatment over the past twenty years. People with breast cancer are living longer and healthier lives than ever before and many new breast cancer treatments have fewer side effects.

The New York State Department of Health developed this booklet for your doctor to help you to understand your treatment options. This booklet is intended to be a guide to help you become a partner with your health care team to make choices about your health and treatment. These tips may make it easier for you to use this booklet:

- Ask a friend or someone on your health care team to read this booklet along with you. Or have them read it and discuss it with you when you feel ready.
- It may be helpful to read this booklet in sections rather than all at once. For example, if you have just been diagnosed with breast cancer, you may only want to read sections 1-4 for now. Sections 5-8 may be helpful while you are choosing your treatment options, and Section 9 may be helpful to read as you are finishing treatment.
- Medical words that you may hear as you go through diagnosis and treatment are **written in bold italics** throughout this booklet. Definitions of these words are in Section 12 at the end of this booklet. Knowing the meaning of the words that you are hearing can help you understand what is happening and help you make informed choices.

- As you go through the treatment process, it may be useful to write questions before you meet with your doctor. Suggested questions are written throughout this booklet. If agreeable to the health care team, you may also want to tape record information that is given to you. Consider asking a friend or family member to be with you at your appointments to listen to the information and give you emotional support.
- Remember, there is no one “right” treatment for every person. New options are available today that were not offered even a few years ago.
- Most important, never be afraid to have information repeated and to ask questions. There is no such thing as a “dumb” question. Asking questions and seeking information will allow you to make choices that you are comfortable with.

2 Taking Care of Yourself After Your Breast Cancer Diagnosis

Every person reacts differently when they are diagnosed with breast cancer. Many people feel a sense of fear, anxiety, anger, or disbelief. It can be difficult to concentrate and move forward with treatment decisions. Talk with someone you trust. Most people find it helpful to have someone they trust help them sort through the many feelings they experience and assist them to find information about treatment options and other resources.

You might want to talk with someone you trust who will listen to you and support you, such as:

- A relative
- A close friend
- A clergy member
- A breast cancer hotline
- A fellow ***cancer survivor***
- An online message board or chat group
- A professional counselor
- Your doctor
- A ***support group***

Support groups can have many benefits. Although you may receive support from friends and family, you might want to consider joining a support group to speak with others who have had similar experiences to yours. Support groups can:

- Give you an opportunity to talk about your feelings in a safe and comfortable setting.
- Help you deal with practical problems, such as cancer-related personal, work, or financial issues.
- Educate you about dealing with side effects of treatment.

Ask your doctor if your hospital has a breast cancer support group. Some breast cancer support groups, hotlines and other resources in New York State (NYS), along with their contact information, are listed in Section 11 of this booklet.

Get to know your health care team. One of the most important things you can do to make sure that you feel in control of your breast cancer treatment is to get to know your health care team. Find a member of the health care team who communicates with you in a way that makes you feel comfortable, who listens to you, and takes your concerns seriously. Make sure your health care team knows what role you want to take in your treatment decisions.

Take time for yourself. Take time for yourself doing things that make you happy and most importantly, create a positive attitude – for example, watch movies, pray, or exercise. Surround yourself with positive people who accept you the way that you are. Ask your friends and family to help with stressful things like balancing the checkbook or cleaning your house.

3 Working with Your Doctor or Health Care Provider

It is important that you be able to share your concerns with your doctor. You may want to talk with your doctor about a referral to a specialist or getting a second opinion, and you may have many questions for your health care team. It may help you to bring a list of questions such as the one in Section 10 to your visits, and to take notes on the answers.

Referral to a Specialist

Cancer is a complex disease, and no one doctor is able to provide all the care and services you may need. A specialist is a doctor or other health care provider who focuses on a certain part of your health care needs. You may be referred to many specialists during the course of your cancer care. Some of these may include a ***clinical nurse specialist, breast surgeon, medical oncologist, nutritionist, physical therapist, plastic surgeon, radiation oncologist, radiologist, social worker, surgical oncologist, or genetic counselor.***

This website explains more about **how to find a doctor or treatment center that specializes in cancer care:** www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility

Second Opinions

A second opinion is a visit to a doctor other than the one you have already seen to get another point of view on your health care needs. Second opinions are commonly requested. Most doctors welcome hearing another doctor's views and, with your permission, will share your records with others for the purpose of providing you care.

Second opinions should not hold up your treatment or cost you extra as they are covered by most health insurance plans in New York State. Get a second opinion if you:

- Want to confirm your diagnosis or treatment,
- Want to explore all of your treatment options, or
- Feel uncomfortable with your doctor.

If you are in a Health Maintenance Organization (HMO), you may get a second opinion outside your health plan (including seeing a specialist at a cancer care center) at no extra charge if you are referred by a health plan doctor. Contact your HMO to discuss getting a second opinion. If you get a second opinion without a referral from your health plan doctor, you may have to pay all or part of the cost.

TO GET A SECOND OPINION

- Ask your doctor to refer you to a breast cancer specialist who is outside of his or her treatment team.
- Contact local or national medical associations.
 - The American Medical Association Doctor Finder database at: [https:// extapps.ama-assn.org/doctorfinder/recaptcha.jsp](https://extapps.ama-assn.org/doctorfinder/recaptcha.jsp) provides basic information on licensed doctors in the United States.
 - The American Society of Clinical Oncology provides an online list of cancer doctors available at: www.cancer.net/patient/All+About+Cancer/Newly+Diagnosed/Find+an+Oncologist/Find+an+Oncologist+Database
 - The American College of Surgeons membership database provides an online list of surgeons located at: web3.facs.org/acmdir/default_public.cfm (search by subspecialty “breast disease/cancer”).
 - The American College of Surgeons’ Commission on Cancer can direct you to hospitals and breast cancer centers of excellence that have been accredited to provide state of the art and multidisciplinary care in breast cancer at: www.facs.org/cancer/index.html
- Talk to members of breast cancer organizations or to people who have been through the same experience to get their opinions. Please see Section 11 of this booklet for a list of breast cancer organizations and their contact information.

