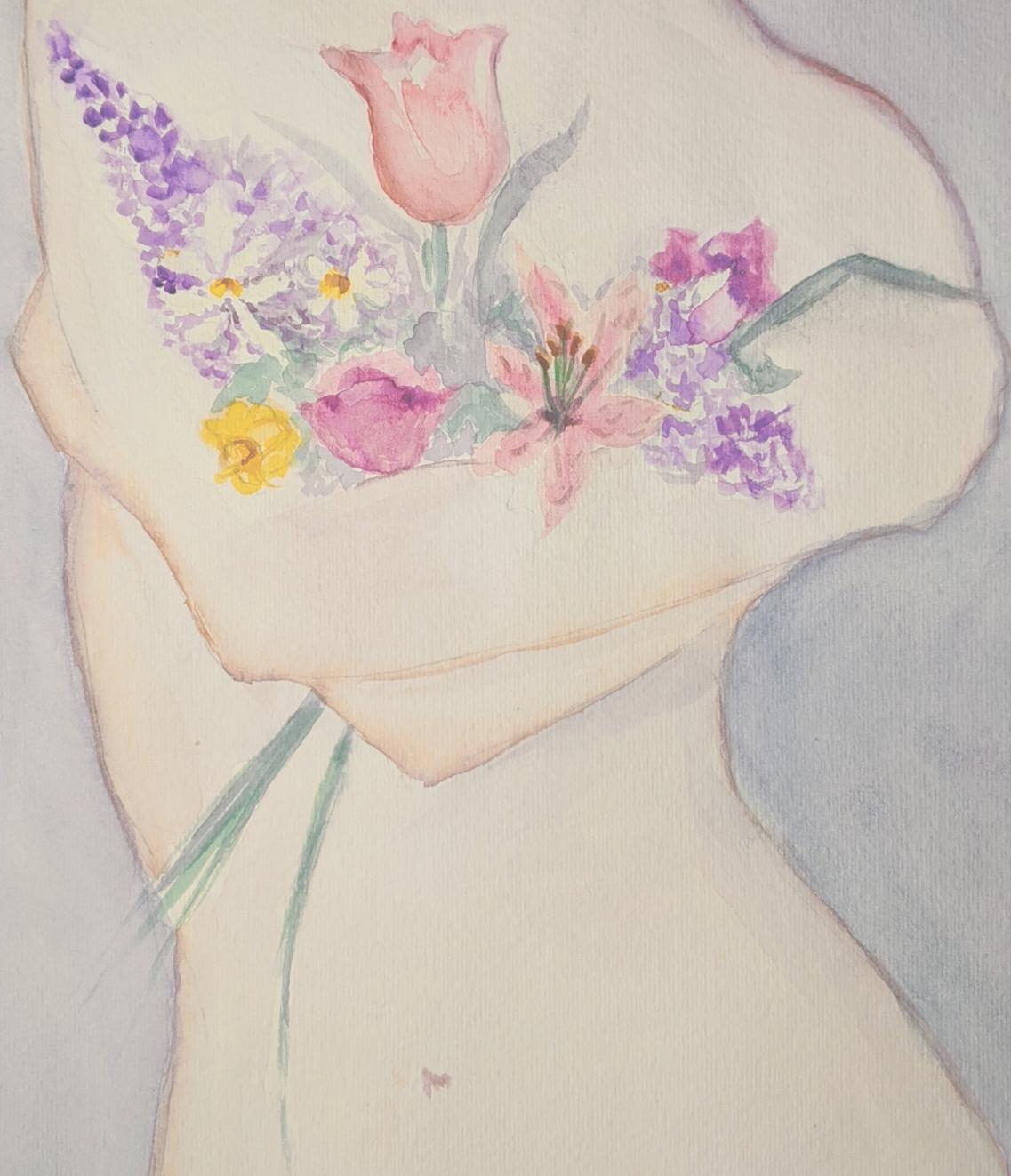


Breast Cancer:

Common questions after diagnosis



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2010

Breast Cancer: Common questions after diagnosis

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Being diagnosed with cancer is a life-changing experience for many and life-disruptive for nearly everyone. This reference guide provides information and support and addresses many of the common questions that come up as you go through each step.

Dealing with a diagnosis

Why do I feel this way?

It is normal to be overwhelmed by emotions such as depression, fear, and anxiety. You are not alone. Many patients struggle with their emotions, the decisions to be made, and the feeling of a loss of control. Each person works through these emotions in her/his own time and own way. Some emotions come back time and again. All of this is normal. Remember that tears are okay and part of the process includes grieving for the change in your life and your body image. Be gentle with yourself and give yourself the time, permission, and support that you need to get through this life challenge.

How do I tell people about my diagnosis?

You decide when to tell your loved ones. It is your story and you get to share it in your own time. Sometimes, using technology to communicate can help avoid having to repeat the same news to many people. You might choose a trusted friend or family member to get the word out on your behalf. This can shield you from having to respond to people when you don't feel up to it.

Prepare yourself for the reactions people may have. They are also in emotional pain. Some people in your life may withdraw, or act out. While this can be surprising or feel hurtful, it is helpful to realize their reaction is about them, not you. You may also have people surprise you with their compassion and generosity. New friends are often made during treatment. Accept support in ways you feel comfortable.

When should I tell my children?

Talk to your children as soon as you can about your diagnosis to establish trust and open communication with them. Reading an age-appropriate book that touches on the issues can be a helpful tool. When helping your children cope with your diagnosis, it's almost impossible to be prepared for every situation. Sometimes you may not know what to say. This is normal and okay. Remember that you know your children best and trust your sense of how to best support them during this time. Sometimes children will need to talk to a therapist to work through their feelings and your healthcare team can refer you to appropriate professionals

Should I get a second opinion?

Second opinions are often helpful. Your care team can recommend and facilitate referrals to major cancer centers. You can pursue a second opinion even after a treatment plan has been established. Insurance often pays for second opinions. You will need the initial doctor's office to send copies of your records to the new doctor, usually in advance of your appointment.

Where can I find more information?

Be very careful about doing online research; look for websites that end in .org, .gov, or .edu. Ask CRC or your doctor for reliable websites. Local or online breast cancer support groups can provide an opportunity to hear the experiences of others who have undergone the treatment options you are considering.

Helpful communication websites:

My Life Line

<https://www.mylifeline.org/>

Caring Bridge

<https://www.caringbridge.org>

General information websites:

American Cancer Society

<https://www.cancer.org/breast-cancer.html>

BreastCancer.org

<https://www.breastcancer.org/>

National Cancer Institute

<https://www.cancer.gov/types/breast>

Talking to your healthcare team

It is important to understand your diagnosis and options because this will help you make the best decisions possible. A lot of information will come at you all at once. It is a good idea to bring another person with you to appointments. Another set of ears can be very helpful for understanding everything your doctor is saying. Some people prefer to write down the information, as it helps them remember; others prefer to have someone else take notes. Repeating the information back to the doctor can ensure your understanding. You can also ask to record your appointments using a cell phone. Many offices provide a written summary of the visit at the conclusion of your visit and/or provide it through the patient portal. Reading the visit note (ask for a copy or view through patient portal online) can give you an understanding of the appointment from your doctor's perspective.