4 What Are the Stages of Breast Cancer?

Staging is a way of describing a cancer. Knowing your cancer stage will help you and your health care team decide what kind of treatment is best for you. Early stage cancer is considered to be Stages I and II. Late stage cancer is considered to be Stages III and IV. The treatment choices will depend on:

- How small or large your **tumor** is,
- If cancer is found in the **lymph nodes** in your armpit, and
- If cancer is found in other parts of your body.

About Lymph Nodes

- Lymph nodes are small, bean-shaped structures found throughout your body.
- Lymph nodes are part of your body's immune system.
- Lymph nodes act as filters or traps for germs or cancer cells and help fight off infection and disease.
- Sometimes cancer cells enter the lymph nodes, which is why doctors will look at your lymph nodes when they are staging your cancer.

What Are Axillary Nodes?

- **Axillary nodes** are the lymph nodes in your armpit.
- When breast cancer spreads outside the breast, it usually spreads first to the axillary nodes.
- Finding out whether or not cancer has spread to the axillary nodes (**axillary node dissection**) is important to figure out the stage of cancer and the type of treatment needed.

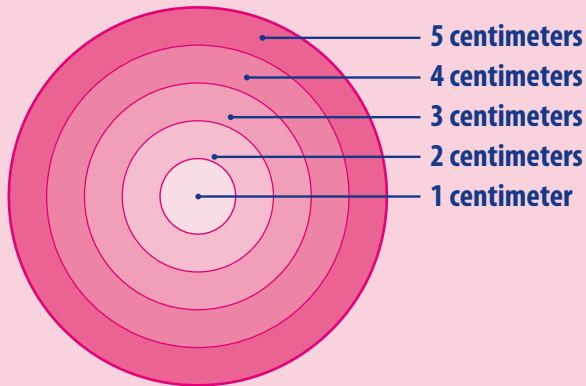
Stages of Breast Cancer

Stage 0

- **In situ cancer** (also called preinvasive or noninvasive cancer).
- Abnormal cells have been found in the lining of the breast **ducts** (ductal carcinoma in situ) and have not spread outside the duct to other tissues in the breast; OR
- Abnormal cells have been found in the **lobules** of the breast (lobular carcinoma in situ).

Stage I

- Cancer has formed. The tumor is 2 cm* (1 inch) or smaller, and cancer HAS NOT spread to the lymph nodes or outside the breast.



**Cm means centimeters. One inch is about 2.5 centimeters. Image above is not exact measurement. Because of varying settings on computers, this graphic may not be to scale.*

(From the website of the National Cancer Institute: www.cancer.gov)

Stages of Breast Cancer

Stage IIA

- No tumor is found in the breast, but is found in the axillary lymph nodes (lymph nodes in the armpit); OR
- The tumor is 2 cm* (1 inch) or smaller and cancer HAS spread to the lymph nodes in the armpit; OR
- The tumor is between 2 and 5 cm* (1 and 2 inches), but cancer HAS NOT spread to the axillary lymph nodes.

Stage IIB

- The tumor is between 2 and 5 cm* (1 and 2 inches) and cancer HAS spread to the lymph nodes in the armpit; OR
- The tumor is larger than 5 cm* (2 inches), but cancer HAS NOT spread to the axillary lymph nodes.

Stage IIIA

- No tumor is found in the breast, but cancer is found in the axillary lymph nodes, or in the lymph nodes near the breast bone; OR
- The tumor is 2 cm* (1 inch) or smaller and cancer has spread to axillary nodes or cancer may have spread to the lymph nodes near the breast bone; OR
- The tumor is between 2 and 5 cm* (1 and 2 inches) and cancer has spread to the axillary lymph nodes, or cancer may have spread to the lymph nodes near the breast bone; OR
- The tumor is larger than 5 cm* and cancer has spread to the axillary lymph nodes, or cancer may have spread to the lymph nodes near the breast bone.

Stages of Breast Cancer

Stage IIIB

- The tumor may be any size and:
 - Cancer has spread to the chest wall and/or the skin of the breast; and
 - Cancer may have spread to the axillary lymph nodes or to lymph nodes near the breastbone.
- Cancer that has spread to the skin of the breast is **inflammatory breast cancer**. Inflammatory breast cancer is considered at least stage IIIB. For more information about inflammatory breast cancer, visit: www.mayoclinic.com/health/inflammatory-breast-cancer/DS00632

Stage IIIC

- There may be no sign of cancer in the breast, or the tumor may be any size and may have spread to the chest wall and/or the skin of the breast. Also, cancer has spread to the lymph nodes above or below the collarbone and may have spread to the axillary lymph nodes or to lymph nodes near the breastbone.
- The cancer is either operable or inoperable. In the operable stage, the cancer:
 - Is found in ten or more axillary lymph nodes; OR
 - Is found in lymph nodes below the collarbone; OR
 - Is found in axillary lymph nodes and in lymph nodes near the breastbone.
- In the inoperable stage, the cancer has spread to the lymph nodes above the collarbone.

Stage IV

- The tumor HAS spread to other organs of the body, most often the bones, lungs, liver or brain.

5 Your Treatment Options

Many treatment options are available for breast cancer. The treatment you and your health care team choose for you depends on many things, such as:

- The stage of the cancer, which in most cases is the most important factor (See Section 4)
- Your age
- Whether or not you are experiencing menopause
- Your general health
- The size of your breast
- The results of lab tests and **tumor markers**
- Your ability and agreement to receive **radiation**

Side Effects

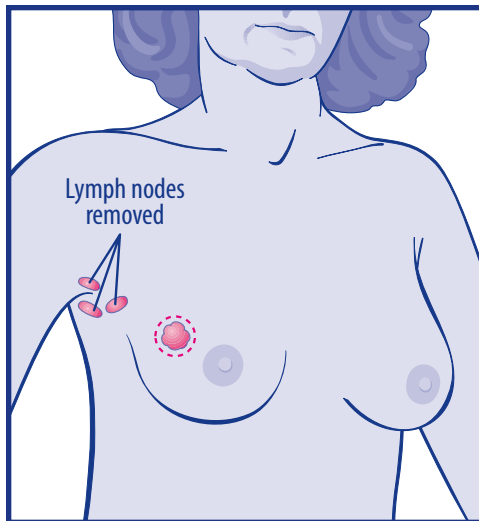
Side effects are symptoms or problems you may have as a result of treatment (surgery or medications). Some side effects are common, others are rare. Many side effects can be treated to reduce their effect or managed so that you can continue to function normally. It is important to talk to your health care team about any side effects you are experiencing and to not stop medications or treatment because of side effects without consulting with your health care team. Side effects for each treatment type are listed below.