You will be faced with many decisions when you are diagnosed with breast cancer. It is important to establish good communication with your care team. Ask questions when things are unclear. When things feel overwhelming consider asking yourself and your provider, "What are the top three things I need to know TODAY?"

Common questions regarding diagnosis:

- What type of breast cancer do I have and what stage is it?
- Do you have written information on my cancer diagnosis that I can take home to read?
- What are the options I have for treating my cancer?
- Are there any clinical trials that I might qualify for?
- What are the local support agencies that can help me?

Common questions regarding treatment plan:

- What are my treatment options?
- What are the goals of this treatment?
- How long will each treatment last, how often are they, and how many will I need?
- How long can I wait before starting treatment?
- Can I have treatment locally?
- What are the side effects and/or risks of this treatment?
- How well can potential side effects be managed to minimize discomfort?
- Is there information I can read on this treatment and potential side effects?
- Once I begin treatment, how do I know when a side effect is serious enough to call the office? Is there a special number to call? How do I get in touch with my doctor?
- If I have questions during my treatment, to whom should I speak?
- Can I go alone to treatments or should someone be prepared to accompany me?
- Can someone stay with me during my treatments?
- How will I know if the treatments are working?
- How much will my treatment cost?
- Is there a less expensive alternative?
- Is there anything I can do during my treatment to take better care of myself?
- How will insurance for my treatments be handled? Will you send bills directly to insurance for me?
- Does my insurance participate with this hospital/provider?

Questions every cancer patient should ask

These three questions may sound simple, but they aren't asked nearly enough. Not only is it more than OK to ask – it's encouraged!

1. Can you repeat that?

Getting diagnosed with cancer can be like walking through a hurricane. Winds are swirling all around and you're just trying to stay on your feet. It can be difficult to remain clear-headed and to absorb all that you are being told. No one expects you to hear and understand everything the first time.

Patients (and family members) are encouraged to ask questions and to request that physicians and other health professionals repeat themselves if something is unclear. If you still don't understand, ask about other resources that might be helpful. Often there's a nurse, patient navigator, or other individual who can answer additional questions and explain what you can expect. You can ask for information in writing, so that you don't have to rely solely on your memory.

2. How long can I safely wait before beginning treatment?

Cancer treatment is often not an emergency. Many people feel pressured to begin treatment immediately after diagnosis. In most cases, it's quite reasonable to wait a few weeks. This provides the opportunity to seek second opinions if you desire, or to complete necessary life tasks. A few cancers are especially aggressive and do require the initiation of treatment within a few days. Ask your doctor how long you can safely wait before beginning treatment.

3. Which doctor is coordinating my care?

While it is common to have multiple doctors involved in your treatment, it's helpful to have one doctor serve as the captain of your ship. If you suddenly feel ill or have another problem, you'll want to know which doctor to call. If the answer isn't clear, please ask.

Confusion also exists when your treatment is completed and you're transitioning back to your primary care physician. It's not always obvious who is going to order your mammograms or other routine tests. Be sure to ask.

Breast cancer basics

What is it and why?

Cancer is a broad term for a class of diseases characterized by abnormal cell growth in the body. Cancer begins in the cells which are the basic building blocks that make up tissue.

Sometimes, the process of cell growth goes wrong; new cells form when the body doesn't need them and old or damaged cells do not die as they should. When this occurs, a buildup of cells forms a mass called a lump, growth, or tumor.

Breast cancer starts in the cells of the breast as a group of abnormal cells that grow uncontrolled and can then invade surrounding tissues or spread (metastasize) to other areas of the body. Breast cancer is not a sudden occurrence but a growth that has been developing for a period of time.

Cancer cells can spread by breaking away from the original tumor and enter blood vessels or lymph vessels, which branch into tissues throughout the body. When cancer cells travel to other parts of the body and begin damaging other tissues and organs, the process is called metastasis.

Types, cells, hormones, and genetics

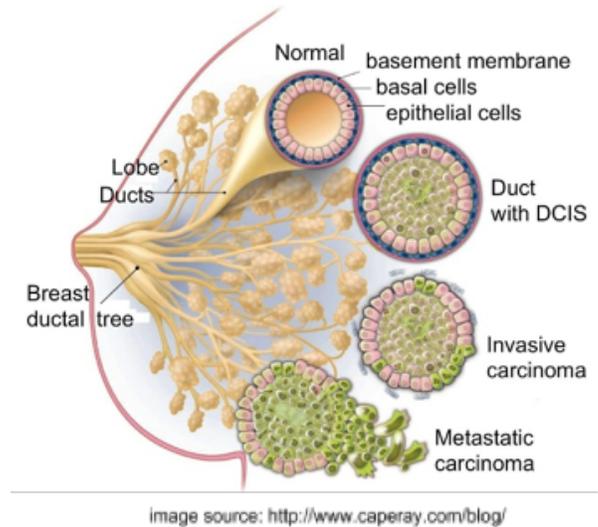
Not all breast cancers are the same. The type of tissue where your breast cancer arises determines how the cancer behaves and what treatments are most effective.

Where does breast cancer begin in the breast?

LOBULAR carcinoma starts in the milk producing lobules of the breast. Groups of lobules are called lobes. The lobes are connected to the ducts, which carry breast milk to the nipple.

DUCTAL carcinoma is the most common type of breast cancer. This type of cancer forms in the lining of a milk duct within the breast. The ducts carry breast milk from the lobules, where it's made, to the nipple.

SARCOMA (connective tissue): Rarely breast cancer can begin in the connective tissue that's made up of muscles, fat, and blood vessels. When cancer begins in the connective tissue, it is called sarcoma. Examples of sarcomas that can occur in the breast include phyllodes tumor and angiosarcoma.



What are the different types of breast cancer?

Ductal carcinoma in situ (DCIS) is a non-invasive breast cancer where abnormal cells are contained within the ducts.

Invasive ductal carcinoma means abnormal cells that started in the lining of the duct have invaded surrounding tissue.

Inflammatory breast cancer is a less common form of breast cancer that may not develop a tumor and often affects the skin.

Metastatic breast cancer means breast cancer cells have spread beyond the breast - sometimes into the lungs, liver, bones, or brain.

Less common types of breast cancer include medullary carcinoma, tubular carcinoma, and mucinous carcinoma. For further description, please visit the following websites:

<https://www.cancer.org/breast-cancer.html> (American Cancer Society)

breastcancer.org

nationalbreastcancer.org

Are my cancer cells fueled by hormones?

Some breast cancer cells are sensitive to your body's naturally occurring hormones — estrogen and progesterone. They have receptors, which are proteins found inside and on the surface of cells. These receptor proteins are the "eyes" and "ears" of the cells, receiving messages from substances in the bloodstream and then telling the cells what to do. Treatments have been developed that utilize these receptors to treat breast cancer.

Knowing whether your breast cancer is sensitive to hormones gives your doctor a better idea of how best to treat the cancer or prevent cancer from recurring.

Hormone status of breast cancers includes:

Estrogen receptor (ER) positive. The cells of this type of breast cancer have receptors that allow them to use the hormone estrogen to grow. Hormonal therapy can include medications that either (1) lower the amount of estrogen in your body or (2) block estrogen from supporting the growth and function of breast cells.

Progesterone receptor (PR) positive. This type of breast cancer is sensitive to progesterone, and the cells have receptors that allow them to use this hormone to grow. Treatment with endocrine therapy blocks the growth of the cancer cells.