Surgery

Most people with breast cancer today can choose between **breast conservation therapy** (also known as **lumpectomy**) and **mastectomy**. Breast conservation treatment is breast conservation surgery followed by radiation therapy. In most cases, breast conservation surgery and mastectomy are equally effective for people with early stage breast cancer (Stages I and II). However, there is no guarantee that the cancer will not return.

LUMPECTOMY

During a lumpectomy, a surgeon removes the tumor, a little normal breast tissue around the tumor, and some lymph nodes in the armpit. Radiation therapy is almost always given after a lumpectomy to decrease the risk of cancer coming back in the remaining breast tissue.



Lumpectomy

Possible Side Effects of Lumpectomy

There may be a change in the shape of the breast or numbness in part of the breast. Infection, poor wound healing, bleeding, and a reaction to the drugs used in surgery (**anesthesia**) may occur after a lumpectomy.

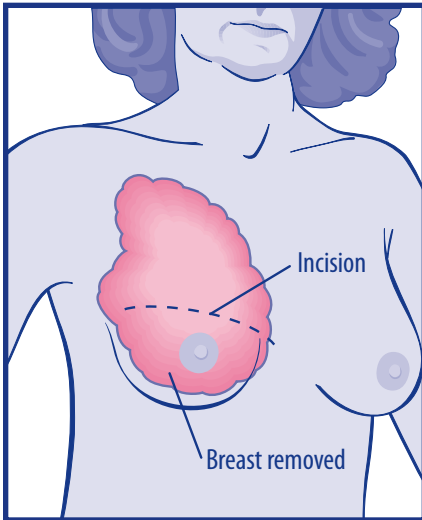
MASTECTOMY

A mastectomy is the surgical removal of the breast. There are different types of mastectomy, a total mastectomy (also known as simple mastectomy) and modified radical mastectomy. A mastectomy is most often recommended when:

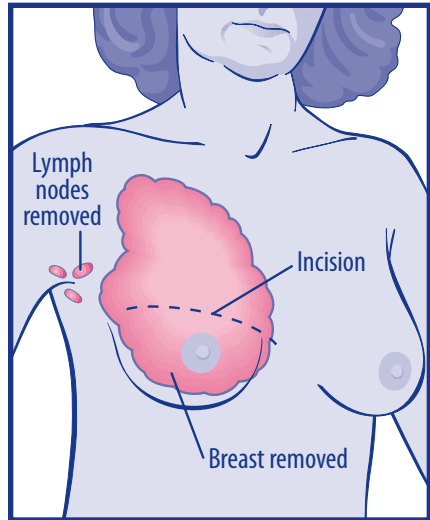
- There are multiple areas of cancer within your breast
- The tumor is greater than 5 cm (2 inches)
- Your breast is small or shaped such that removal of the entire cancer will leave little breast tissue or a deformed breast
- You do not want or cannot have radiation therapy

Total mastectomy is surgery that removes as much breast tissue as possible, the nipple, and some of the overlying skin of the breast. The lymph nodes in the armpit are NOT removed.

Modified radical mastectomy is surgery that removes as much breast tissue as possible, the nipple, the tissue lining the muscles of the chest, and some lymph nodes in the armpit.



Total mastectomy



Modified radical mastectomy

Possible Side Effects of Mastectomy

Infection, poor wound healing, a reaction to the drugs used in surgery (anesthesia), and a collection of fluid or blood under the skin may occur after a mastectomy.

REMOVAL OF LYMPH NODES

Whether you have a lumpectomy or mastectomy, your surgeon will usually do a **sentinel node biopsy** to learn if cancer has spread to lymph nodes, without removing all of the lymph nodes. The sentinel node is the first lymph node to which cancer is likely to spread. When cancer spreads, the cancer cells may first appear in the sentinel node. If the sentinel node shows no cancer cells, then it is more than 97% likely that the other axillary nodes will also be cancer-free. If the sentinel node does show cancer cells, the surgeon will remove many more lymph nodes in the armpit (**axillary node dissection**) to see how many other lymph nodes are involved.

Possible Side Effects of Lymph Node Removal

Numbness in the upper arm or armpit, or arm swelling called **lymphedema** may occur after lymph node removal. Lymphedema is the unhealthy buildup of fluid in your body that causes swelling. Careful management to avoid injury to the arm is often the best way to reduce the chance of lymphedema, but treatment is available for lymphedema. Other conditions may cause the same symptoms. A doctor should be consulted if any of the following problems occur:

- Swelling of an arm, which may include fingers
- A full or heavy feeling in an arm
- A tight feeling in the skin
- Trouble moving a joint in the arm
- Thickening of the skin, with or without skin changes such as blisters or warts
- A feeling of tightness when wearing clothing, shoes, bracelets, watches, or rings
- Trouble sleeping
- Loss of hair

Daily activities and the ability to work or enjoy hobbies may be affected by lymphedema. These symptoms may occur very slowly over time or more quickly if there is an infection or injury to the arm or leg.

For more information on **lymphedema**, visit: www.health.ny.gov/publications/0399/

For more information about **surgery for breast cancer**, visit: www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-treating-surgery

Systemic Treatments

Systemic treatments are used to kill cancer cells throughout the body. They affect all of the cells in your body and not just the cancer cells in your breast. Systemic treatment can be given before (***neoadjuvant therapy***) or after (***adjuvant therapy***) surgery or radiation. ***Chemotherapy, hormonal therapy*** and ***targeted therapy*** are systemic treatments.

CHEMOTHERAPY

Chemotherapy is the use of drugs to kill cancer cells. Most often the drugs are injected into the bloodstream through an ***intravenous*** (IV) needle that is inserted into a vein. Other times, drugs may be given as pills. Chemotherapy is given in cycles. You get one treatment and are given a few weeks to rest before the next treatment. Most patients have chemotherapy in an outpatient clinic of the hospital, at the doctor's office, or at home. Rarely, patients need to stay in the hospital during treatment.

Possible Side Effects of Chemotherapy

Each person reacts differently to chemotherapy. Some **common side effects** are:

- Being very tired (called fatigue)
- Loss of appetite
- Nausea and/or vomiting (see coping suggestions below)
- Diarrhea or constipation
- Weight change
- Mouth and lip sores
- Short-term hair loss
- Lowered blood counts that can increase the risk of infections or bleeding

Other potential side effects associated with chemotherapy are changes in menstrual periods, bone thinning, tingling or numbness in hands and feet, changes in the color of the skin, and changes in concentration and memory (often called "chemobrain").

The following suggestions may help with nausea or vomiting:

- Ask for drugs that reduce nausea and vomiting.
- Eat small meals often; do not eat 3 to 4 hours before your treatment.

- Eat popsicles, gelatin desserts, cream of wheat, oatmeal, baked potatoes, or fruit juices mixed with water.
- Chew your food thoroughly and relax during meals.
- Learn exercises to reduce stress.

Your body is less able to fight infections while you are on chemotherapy. The following steps can help you stay healthy while on chemotherapy:

- Avoid large crowds and people with colds and other contagious diseases.
- Bathe daily, wash your hands with soap or a hand sanitizer often, and gently brush your teeth after each meal.
- Wear gloves when you are gardening or doing other work that may expose your hands to dirt or sharp tools to protect hands against cuts.
- If you get a cut, keep the wound clean and covered.
- Eat a healthy diet and get plenty of rest.

For more information about **chemotherapy**, including a guide to cancer drugs, visit: www.cancer.org/docroot/ETO/ETO_1_5x_Guide_for_Patients_and_Families.asp

HORMONAL THERAPY

Some breast cancers are sensitive to **estrogen** and **progesterone**, two **hormones** that are made by your body. Hormonal therapy keeps sensitive cancer cells from getting these hormones that the cancer needs to grow. This treatment uses drugs that may either block the hormones from reaching the cancer or reduce the level of hormones in the body. Occasionally, surgery to remove the ovaries which make estrogen and progesterone may be recommended. Tamoxifen is an example of a hormonal therapy.

Possible Side Effects of Hormonal Therapy

Each person reacts differently to hormonal therapy. Some **common side effects** are:

- Fatigue
- Hot flashes
- Vaginal discharge or irritation
- Nausea
- Weight gain
- Changes in menstruation

Other potential side effects associated with hormonal therapy include bone pain, diarrhea, decreased muscle mass and strength, and bone thinning.

For more information about **hormonal therapy**, visit: www.cancer.org/Cancer/BreastCancer/OverviewGuide/breast-cancer-overview-treating-hormone-therapy

TARGETED THERAPY

Targeted cancer therapies use drugs or other substances to specifically target changes in cells that cause cancer. These therapies only work against certain cell changes that may not happen in all people with breast cancer. Targeted therapies are generally less likely than chemotherapy to harm normal, healthy cells.

Possible Side Effects of Targeted Therapy

Each person reacts differently to targeted therapy. Some **common side effects** are:

- Rashes or swelling where the targeted therapy is injected
- Flu-like symptoms
- Fatigue
- Diarrhea or vomiting
- Nosebleeds
- High blood pressure

For more information about **targeted therapy**, visit: www.cancer.org/Cancer/BreastCancer/OverviewGuide/breast-cancer-overview-treating-targated-therapy

Radiation Therapy

Radiation therapy (also called radiotherapy) uses high-energy rays to kill cancer cells. **Radiation** may be given before or after surgery. Most patients receive external radiation, in which a machine delivers radiation to the part of the body affected by cancer. Radiation can also come from radioactive material placed directly in the breast. Some people may have both kinds of radiation. The amount of radiation therapy and how often you get it depends on the size of your tumor, the type of surgery that you have had, the type of radiation that you receive, and your and your health care team's preference.

Possible Side Effects of Radiation Therapy

Each person reacts differently to radiation therapy. Some **common side effects** are:

- Swelling and heaviness in the breast
- Sunburn-like skin changes in the treated area
- Fatigue

Less common side effects of radiation therapy include armpit discomfort, chest pain, feeling as though your heart is racing, dry cough, and shortness of breath.

For more information about **radiation therapy**, visit: www.cancer.org/Treatment/TreatmentsandSideEffects/PhysicalSideEffects/DealingwithSymptomsatHome/caring-for-the-patient-with-cancer-at-home-radiation-therapy

6 Breast Reconstruction

After a mastectomy, a woman might choose to wear a breast form (*prosthesis*) that fits in her bra or a specially designed bra with a breast form built into it, have her breast reconstructed by a plastic surgeon, or do neither. Some women choose to get body art tattooed over their mastectomy scars. Others opt not to have a breast form, tattoo, or reconstructed breast. This is a highly personal decision. Discuss your options with your plastic surgeon to help you decide the best option for your comfort and appearance.

If you have a mastectomy, there are different types of breast reconstruction available. It is important to know that a rebuilt breast will not have natural feelings or functions; but the surgery can give you a result that looks like a breast. If you think that you want breast reconstruction, it is important to discuss reconstruction with your surgeon *before* your mastectomy and ask for a referral to an experienced plastic surgeon. Many women start reconstruction at the same time as their mastectomy; some wait several months or even years.