Hormone-receptor (HR) negative breast cancers won't be affected by endocrine treatments aimed at blocking hormones in the body.

What is HER2 status?

Another receptor that is NOT a hormone receptor, but equally important in breast cancer, is HER2, a protein called human epidermal growth factor receptor 2 (HER2), which promotes the growth of cancer cells. Doctors will evaluate whether your breast cancer involves a gene mutation that makes an excess of the HER2 protein.

HER2-positive breast cancer is a breast cancer that tests positive for HER2. About 20% of breast cancers are HER2-positive. Newer drugs, including trastuzumab and other biosimilars, specifically target this protein and are used for treating this type of breast cancer.

Triple negative breast cancer

Some breast cancers are known as "Triple Negative Breast Cancer" because they are negative for estrogen, progesterone, and HER2/neu receptors. This means the growth of the cancer is not fueled by the hormones estrogen and progesterone, or by the HER2 protein. So, triple-negative breast cancer does not respond to hormonal therapy medicines or medicines that target HER2 protein receptors. However, other medicines are used to successfully treat triple-negative breast cancer.

What is the genetic makeup of my breast cancer cells?

Cancer arises due to the mutations in the DNA genome of a cell. These mutations can be inherited (passed down from parents) or may arise during the lifetime of an individual. Doctors are just beginning to understand how the individual DNA changes within cancer cells can be used to determine treatment options. By analyzing the genes of cancer cells, doctors hope to find ways to target specific aspects of cancer cells to kill them.

A sample of your tumor tissue from a biopsy procedure can be tested in a laboratory to look for:

- **HER2 gene.** Cancer cells that have too many copies of the HER2 gene (HER2-positive cancers) produce too much of the growth-promoting protein called HER2. Targeted therapy drugs are available to shut down the HER2 protein, thus slowing the growth of these cancer cells.
- **Other tumor markers.** Researchers are studying ways to interpret the genetic makeup of tumor cells. Doctors hope this information can be used to predict which cancers will spread and which may need aggressive treatments. That way, women with relatively low-risk breast cancers may avoid aggressive treatments.
- **Tests that analyze the genetic makeup of breast cancers** are available but aren't recommended in all situations. Ask your doctor whether this type of test might be helpful in your case.

Genetic testing

Your physician may suggest genetic testing to see if your breast cancer may be caused by an inherited genetic mutation. Examples for why genetic testing may be considered:

- You are diagnosed with breast cancer before the age of 50.
- You have cancer in both breasts.
- You have a family history with multiple family members diagnosed with breast cancer, or a combination of both breast and ovarian cancers.
- A single family member has two or more primary types of BRCA1 or BRCA2 related cancers.
- You are of Ashkenazi Jewish ethnicity.
- You are a male with breast cancer.

For further information about genetic testing:

<https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet>

<https://www.facingourrisk.org/>

Understanding more about the genetic makeup of your cancer may help doctors choose the most effective treatment for your specific cancer. As more research is done, the treatment of your breast cancer will become more personalized.

What role does my lymphatic system play?

The lymphatic system is a network of thin, tube-like vessels. They carry a clear lymph fluid to all parts of the body to remove cellular waste. They follow very closely to blood vessels and “pick up their waste products.” The lymphatic fluid then flows into the rounded areas of the lymph system; the lymph nodes, which act as filters by stopping bacteria, cellular waste, and cancer cells from entering the bloodstream. The lymphatic system is a major route by which cancer spreads or metastasizes. Cancer cells can reach the lymphatic system, travel through it, and begin to multiply in a part of the body far away from the original tumor. Some cancer cells may get through this lymphatic filter system and enter the bloodstream.

The majority of lymphatic fluid leaving the breast is drained through lymph nodes located around the armpit; referred to as the axillary nodes. A small amount of fluid is drained through other lymph nodes nearby.

Can men get breast cancer?

Yes, they can. Male breast cancer accounts for about one percent of the breast cancers diagnosed yearly. Most male breast cancers are found by the man noticing a change in his breast such as a hard lump or discharge from his nipple. Diagnostic and biopsy procedures are the same for men and women. Treatments including surgery, chemotherapy, and radiation are also similar to the treatment for women. Men are often encouraged to have genetic testing because of a higher incidence of BRCA2 mutations. A good online source for further information about male breast cancer is: <https://www.cancer.gov/types/breast/patient/male-breast-treatment-pdq>

Since male breast cancer is relatively rare, online support can be especially helpful. One advocacy organization focusing on this population is: <https://malebreastcancercoalition.org/>

Breast cancer and pregnancy

If you are diagnosed with breast cancer while pregnant, your treatment may be altered in order to get the best treatment for your cancer while protecting your developing baby. The type and timing of treatment will need to be planned carefully and coordinated between your cancer care team and your obstetrician.

The goal when treating a pregnant woman with breast cancer is the same as when treating a non-pregnant woman: to cure the cancer whenever possible, or to control it and keep it from spreading if it can't be cured. The extra concern of protecting a growing fetus may make treatment more complicated. Most treatment options can be adapted to allow the woman to continue with a successful pregnancy.

Surgery

What is the difference between a mastectomy and a lumpectomy?

Under certain circumstances, people with breast cancer have the opportunity to choose between total removal of a breast (mastectomy) or breast-conserving surgery (lumpectomy). For people with only one site of cancer in the breast and with a small enough tumor size, a lumpectomy followed by radiation is generally considered to be equally effective as mastectomy. Talk with your care team about the best options for your individual situation.

Lumpectomy

During lumpectomy, the surgeon removes the cancer tumor and some of the normal tissue around it, called the margins (See image.) In general, a lumpectomy is considered to provide better patient quality outcomes compared to a mastectomy because lumpectomy is a less invasive surgery and usually comes with a shorter recovery time.

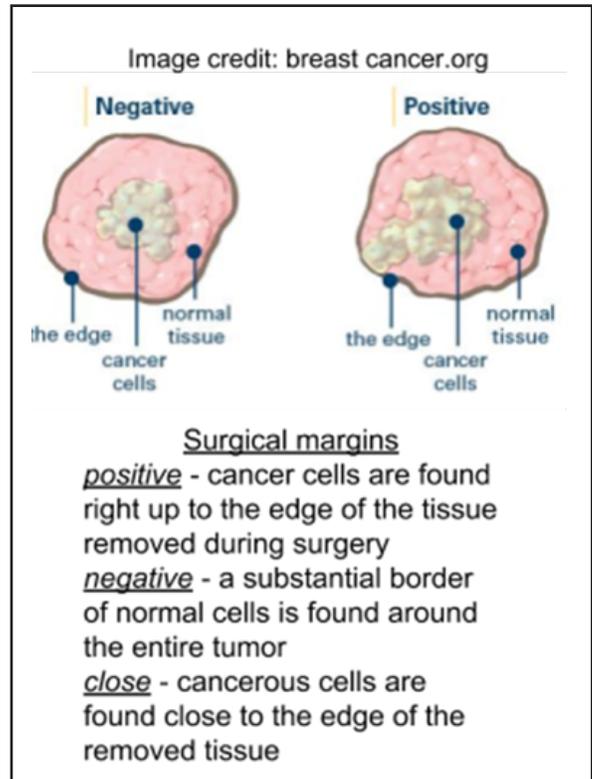
Other factors to consider if lumpectomy is an option:

- Much of the appearance and sensation of your breast can be preserved.
- If cancer cells are found in the margins with the pathology report, more surgery will be needed to remove tissue until the margins are free of cancer (this is known as a re-excision).
- Radiation therapy is commonly given after lumpectomy. Radiation therapy may affect the timing of reconstruction and possibly reconstruction options after surgery.
- If a local recurrence does occur, usually a mastectomy is recommended.