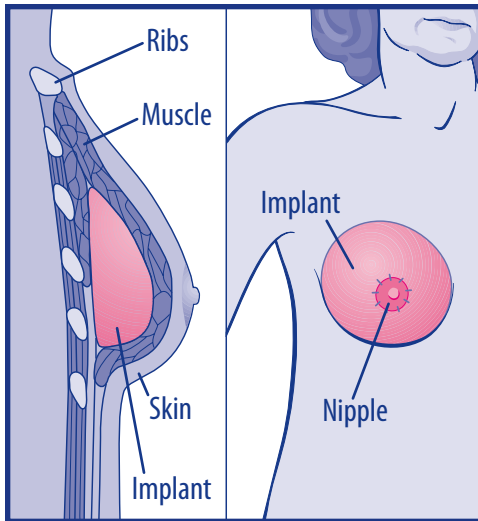
Breast reconstruction – surgery to “rebuild” a breast – is an option for anyone who has lost a breast because of cancer. New York State law requires health insurance policies that provide medical and surgical coverage to pay for reconstruction and for surgery to the other breast to obtain a good match. Required payment for breast reconstruction does not apply to self-insured health plans or to some plans paid for by out-of-state employers. If you have questions about legislation on breast reconstruction or other insurance legislation, call the New York State Insurance Department at 1-800-342-3736.

If you are considering breast reconstruction surgery, this section gives information on the types of surgeries available.

Reconstruction with Implants

Implants are plastic sacs filled with **silicone** (a type of liquid plastic) or **saline** (salt water). The sacs are placed under your skin behind your chest muscle. Implants may not last a lifetime, and you may need more surgery to replace them later. Sometimes saline implants “crinkle” at the top, or can shift with time, but many women don’t find these changes troubling enough to have the implant replaced.

The Food and Drug Administration (FDA) has studied the safety of silicone breast implants and the immune system for several years; the most recent research shows that these implants do not cause immune system problems. The FDA approved two kinds of silicone implants for breast reconstruction surgery in 2006. If you are thinking about having silicone implants, you may want to talk with your surgeon about the FDA findings and whether silicone implants are an option for you.



Breast reconstruction with implants

Possible side effects of reconstruction with implants

People who have had reconstruction with implants sometimes have pain, infection, or rupture (breaking) of the implant. Additionally, some people may not be happy with how the results look, or scarring could form around the implant over time, making the reconstructed breast look less attractive.

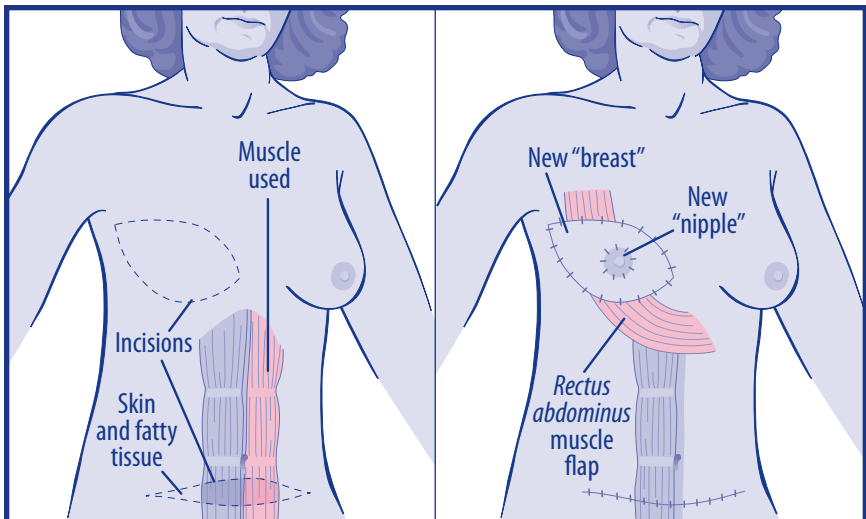
Reconstruction with Tissue Flaps

Tissue flap surgeries use muscle, fat, skin, and blood vessels moved from another part of the body to rebuild the breast. This tissue can be taken from the:

- Lower stomach area (known as **TRAM Flap** or **DIEP Flap**)
- Back
- Buttocks

These surgeries also sometimes use an implant to make the new breast match the opposite breast.

A woman starting this process should know that it often takes more than one surgery. Extra steps may include adding a nipple, surgery on the opposite breast to create a good match, and perfecting the shape of the rebuilt breast.



Breast reconstruction with tissue flaps

Possible side effects of reconstruction with tissue flaps

These surgeries leave scars in two places – one where the tissue was taken from and one on the new breast. The scars may fade over time and may never go away completely. There also might be muscle weakness where the tissue was taken, differences in the size and shape of the breasts, or poor blood supply to the new breast. Choosing a plastic

surgeon who has been trained in this surgery and has performed it successfully on many other women can reduce the risks.

To find **certified plastic and reconstructive surgeons in your area**, visit the American Society of Plastic Surgeons website at: www.plasticsurgery.org/ or call 1-888-4PLASTI (1-888-475-2784).

For more information about **companies that sell breast prostheses**, visit: www.cancer.org/Cancer/BreastCancer/MoreInformation/breast-prostheses-and-hair-loss-accessories-list

7 Will Insurance Pay for Surgery?

Under New York State law, all health insurance plans that cover hospital stays must cover hospital care following surgery for breast cancer for the period of time that you and your health care team feel is appropriate for your recovery. Health insurance plans providing medical and surgical coverage in New York State are also required to pay for costs of breast reconstruction after surgery for breast cancer and for surgery on the other breast, if needed. Self-insured plans and some plans issued by out-of-state employers are not required to pay for breast reconstruction. Some plans may have restrictions about where breast reconstruction surgery is performed. Contact your insurance company or HMO for details about your plan. If you have questions about this law or other insurance legislation, call the New York State Insurance Department at 1-800-342-3736.

To find your **local Insurance Department Consumer Services office**, visit:
www.ins.state.ny.us/hpoffnos.htm

8 If You Don't Have Health Insurance

If you are a New York State resident who does not have health insurance and need treatment for breast cancer, you might be eligible for the Medicaid Cancer Treatment Program (MCTP) or a public health insurance program such as Medicaid or Family Health Plus. The MCTP provides full Medicaid coverage for breast cancer treatment, breast reconstruction following surgery for breast cancer, and other medical expenses for people who meet certain eligibility criteria. People enrolled in the MCTP must use a participating New York State Medicaid provider for all covered medical expenses.

For more information about the **MCTP** or to find out whether you might be eligible, visit: www.health.ny.gov/nysdoh/bcctp/bcctp.htm or call the New York State Cancer Services Program at 1-866-442-2262.

For more information about **Medicaid**, visit: www.health.ny.gov/health_care/medicaid/ or call the New York State Medicaid Help Line at 1-800-541-2831.

For more information about **Family Health Plus**, visit: www.health.ny.gov/nysdoh/fhplus/ or call the Family Health Plus Information Line at 1-877-9FHPLUS (1-877-934-7587).

9 Life After Breast Cancer Treatment

A cancer survivor is someone who has been diagnosed with cancer, from the time they receive a diagnosis, during cancer treatment, and after treatment. There are steps that survivors can take to keep themselves healthy after they have finished cancer treatment.

Follow-up Care

It is important to follow up and continue seeing your health care team even after you finish treatment. At first, you will probably have appointments every 3 to 6 months. It is likely that the longer you have been free of cancer, the less often the appointments will be needed. Remember to:

- Continue seeing your primary care provider for regular medical checkups,
- Tell your provider right away about any health problems or any changes in the area where you had treatment or in your other breast, and
- Continue getting **mammograms** and clinical breast exams as recommended by your doctor.

Medical Records

Keeping copies of your medical records allows you to keep track of your own care and gives you accurate information to share with other doctors in case you move or change insurance plans. You can request records by filling out a medical record release form at your doctor's office or hospital. Remember to keep all of your records together in one easy-to-find place.

You may also want to ask your cancer doctor for a brief (1-2 pages) summary to help your primary care provider give you the best possible care over the course of the rest of your life. The summary should include:

- Your cancer diagnosis and stage,
- All of your test results,
- Descriptions of all of your surgeries, including their findings,
- All of your treatments: for chemotherapy – the name of the drugs, including the dose, timing, and any side effects; for radiation – the location of where the radiation was directed and the total amount received,
- Any other therapies, such as nutrition or counseling,
- A list of recommended follow-up tests and how often they should be done, and
- Full contact information for all of the specialists involved in your cancer care.

Encourage your close relatives (daughters, sisters) to have recommended breast cancer screenings. Remember, breast cancer survivors can become champions and leaders for others.

For more information on **cancer survivorship and life after cancer treatment**, visit: cancernet.nci.nih.gov/cancertopics/life-after-treatment

10 Questions to Ask Your Health Care Team

Here are suggested questions to ask when you are first diagnosed. Write these down and take them with you when you see your doctor.

Questions to Ask Your Health Care Team

Cancer Diagnosis

- Would you please write down the specific kind of breast cancer I have?
- Do my lymph nodes show any signs of cancer?
- What stage of breast cancer do I have?
- What are the chances that my cancer has spread beyond my breast?
- What are the advantages to being treated at a specialized cancer center?
- What other tumor markers has my breast cancer been tested for (e.g. estrogen and progesterone **hormone receptors**)?

Genetic Testing

- Should I see a **genetic counselor**?
- Is there any chance that I inherited this cancer from my family?
- Are my other family members at increased risk for breast cancer?
- Are there other cancers that I may be at increased risk for?

For more information about genetic testing, visit: www.cancer.gov/cancertopics/Genetic-Testing-for-Breast-and-Ovarian-Cancer-Risk

Questions to Ask Your Health Care Team

Cancer Treatment

- When will my treatment or treatments start? When will it end?
- What are my treatment choices?
- How often will I have treatments?
- How long will each treatment last?
- Where will I go for my treatment?
- Will I be able to drive home afterward?
- What side effects may I get?
- Are there medications or other ways to help me manage side effects?
- What can I do to take care of myself before, during, and after treatment?
- Are there any long-term effects that I should expect?
- Who will be in charge of my treatment?

Breast Cancer Surgery

- Is breast conservation therapy an option for me? What operation do you recommend for me? Why?
- How large will my scar be? Where will it be?
- How much breast tissue will be removed?
- Will a sentinel node biopsy be done to see if I need more lymph nodes removed with an axillary node dissection? Why or why not?
- Will my lymph nodes be removed? Why or why not?
- Will I need to stay in the hospital? If so, for how long?
- Is there someone I can talk with who has had the same kind of surgery I'll be having?
- What activities should I avoid? When can I return to my regular activities?

Questions to Ask Your Health Care Team

- Will my surgical area need special care?
- Will I go home with a surgical drain, sutures, clips that need special care and removal?
- What should I do if I experience side effects? Who should I call?

Chemotherapy

- Do I need chemotherapy?
- How successful is chemotherapy for the type of cancer that I have?
- Can I work while I'm having chemotherapy?
- How can I prevent or manage nausea?
- Will I lose my hair?
- Will I stop menstruating?
- Will it affect my ability to have a child?

Hormonal Therapy

- Will hormonal therapy help me?
- How successful is hormonal therapy for the type of cancer that I have?
- Is there anything that will help me deal with side effects?
- How long will I need to be on hormonal therapy?

Targeted Therapy

- Will treatment with a targeted therapy help me?
- How successful is targeted therapy for the type of cancer that I have?
- Is there anything that will help me deal with side effects?

Questions to Ask Your Health Care Team

Radiation Therapy

- Do I need radiation therapy?
- How successful is radiation therapy for the type of cancer that I have?
- How will radiation be given?
- How will treatment affect my skin?
- How can I manage skin discomfort during radiation therapy?

Breast Reconstruction

- Which type of surgery will give me the best result? What other options do I have?
- How many surgeries will I need?
- Are breast implants safe?
- How many breast reconstructions have you done?
- Can I see pictures of women you have reconstructed? Can I contact any of them?
- How long will my recovery take?
- What activities should I avoid? When can I return to my regular activities?