Mastectomy

For some women, removing the entire breast provides greater peace of mind - "just get the whole thing out of there!" However, mastectomy is more extensive than lumpectomy, with more post-surgery side effects and a longer recuperation time. Several other factors to consider about having a mastectomy are:

- Mastectomy means a permanent loss of your breast, so a choice will need to be made about whether to have reconstruction surgery, an implant, use breast prosthesis, or do nothing to replace your breast.
- Breast reconstruction is performed by a plastic surgeon either at the same time as the mastectomy, or at a later date. Additional surgeries will be needed to reconstruct your breast after mastectomy.
- Radiation therapy may still be needed, depending on the results of the pathology.



What is sentinel lymph node mapping?

Sentinel lymph node mapping is a part of your surgical procedure and it is used to determine whether cancer has spread beyond a primary tumor into your lymphatic system. The sentinel nodes are the “gate keepers” to the rest of the lymph nodes. The surgeon will inject either a radioactive solution or dye prior to the surgery. During the surgery, the surgeon will see which of the lymph nodes are the first ones to drain from the breast and will remove the first one or two nodes. The sentinel node is more likely than other lymph nodes to contain cancer. This information will be used to help determine your care plan. For further information: <https://www.cancer.gov/about-cancer/diagnosis-staging/staging/sentinel-node-biopsy-fact-sheet>

What questions should I ask my surgeon?

It is important to have as much information as you can when making your decision about surgery so that you know your options. If you don't understand something, ask your surgeon about it. Here's a list of questions to get you started.

- What are the advantages and disadvantages of each surgical approach for me?
- What's the average cost of each type? Will my insurance cover them?
- What possible problems should I know about?
- What results can I expect?
- How long will I be in the hospital?
- How much discomfort or pain will I feel?
- Will I need blood transfusions?
- What will I need to do at home to care for my incisions (surgical wounds)?
- How much help will I need at home to take care of my wound?
- How long will it take me to recover and when will I be able to go back to normal activities such as driving and working?
- How much activity can I do at home? Will I be taught exercises to do after surgery?
- What do I do if my arm swells? (this is called lymphedema)

When considering a mastectomy, there are some additional questions to consider:

- Can I have breast reconstruction?
- What is the best timing for me to have reconstruction?
- How many of these procedures have you (plastic surgeon) done?
- Will the reconstructed breast match my other breast?
- How will my reconstructed breast feel to the touch?
- Will I have any feeling in my reconstructed breast?
- Will there be pain, scars, or other changes in the parts of my body the tissue is taken from (if using a tissue flap)?
- Will reconstruction interfere with chemotherapy?
- Will reconstruction interfere with radiation therapy?
- How long will the implant last?
- What kinds of changes to the breast can I expect over time?
- How will aging affect the reconstructed breast?
- What happens if I gain or lose weight?
- Are there any new reconstruction options that I should know about, including clinical trials?

If I choose to have a mastectomy, should I have breast reconstruction?

Your breasts may be such an important part of your identity - your sense of who you are - that you'll go to great lengths to preserve them. That's a completely acceptable approach to take, no matter what your age or figure - AS LONG AS it doesn't endanger your overall health and chances for a full recovery. To connect with others who are facing breast cancer surgery, join the breastcancer.org discussion board for surgery (<https://community.breastcancer.org/forum/91>) which includes threads connecting members based on their surgery month.

The decision to have breast reconstruction is yours to make. Try to learn as much as you can before deciding what to do. You and those close to you should talk with your healthcare team about your questions and concerns.

Things to consider if you are thinking about breast reconstruction:

- Are you comfortable with the way your chest will look (without a breast) after mastectomy? If so, you may not want breast reconstruction. This is becoming a more popular choice. Breast Free (breastfree.org) is a great website to find information and support if you are considering not having reconstruction.
- Have you talked with your plastic surgeon about your options? You may not be able to have some types of reconstruction. For example, it can be hard to place a breast implant if you have had radiation. But, it can be done before radiation.
- Are you willing to have a second surgery? Not all types of breast reconstruction can be done at the same time as mastectomy and may require further surgery.
- You may not have to make a decision right away. Your options may be different based on the timing of the surgery. Talking with others who have made the choices that you are considering can be helpful.

What type of reconstructive surgery should I have?

Talk with your doctor about which reconstruction option would be best for you. Remember to ask about the recovery time and any pain after surgery or scarring that may result. Discuss how treatment with radiation may impact your options. If you are having immediate breast reconstruction, the surgeon may try to keep as much of the skin of the breast as possible intact. This skin can then be used to cover a tissue flap or an implant.

Natural tissue flaps

This method of breast reconstruction uses your own tissue to form a breast. The most common flaps use tissue from the back, abdomen, or buttocks. These surgeries take longer and have a higher risk of complications than reconstruction with an implant. Since they use your own skin, muscle, and fat, the reconstructed breast will have a more natural look and feel than an implant. In some flaps, an entire muscle is removed to reconstruct the breast. This can cause weakness in the area of the removed muscle and might affect certain physical or athletic activities. If you are active, talk with your plastic surgeon. Your body size may also affect which procedures you can have.

Natural tissue flap methods:

- Latissimus dorsi muscle flap. The large muscle in the back, skin, and underlying fatty tissue are used to form the new breast.
- Transverse rectus abdominis myocutaneous (TRAM) flap. The skin, muscle tissue, and fatty tissue from the lower abdomen are used to form the new breast.
- Deep inferior epigastric perforator (DIEP) flap. The skin and fatty tissue from the lower abdomen are used to form the new breast. The abdominal muscle stays intact.
- Superficial inferior epigastric artery (SIEA) flap. The skin, fatty tissue, and blood vessels from

the abdomen are used to form the new breast. This leaves the muscles and most connective tissue of the abdomen untouched.

- Superior gluteal artery perforator (S-GAP) flap and inferior gluteal artery perforator (I-GAP) flap. The skin and fatty tissue from the upper part of a buttock (S-GAP) or lower part of a buttock (I-GAP) are used to form the new breast. If needed, liposuction can be used later to create a more even look in the buttocks.

Implants

This method of reconstruction involves placing an artificial implant into the breast. There are different types of implants to choose from including saline, silicone, and a combination. Implants require the least amount of surgery for reconstruction. Inserting an implant can be a two- or three-step process. In the first step, a tissue expander is put between the skin and chest muscle. This is done to stretch the skin to make room for a permanent implant. During repeated office visits, more saline is added to the expander until it reaches the desired size. Then, the expander is removed and the final implant is put in. Breast implants may need to be replaced at some time in the future.

Flap + implant

Some types of reconstruction combine a flap procedure with an implant.

Important steps to follow if you choose to have reconstructive surgery:

STEP 1 — Ask your doctor to refer you to a plastic surgeon who is an expert in breast reconstruction. This is important if you choose to have the reconstruction at the same time as the mastectomy.