11 Breast Cancer Hotlines, Support Groups, and Other Resources

These statewide or national organizations can provide you with information about support groups, hotlines with trained volunteers that can answer questions about treatment and support, and other information, materials, and services related to breast cancer. Calling these hotlines or going to these websites will connect you to support organizations in your area.

Adelphi University Breast Cancer Hotline

1-800-877-8077

A statewide hotline that provides information, referrals and emotional support for people with questions about breast cancer. Operates seven days a week; staffed by trained volunteers, many of whom are breast cancer survivors.

Website: www.adelphi.edu/nysbreastcancer/

American Cancer Society (ACS) National Hotline

1-800-ACS-2345 (1-800-227-2345)

Local chapters are listed in the white pages of your telephone book and may be found on the ACS website. Provides free information and emotional support from trained volunteers anytime before, during, or after treatment. **Website:** www.cancer.org

Breast Cancer Network of Strength Your Shoes Hotline
English 1-800-221-2141, Spanish 1-800-986-9505

Cancer survivor volunteers share personal experiences on everything from treatment information to emotional recovery. Local branches also provide wig and prosthesis banks. **Website: www.networkofstrength.org/**

Breastcancer.org

An online nonprofit organization that provides comprehensive information on breast cancer diagnosis, treatment, research and day-to-day matters that affect the lives of breast cancer survivors. **Website: www.breastcancer.org/**

Cancer and Careers

An on-line resource for women returning to work after cancer treatment.
Website: www.cancerandcareers.org

Cancer Care, Inc.

275 Seventh Avenue, New York, NY 10001

1-800-813-HOPE (1-800-813-4673) or (212) 712-8080

An organization which provides a variety of counseling and emotional support services for cancer patients in person, over the phone, and via e-mail; also runs educational programs and provides financial assistance for patients in need. All services are free.

Website: www.cancercare.org

Cancer Hope Network

2 North Road – Suite A, Chester, NJ 07930

1-877-HOPENET (1-877-467-3638)

Provides free one-on-one support for cancer patients and their families by volunteers who have been through the cancer experience. **Website: www.cancerhopenetwork.org/**

Cancer Survivors Network

A web-based social network for cancer survivors, their families, caregivers, and friends where members can share experiences and learn about services.

Website: www.acscsn.org

CancerNet

Cancer information from the American Society of Clinical Oncology. Provides comprehensive information for anyone with a question about cancer, for patients, caregivers, health care professionals, researchers, and others. **Website:** www.cancer.net/

Coping: Living with Cancer

P.O. Box 682268, Franklin, TN 37068-2268

(615) 791-3859

A magazine for people living with cancer, whether their own or that of a friend or family member. **Website:** www.copingmag.com/cwc/

Gilda's Club

A free emotional and social support community for people with cancer and their families and friends. Sponsors workshops, lectures, support groups, and social events; local branches listed on their website. **Website:** www.gildasclub.org

Lance Armstrong Foundation

Offers information on cancer, clinical trials, and cancer survivorship, as well as advocacy, fundraising and volunteer opportunities. **Website:** www.livestrong.org/

Living Beyond Breast Cancer

10 East Athens Avenue, Suite 204, Ardmore, PA 19003

1-888-753-5222

Offers up-to-date information to women living with breast cancer on breast cancer treatment, recurrence, and research. **Website:** www.lbbc.org/

Look Good... Feel Better

This program focuses on techniques that can help people undergoing cancer treatment improve their appearance. **Website:** www.lookgoodfeelbetter.org/

National Breast Cancer Coalition

1707 L Street NW, Suite 1060, Washington, DC 20036
(202) 296-7477

A national advocacy group that lobbies for increased research funding, access to medical services, and education. **Website:** www.natlbcc.org

National Cancer Institute Cancer Information Hotline

1-800-4-CANCER (1-800-422-6237)

Offers free state-of-the-art information in English or Spanish on treatment, clinical trials, eating hints, advanced cancer, and services in your area. **Website:** www.nci.nih.gov

The National Cancer Institute has information on its website on how to find a *clinical trial* (a research study that tests the safety and/or effectiveness of a new cancer treatment or surgery). **Website:** cancernet.nci.nih.gov/dinicaltrials/finding/treatment-trial-guide

National Lymphedema Network

Latham Square, 1611 Telegraph Avenue, Suite 1111, Oakland, CA, 94612-2138
1-800-541-3259

Provides complete information on prevention and treatment of lymphedema and support groups. **Website:** www.lymphnet.org

National Women's Health Network

514 10th St. NW, Suite 400, Washington, DC 20005
(202) 347-1140

Advocate for women's health issues. Provides newsletters and position papers on women's health topics. **Website:** nwhn.org/

New York State Department of Health Cancer Services Program
1-866-442-CANCER (1-866-442-2262)

Oversees programs in every county and borough in NYS that: offer breast, cervical and colorectal cancer screening and diagnostic testing for eligible, uninsured and underinsured New Yorkers and assistance enrolling in the Medicaid Cancer Treatment Program providing coverage for eligible people diagnosed with breast, cervical, colorectal and prostate cancer. Callers to the phone line and website visitors can also access community-based programs funded by the NYS DOH that provide support, education, and counseling for breast cancer survivors and long- and short-term supportive services for legal, financial and medical access issues as well as contact information for genetic counselors. **Website: www.health.ny.gov/nysdoh/cancer/center/partnerships/**

Oncolink: The University of Pennsylvania Cancer Center Resource

A comprehensive source of information about all kinds of cancers, including breast cancer. Includes links to on-line cancer discussion lists and to the National Cancer Institute's Physician Data Query database. **Website: www.oncolink.com**

SHARE: Self-Help for Women with Breast or Ovarian Cancer

1501 Broadway, Suite 1720, New York, NY 10036

(212) 719-0364

Breast Cancer Hotline: English (212) 382-2111, Spanish (212) 719-4454

A self-help organization that offers support groups, educational programs, hotlines, wellness programs and advocacy for women with breast or ovarian cancer. All programs for patients and their families/caregivers are free of charge.

Website: www.sharecancersupport.org

Sisters Network, Inc.

2922 Rosedale St., Houston, TX, 77004

1-866-781-1808

A national African-American breast cancer survivorship organization. Offers community outreach educational programs, an Annual National African American Breast Cancer Conference, and an online Breast Cancer Social Network.

Website: www.sistersnetworkinc.org/

Susan G. Komen Breast Cancer Foundation

Komen Help Line 1-800-462-9273

Volunteers “who have been there” are available to offer support, answer questions, and provide education about issues related to cancer. **Website: www.komen.org**

The Wellness Community

Provides online support groups for cancer patients and their families in both English and Spanish. **Website: www.thewellnesscommunity.org/mm/Newly-Diagnosed/Find-Support.aspx**

YWCA Encore Plus

Provides discussions and rehabilitative exercises for women with breast cancer. Contact your local YWCA to find out if they offer the Encore Plus program; locations and contact information for local YWCAs are listed on the website. **Website: www.ywca.org/siteapps/custom/ywca/local.aspx?c=djISl6PIKpG&b=281414**

12 Definitions

Adjuvant therapy Treatment given after surgery to destroy any remaining cancer cells and prevent the cancer from coming back in the breast or to treat cancer that has spread to other areas of the body.

Anesthesia Drugs given before and during surgery so you won't feel the surgery. You may be awake or asleep.

Axillary nodes The lymph nodes in the armpit.

Axillary node dissection Removal of the lymph nodes in the armpit.

Breast surgeon A surgeon who specializes in operating on the breast.

Breast conservation therapy A treatment of early-stage breast cancer involving surgery (usually lumpectomy).

Cancer survivor Anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life.

Chemotherapy Treatment with drugs to kill or slow the growth of cancer.

Clinical nurse specialist A nurse with special training who can help answer questions and provide information on resources and support services.

Clinical trial A study done with cancer patients to find out whether promising approaches to cancer prevention, diagnosis, and treatment are safe and effective

DIEP (Deep inferior epigastric perforator flap) Fat, skin and blood vessels from the lower belly are surgically moved to the chest to reconstruct a breast, creating a new one.

Ducts Tubes or channels that transport breast milk from the lobules to the nipples.

Estrogen An important hormone that regulates the menstrual cycle and contributes to the development of female sexual characteristics, such as breasts.

Genetic counselor A health professional with training in genetics and counseling who can help review your family history, understand your risk of having an inherited gene mutation for cancer, describe your options, and help you decide if genetic testing is right for you.

Hormonal therapy A breast cancer treatment that is used to block female hormones (estrogen and progesterone). These hormones promote the growth of some types of breast cancer tumors.

Hormone receptors Tell the body to “turn on” breast cell growth, both normal and abnormal growth.

Hormones Substances produced by various glands in the body that affect the function of body organs and tissues.

Implant A silicone or saline-filled sac inserted under the chest muscle to restore breast shape.

In situ cancer Very early or noninvasive growths that are confined to the ducts or lobules in the breast.

Inflammatory breast cancer A rare type of cancer where the skin of the breast is bright red and swollen.

Intravenous (IV) Medicine or fluids are given directly into the vein.

Lobules The glands that produce breast milk.

Lumpectomy Surgical removal of breast cancer, a small amount of normal tissue surrounding the cancer, and lymph nodes.

Lymph nodes Part of the immune system that filters fluids and removes germs and other materials from the body. Lymph nodes in the armpit are usually removed to find out whether the breast cancer has spread.

Lymphedema Swelling in the arm caused by fluid that can build up when the lymph nodes are removed during surgery or damaged by radiation.

Mammogram An x-ray of the breast.

Mastectomy Surgery to remove the breast.

Medical oncologist A doctor who is specially trained to diagnose and treat cancer with chemotherapy or other drugs.

Neoadjuvant therapy Treatment to shrink cancer before surgery.

Nutritionist A health professional with training in nutrition who can offer help with choices about the foods you eat during cancer treatment.

Physical therapist A health professional who teaches exercises that help restore arm and shoulder movements after surgery.

Plastic surgeon A doctor who can rebuild (reconstruct) your breast.

Progesterone A female hormone produced by the ovaries, placenta and adrenal glands.

Prosthesis Can either refer to a breast form that may be worn in a bra after a mastectomy or to the technical name of a breast form that is placed under the skin in breast reconstruction.

Radiation Energy carried by waves or by streams of particles. Various forms of radiation can be used in low doses to diagnose cancer and in high doses to treat breast cancer.

Radiation oncologist A doctor who uses radiation therapy to treat cancer.

Radiation therapy Treatment that uses radiation to kill cancer cells.

Radiologist A doctor who reads mammograms and performs other tests, such as x-rays or ultrasound.

Saline Salt water used to fill some breast implants.

Sentinel node biopsy Addition of dye during breast surgery to help locate the first lymph node into which the tumor drains; the node is then removed to prevent spread of cancer and tested to determine whether cancer cells are present.

Silicone A liquid gel that is used as an outer coating on implants and to make up the inside filling of some breast implants.

Social worker A professional who can talk with you about your emotional or physical needs.

Staging/Stage Classifying breast cancer according to its size and spread.

Support group A group of people with similar concerns or experiences who gather to share feelings, problems, and information with each other.

Surgical oncologist A doctor who specializes in performing surgeries to treat cancer such as the removal of your lump (lumpectomy) or your breast (mastectomy).

Targeted therapy Targeted cancer therapies use drugs or other substances to specifically target changes in cells that cause cancer.

TRAM (Transverse rectus abdominis muscle flap) A muscle from the lower belly, along with skin and fat, is surgically moved to the mastectomy site and shaped like a breast.

Tumor An abnormal growth of tissue. Tumors may be either benign (not cancer) or malignant (cancer).

Tumor markers Substances that can be found in abnormal amounts in the blood, urine or tissues of some people with cancer.



State of New York
Department of Health