STEP 2 — Talk with the plastic surgeon and find out about his or her skills and experience. The surgeon you choose should ask questions, listen to your answers, and make a recommendation about the best surgery for you. If you have concerns, get a second opinion.

STEP 3 — Find out what your health insurance will cover. Know and understand your rights. The Women's Health and Cancer Rights Act requires all health insurance providers and health maintenance organizations (HMOs) that pay for mastectomy to also pay for prostheses or reconstruction. Reconstruction of the breast removed, surgery, and reconstruction of the other breast is covered to get a symmetrical look.

STEP 4 — Decide if you want the reconstruction right away or later. It is never too late to have reconstruction.

Nipple and areola reconstruction

If desired, nipple and areola reconstruction can complete the breast reconstruction process. A nipple can be formed using skin from the reconstructed breast itself. A tattoo or skin graft can be used to create the areola. These procedures are usually done at least two months after reconstruction which allows time to correctly position the nipple. Another option is to have the nipple and areola recreated with a 3D tattoo. Check with your surgeon about what option is best for you.

What is a breast prosthesis?

A breast prosthesis is an alternative for those who want to avoid reconstructive surgery, but wish to maintain the appearance of breasts. Breast prosthetics are made of silicone gel, foam, or other materials which are fitted to your chest. The form is either placed directly on top of your skin or in the pocket of a special bra. Your provider can give you a list of places to get prostheses. Most health insurance plans cover the costs of breast prostheses and special bras.

A member of your healthcare team can suggest places where you can buy prostheses. Many cancer centers have boutiques that offer prostheses and some medical supply stores carry them. Some specialty lingerie stores have sales staff to help fit a prosthesis for women who have had a mastectomy.

Before you go,

- Call ahead for an appointment with a fitting specialist.
- Wear a form-fitting top.
- Try on different ready-made prostheses. Prostheses come in a wide variety of shapes and sizes.
- Find out what your insurance will cover. Most plans will pay for a standard, new prosthesis every two years.

Once you have been fitted, you can buy bras and mastectomy bathing suits online. The American Cancer Society's Tender Loving Care website (<https://www.tlcdirect.org/>) has many items for women who have had a mastectomy.

Understanding the pathology report

Your pathology report is one of the resources containing information about your tumor. This report will help guide your healthcare team in planning the appropriate treatment for you. Ask your doctor if there are additional tests you should consider to ensure you have the most complete picture of your unique cancer.

Stage	Staging is the assessment of how far the cancer has progressed. In most cases, the lower the stage, the better the prognosis (Stage 0 to Stage IV).
Tumor Size	The size of the cancer tumor is one of the factors that determines the stage of the breast cancer.
Tumor Grade	The tumor grade is a measure of how different the cancer cells are from normal cells.
Invasive vs. Non-invasive	If breast cancer is found, it's important to know whether the cancer is non-invasive (confined within the milk ducts or lobules in the breast) or invasive (spread outside the milk ducts or lobules of the breast).
Margins	The margin is the edge or border of the tissue removed in cancer surgery. The margin is described as negative or clean when the pathologist finds NO cancer cells at the edge of the tissue, suggesting that all of the cancer has been removed. The margin is described as positive or involved when the pathologist does find cancer cells at the edge of the tissue, suggesting that all of the cancer has not been removed.
Hormone Receptor Status	This tells you whether or not the breast cancer cells have receptors for the hormones estrogen and/or progesterone.
HER2 Status	HER2 is a specific gene that can play a role in the development of breast cancer. Breast cancers with HER2 gene amplification or HER2 protein overexpression are called HER2-positive in the pathology report.
Lymph Node Status	This indicates whether the breast cancer has spread to your lymph nodes.
Lymphovascular invasion	This indicates if cancer cells are found in the fluid channels of the breast.

What does breast cancer staging mean?

After being diagnosed with breast cancer, doctors will try to figure out if it has spread, and if so, how far. This process is called staging. The stage of a cancer describes how much cancer is in the body. It helps determine how serious the cancer is and how best to treat it. Doctors also use a cancer's stage when talking about survival statistics.

Since 1959, the American Joint Committee on Cancer (AJCC) has published eight editions of the tumor-node-metastasis (TNM) system for cancer staging. In the past, stage number was calculated based on just three clinical characteristics, T, N, and M:

Tumor (T): Provides information about aspects of the original (primary) tumor – ex: size, how deeply it has grown, and whether it has spread into nearby tissues.

Lymph Node (N): Describes whether the cancer has spread into nearby lymph nodes and, if so, how many lymph nodes are affected.

Metastasis (M): Tells whether the cancer has spread (metastasized) to distant parts or organs of the body, such as the lungs or bones.

Numbers or letters after T, N, and M give more details about each characteristic. Higher numbers mean the cancer is more advanced.

The most recent AJCC system, effective January 2018, has made fundamental changes to staging and breast cancer is now recognized as a group of diseases with different characteristics that indicate different prognoses, patterns of recurrence, how cancer cells spread, and sensitivities to available therapies. There are both clinical and pathologic staging systems for breast cancer

Clinical staging is based on the results of tests done before surgery, which may include physical examinations, mammogram, ultrasound, and MRI scans.

Pathologic staging is based on what is found during surgery to remove breast tissue and lymph nodes. The results are usually available several days after surgery. In general, pathological staging provides the most information to determine a patient's prognosis.

In both staging systems, all factors are considered when assigning an overall stage including the TNM, estrogen and progesterone hormone receptor status, HER2 status and the grade of the cancer, which evaluates how much the cancer cells look like normal cells.

Breast cancer stage is usually expressed as a number on a scale of 0 through IV — with stage 0 describing non-invasive cancers, such as DCIS (ductal carcinoma in situ), that remain within their original location and stage IV describing invasive cancers that have spread outside the breast to other parts of the body.

For more detailed information on the different stages of breast cancer, go to:

<https://www.breastcancer.org/symptoms/diagnosis/staging#stage0>

What happens after surgery?

The pathology results from your biopsy and/or surgery will help your team decide if you need additional treatment for your breast cancer. The majority of patients will receive some type of additional treatment - radiation, chemotherapy, immunotherapy, or hormonal therapy. These treatments are called adjuvant therapy. Adjuvant therapy is given to prevent a recurrence or metastasis by killing any undetected cancer cells in your body. Chemotherapy, immunotherapy, and hormonal therapy are systemic which means they travel through your body, while radiation is a local therapy that only treats the area of the cancer.

Your treatment plan will be designed depending on your cancer cell type, size of the tumor, if it is invasive or not, growth rate, lymph node involvement, presence of cancer cells elsewhere in your body, hormonal status, HER2 status, your menopausal state and your overall medical history and health. Do not compare your treatment to another patient's cancer treatment! Treatments are very individualized. You may be comparing treatments for two very different types of tumors. Also, be aware that advertisements, newspaper, and magazine articles may discuss treatments that are not applicable to your cancer. Also, many are experimental and may not have been researched and tested. Your oncologist (cancer treatment specialist) is a reliable source.

Your doctor may suggest doing genomic testing on your tissue sample. (Oncotype DX is the best-known). These tests analyze the biology of your tumor and may help predict if the tumor is likely to be more aggressive or less aggressive. The results can help guide treatment decisions.

For further information about the Oncotype DX and the test results, go to:

<http://www.mybreastcancertreatment.org/en-US/LearnAboutOncotypeDX/OncotypeDXScores>

What is radiation therapy for breast cancer?

Radiation therapy (also called radiotherapy) is a cancer treatment that uses high doses of radiation (high-energy particles or waves, such as x-rays, gamma rays, electron beams, or protons) to kill cancer cells. For some people, radiation may be the only treatment you need. But, most often, you will have radiation therapy with other cancer treatments, such as surgery, chemotherapy, and immunotherapy. After breast-sparing surgery, radiation treatments may help destroy any remaining breast cancer cells. In some cases, when a breast tumor is large or not easily removed by surgery, radiation therapy can be used before surgery to shrink it.

Radiation therapy may be given before, during, or after these other treatments to improve the chances that treatment will work. The timing for when radiation therapy is given depends on the type of cancer being treated and whether the goal of radiation therapy is to treat the cancer or ease symptoms.

How does radiation work?

Radiation works by making small breaks in the DNA inside cells. These breaks keep cells from growing and dividing and cause them to die. Radiation therapy is designed to target cancer cells, but nearby, normal cells are also affected by radiation and side effects come from this impact. Most of these cells recover and go back to working the way they should.

Radiation therapy does not kill cancer cells right away. It takes days or weeks of treatment before DNA is damaged enough for cancer cells to die. Cancer cells keep dying for weeks or months after radiation therapy ends. Radiation treatment is planned to damage cancer cells, with as little harm as possible to nearby healthy cells.

Are there different types of radiation therapy?

There are two main types of radiation therapy, external beam and internal. The type of radiation therapy that you may have depends on many factors, including: the type of cancer, size and location of the tumor, other types of cancer treatment, your age, health and medical history. There is a limit to the amount of radiation an area of your body can safely receive over the course of your lifetime.

Depending on how much radiation an area has already been treated with, you may not be able to have radiation therapy to that area a second time. If one area of the body has already received the safe lifetime dose of radiation, another area might still be treated if the distance between the two areas is large enough.

External beam radiation, sometimes called external beam whole-breast radiation, is the most common type of radiation. In this technique, a large machine called a linear accelerator aims a beam of high-energy radiation at the breast affected by the cancer.

Radiation treatment schedules are often on an outpatient basis 5 days a week. In the past, treatment took place over 5-7 weeks. More recently, schedules have changed so that fewer treatments with higher doses of radiation are given at each treatment, with the same total radiation dose. This accelerated schedule can put the same radiation dose into a 3-5 week schedule.

Internal radiation, sometimes called partial-breast radiation, is typically used after a lumpectomy. Small pieces of radioactive material are placed in the area around where the cancer was to emit radiation into the surrounding tissue. The area that's very close to the site of the original cancer is the area that is at highest risk of recurrence.

Intraoperative radiation can be given during lumpectomy surgery, after the cancer has been removed. This is called intraoperative radiation therapy (sometimes abbreviated as IORT). While the underlying breast tissue is still exposed, a single, high dose of radiation is given directly to the area where the cancer was.

Does radiation therapy have side effects?

Common radiation side effects include redness, dryness or irritation of the skin in the treated area, and fatigue. Talk with your radiation doctor about what to expect and how best to care for your skin.

Additional online resources

- Radiation Therapy and You: Support for People With Cancer: <https://www.cancer.gov/publications/patient-education/radiation-therapy-and-you>
- Understanding Radiation Therapy: What To Know About External Beam Radiation Therapy Understanding Radiation Therapy: What To Know About Brachytherapy (A Type of Internal Radiation Therapy): <https://www.cancer.gov/about-cancer/treatment/types/radiation-therapy/brachytherapy>
- PDQ® Cancer Information Summaries: Adult Treatment PDQ® Cancer Information Summaries: Pediatric Treatment: <https://www.cancer.gov/publications/pdq/information-summaries>

What is chemotherapy?

Chemotherapy (often referred to as “chemo”) is a widely used treatment for cancer that works by targeting and killing rapidly dividing cancer cells. Chemotherapy for breast cancer is frequently used in addition to other treatments, such as surgery, radiation or hormone therapy. There are many different chemotherapy drugs and new treatments are always being developed.

Standard chemotherapy is a systemic treatment that travels to all parts of the body through the bloodstream, affecting both cancer cells and normal cells – which leads to certain side effects like hair loss. A single drug or a combination of drugs may be used. Each drug used has a specific purpose and has its own side effects.

Targeted therapy and immunotherapy are other cancer treatments that use medicine to treat cancer. While standard chemotherapy works by killing cancer cells and some normal cells, targeted treatment and immunotherapy zero in on specific targets (molecules) or on cancer cells.

Because your treatment plan is individualized, many teams offer a teaching session or meeting to review the specifics of your plan and what to expect.

When is chemotherapy given?

Chemotherapy for breast cancer is frequently given in conjunction with surgery.

Adjuvant chemo is chemo given after surgery to kill any cancer cells that may have traveled elsewhere in the body through the lymphatic or blood system.

Neoadjuvant chemo is given before turning to surgery and is often used for people with more advanced or aggressive tumors. The goal is to shrink the tumor so it can be surgically removed, and possibly sparing the patient from having to undergo a mastectomy.

Maintenance chemo is almost always milder and less stressful on the body than first-line chemotherapy, if only because the dosages are lower. The idea is to prevent cancer from reappearing and to help extend lifespan when primary chemotherapy has not resulted in remission.

Palliative chemo is treatment designed for metastatic and terminal cancer patients in order to prolong survival and ease symptoms - but not to cure disease.

How often and how long is chemotherapy given?

The length of chemotherapy treatment is determined by many factors, including type and extent of cancer, goal of treatment, and the types of drugs given, along with their expected toxicities and amount of time necessary to recover from these toxicities. Chemotherapy regimens and treatment schedules are determined through research and clinical trials. Your doctor may make individualized adjustments based on your tolerance.

In general, chemotherapy treatment is given in cycles. This allows the cancer cells to be attacked at their most vulnerable times, and allows the body's normal cells time to recover from the damage.

The frequency of treatments depends on the type of cancer, the dosage of chemotherapy, the drugs being used and how the patient responds to the treatment. Some oral drugs are taken daily. Infusions of chemotherapy can be twice a week, once a week, every other week or every three weeks or by other schedules. Your oncologist will decide which treatment plan and schedule is best for you. Schedules may be adjusted depending on how you tolerate the treatment. Some chemotherapy drugs reduce white blood cells which are important for fighting infections. Drugs to help support your immune system recover may be appropriate. These are called colony growth stimulating factors and you should discuss with your provider if they are needed.

How is chemotherapy given?

Chemotherapy may be given in many ways. Some common ways include:

Intravenous (IV): The chemotherapy goes directly into a vein.

Oral: The chemotherapy comes in pills, capsules, or liquids that you swallow.

Injection: The chemotherapy is given by a shot in a muscle in your arm, thigh, or hip, or under the skin in the fatty part of your arm, leg, or belly.

IV chemotherapy is often given through ports, sometimes with the help of a pump. This device is a small, round disc, placed under your skin during minor surgery. It is placed by a surgeon or radiologist before you begin treatment, and it remains there until you have finished. A catheter connects the port to a large vein, most often in your chest. Your nurse can insert a needle into your port to give you chemotherapy or draw blood. This alleviates the need to have an IV inserted into a vein for each treatment.

Does chemotherapy have side effects?

Side effects differ widely depending on which chemotherapy drugs you're given. Most patients are now given medication before and after the administration of chemo to prevent many of the side effects that were common in the past. Your chemotherapy nurses will explain which side effects you might experience and need to be reported to the office, even after hours. For further information on side effects, check out the website: www.breastcancer.org/treatment/chemotherapy/side_effects

These are some of the side effects that should be reported to your doctor:

- Fever greater than 100.4F
- Shaking chills with or without fever
- Painful urination
- Redness or discharge from any wound, incision or sore
- Uncontrolled bleeding from any site
- Vomit that has a coffee ground appearance, dark tea colored urine, spitting up blood or coughing up blood
- Fast or irregular heartbeat
- Fainting or sudden onset of dizziness; severe headache
- Shortness of breath, chest pain
- Sudden vision changes
- Sudden onset of severe pain
- Nausea or diarrhea not controlled with medication

Are there long-term side effects of chemotherapy?

Some side effects of chemotherapy are temporary and disappear over time. However, there can be long-term effects of treatment and your care team is best able to discuss any issues or concerns that you have about long-term effects. Some long-term effects can include:

Neuropathy - This is numbness or weakness caused by damage to your nerves during treatment. The most common symptoms can include pain, tingling, tickling or numbness in your arms, hands, feet, toes and legs. You may also experience sudden sharp, stabbing, shock-like pain sensations, loss of touch sensation or have trouble picking up objects or fastening clothing. Be sure to let your doctor know if these symptoms are significantly increasing while undergoing chemotherapy treatment.

Chemo Brain - Many people describe problems with memory and thinking, concentration and multi-tasking following chemotherapy and while on endocrine therapy. This is often referred to as "chemo brain" and may last for a short time after treatment or in some cases, it may last much longer. Here are some suggestions to help:

- Use a daily planner
- Make sure you get adequate sleep
- Exercise both your brain and your body
- Track your problems and you may notice a pattern, enabling you to change your routine to fit
- Don't try to cope with too many tasks at once
- Ask for help when you need it

In Tompkins County, there is a brain injury support group that offers support and strategies, and includes those individuals affected by chemotherapy. Contact the Finger Lakes Independence Center for more information about group times.

Does breast cancer treatment affect fertility?

If you are diagnosed before you have had children, you may be concerned about loss of fertility. Chemotherapy can damage the ovaries. Both chemotherapy and tamoxifen can cause irregular periods or can cause your period to stop. Both treatments are likely to bring on natural menopause at an earlier age. It is important to talk to a fertility specialist and your physician before making decisions about treatments. The sooner you consult a specialist the more options you may have in preserving your fertility.

If you are interested in having children after you have completed treatment, you can take steps to help preserve your ability to have children. One option is to store embryos (fertilized eggs) before treatment begins. The embryos can be implanted in the uterus after you have completed your treatment. A second option is to freeze unfertilized eggs. Both procedures have similar pregnancy rates. Finally, it is possible to protect the ovaries using drugs that shut them down during chemotherapy. The option you choose is a very personal decision that you should take time to consider.

What is hormonal therapy?

Hormonal therapy may be recommended if your pathology report shows that your tumor was fueled by estrogen and/or progesterone. You may hear that your tumor was ER positive and/or PR positive. The receptor status determines which treatments will be best to treat your cancer. The use of hormonal therapies often depends on whether you are pre-menopausal (still having your periods) or post-menopausal.

The most common types of hormonal therapies are tamoxifen, which blocks the effects of estrogen on breast cancer cells, and aromatase inhibitors, which stop the production of estrogen in post-menopausal women.

Side effects of hormone therapy

Hormone therapy with tamoxifen and/or aromatase inhibitors is taken for up to 10 years. This is different from other treatments like radiation therapy and chemotherapy, which are completed after a number of weeks or months. Because hormone therapy is taken for a longer period of time than other treatments, possible side effects and health risks from these medications may last longer.

Side effects of tamoxifen can include

The most common side effects include menopausal symptoms such as hot flashes and vaginal symptoms and loss of libido. To read more about tamoxifen: <http://chemocare.com/chemotherapy/drug-info/tamoxifen.aspx>.

Side effects of aromatase inhibitors

The most common side effects include menopausal symptoms (such as hot flashes and vaginal symptoms), joint and muscle pain and bone loss. To read more about aromatase inhibitors: <https://ww5.komen.org/BreastCancer/SideEffectsofAromataseInhibitors.html>

How to manage side effects of hormone therapy

Hot flashes - Regular exercise has been shown to reduce the frequency and intensity of hot flashes. Take note of anything that may trigger your hot flashes such as hot drinks, caffeine, alcohol, spicy food, or hot temperatures. Wear loose, natural fabrics (especially cotton) and dress in layers.

Vaginal dryness, irritation - Lower estrogen levels cause the tissues of the vagina to become thin, dry and less elastic. The vagina also becomes narrower and slightly shorter (these changes also occur with menopause). Water based lubricants can reduce the discomfort, particularly during sex. Vaginal moisturizers can also help to rehydrate the vaginal tissue and have a long-lasting effect (up to 3 days). If needed, ask your provider about the possibility of a referral to a sexual health specialist or physical therapist who does pelvic floor therapy.

Vaginal discharge - A small amount of clear or white discharge is normal for many women but hormone therapy can increase the discharge volume. You may need to wear a panty liner. Report any odor or discoloration such as blood to your doctor.

Nausea - This is very common when you first start taking the medication and will often improve. It may help to take your medication with food or at night before going to bed.

Bone and joint pain - It is important to stay physically active to help keep the muscles around the joint flexible. Regular exercise has been shown to reduce joint pain. Ask your doctor about taking an anti-inflammatory or mild analgesic. Also hot packs may be soothing, yoga may help and some people have gained relief from acupuncture.

Loss of bone density - Your doctor may order a DEXA scan to measure your bone density. It is important to have a healthy diet with adequate calcium. Weight-bearing exercise and resistance training can also help maintain bone density.

Rare side effects - Increased cardiovascular risk, deep vein thrombosis, pulmonary embolism and endometrial cancer are rare side effects of tamoxifen. Call your doctor immediately if you experience calf pain, swelling, shortness of breath or abnormal vaginal bleeding. Discuss any concerns about risks with your provider.

What is immunotherapy?

Cancer immunotherapy is a form of cancer treatment that uses the power of the body's own immune system to prevent, control, and eliminate cancer. Cancer immunotherapy is a type of biological therapy and comes in a variety of forms. New developments in cancer immunotherapy include: immune checkpoint inhibitors, t-cell transfer, monoclonal antibodies, treatment vaccines, and immune system modulators.

HER2 targeted therapy

If your tumor is HER2-positive, you will likely be given a drug that specifically targets the biology of that type of tumor. Trastuzumab is the most common of these drugs. For a complete description of HER2 targeted therapy drugs, please visit: <http://www.lbbc.org>.

Long-term effects of trastuzumab

Patients who receive trastuzumab, a HER2 targeted therapy, may be at risk for heart problems. These treatments can reduce the heart muscle's ability to pump efficiently. Discuss with your doctor about the best ways to check for heart problems in the future.

Can I work during treatment?

Navigating work can be challenging when dealing with your cancer diagnosis. Time off for medical appointments and surgery is needed. Some people are able to work full-time during radiation therapy. Others can work only part-time or not at all. Depending on what chemotherapy or other treatments you are undergoing, your care team can help you determine what changes in your work schedule may be needed. Changing expectations about how much you can achieve during primary treatment helps.

Should I be in a clinical trial?

Occasionally some women have the opportunity to participate in clinical trials. There are investigational studies that evaluate new treatment and prevention strategies. There are generally three types (or phases) of clinical trials. Phase One trials are very small and are used to evaluate safety of a new drug and determine the correct dose. Phase Two trials study the effectiveness of the drug in a small group of patients. Phase Three trials compare the new therapy to the standard therapy in a larger group of patients in terms of survival rates and quality of life during treatment.

Will this affect my sexuality and intimacy?

Having breast cancer can impact your sexuality and intimacy. You may experience a change in your sexual relationships, sexual response, libido (desire), and satisfaction. These changes might happen after a diagnosis and before, during, and after treatment. You may feel a change in your body image and how you respond to a sexual relationship. This can happen in every relationship and can occur regardless of your age, stage or diagnosis, treatment type, and if you are in a relationship or not. These changes are very common, and should be addressed with your provider; referrals and help are available.

What complementary and supportive treatments can I do?

The treatment provided through your doctor, nurses and various departments in the hospital are referred to as conventional, Western, mainstream, or biomedicine. Other treatments you may hear about are referred to as complementary, alternative medicine (CAM). Some types of complementary therapies include:

acupuncture	aromatherapy	reflexology	art therapy
biofeedback	chiropractic therapy	prayer	counseling
essential oils	exercise	meditation	healing energy
herbs	hypnotherapy	yoga	journaling
massage therapy	music therapy	tai chi	nutrition
prayer	psychotherapy	spiritual practices	Reiki

Although chemotherapy and radiation have uncomfortable side effects, they have been rigorously tested and proven. There are many scientific studies supporting their effectiveness. Use caution when choosing to use complementary therapies. Many of the complementary therapies have not been part of scientific studies to prove their effectiveness. Always discuss with your physician which therapies may enhance your treatment, rather than interfere. Most doctors are open to complementary medicine, and some will encourage use of these approaches. When considering a complementary therapy, thorough investigation is imperative.

How do I know if the information is good?

Some questions which may be beneficial to ask are:

- Is there published scientific evidence to support this complementary therapy with my type of cancer?
- Do reputable healthcare professionals endorse this therapy?
- Is this therapy or activity validated with scientific, objective testing like lab tests or MRI/PET scans?
- Is the person or group promoting this therapy/activity benefitting personally?
- What is the treatment cost? Is it covered by insurance?
- Can you receive the alternative therapy while receiving your regular treatments?

The internet can also be a valuable source of information, if used wisely. Be critical! Websites by major medical centers, universities and government agencies are your best resources. Therapies or techniques that have been reviewed by qualified professionals are generally better to consider.

Beware of scams and healthcare frauds; the claims made can be very persuasive. Avoid commercial sites, personal testimonials, and red-flag claims (cancer cure, miracle cure, 100% effective, new discovery, satisfaction guaranteed, etc.). And again, ALWAYS discuss with your healthcare provider.

Additional Reliable Internet Sources

Alternative/Complementary Medicine:

- CancerGuide by Steve Dunn: www.cancerguide.org
- National Cancer Institute: www.nci.nih.gov
- National Center for Complementary and Alternative Medicine (NCCAM): www.nccam.nih.gov

Herbal and Food Supplements:

- American Botanical Council: www.herbalgram.org
- Medical Herbalism: A Journal for the Clinical Practitioner: www.medherb.com
- US Pharmacopeia Consumer Information (Botanicals): www.usp.org
- Office of Dietary Supplements (ODS), NIH: www.ods.od.nih.gov
- U.S. Food and Drug Administration (FDA): www.fda.gov
- Sloan Kettering Center for Integrative Medicine: <https://www.mskcc.org/cancer-care/diagnosis-treatment/symptom-management/integrative-medicine/herbs>
- National Council Against Health Fraud: www.ncahf.org

What is the financial impact of cancer?

Cancer is a health issue but it can also be a financial issue. The link between a cancer diagnosis and financial stress is real. Studies have shown that the financial stress caused by cancer can negatively impact a person's health and their treatment outcomes. Your care team can provide referrals for getting support and community advocates can help you find solutions. One helpful resource is: <https://www.oncolink.org>

Survivorship: moving forward

The journey with breast cancer can take many paths and each survivor faces their own individual challenges with each phase of the process. Survivorship looks different depending on where someone starts when diagnosed, whether it is early stage disease or metastatic disease.

For earlier stage diagnoses, most people can't wait until their primary and adjuvant cancer treatment is completed. But once finished, many aren't sure if they're ready for what's next, which may mean no further treatment or ongoing maintenance treatment. Finishing treatment often comes with some worry or fear of cancer growing or coming back, or feeling lost without the same frequency of visits with a cancer care team.

These concerns often get expressed as:

- Will it come back in the same breast, the other breast or elsewhere in the body?
- Will I have to go through treatment again?
- How would a recurrence affect my life, my relationships, finances, family, career?
- Will I die from cancer?

Those with metastatic disease upon initial diagnosis often struggle with the uncertainty of whether their cancer can be treated successfully or how long their life can be extended with treatment.

You are not alone. Knowing what triggers your fears and how to manage your feelings can help you to cope. It may be helpful to find a support group or a therapist to help you find tools that will help you to cope. Be sure to talk to your care team about your worries and fears because they can help!

How long will it take to recover?

Most breast cancer treatments can be physically and mentally exhausting, and recovery time varies depending on your health and what treatment you've had. After receiving any treatment, you'll likely need some time to rest and recover. After completing breast cancer treatment, doctors will want to watch you closely but you will probably see your cancer care team less often.

It can be scary to leave the protective cocoon of doctors and nurses who supported you through treatment. Everything you're feeling right now is normal for cancer survivors. Recovering from cancer treatment isn't just about your body - it's also about healing your mind. Fear of recurrence is common in cancer survivors. Though they may go years without any sign of disease, many cancer survivors say the thought of recurrence stays with them.

You might worry that every ache or pain is a sign of your cancer recurring. Eventually these fears will fade, though they may never go away completely. Once you've done all you can to reduce that risk, acknowledge your fears. Take control of those fears and do what you can to influence your future health.

Try to:

- Take care of your body.
- Go to all of your follow-up appointments.
- Get all of your follow-up tests.
- Be open about your fears.
- Keep busy.
- Devise your own plan for coping with your emotions. Have an open mind and try different strategies to find out what works best for you. During follow-up visits, your doctors will ask if you are having any problems. They may do exams and lab tests or imaging tests to look for signs of cancer or treatment side effects.

Almost any cancer treatment can have side effects. Some might only last for a few days or weeks, but others might last a long time. Some side effects might not even show up until years after you have finished treatment. Visits with your doctor are a good time for you to ask questions and talk about any changes or problems you notice, or concerns you have. However, if you have additional concerns about your cancer, you do not have to wait until your next scheduled visit. You can call your doctor immediately.

What will my quality of life be after treatment?

"Quality of life" is the term used to describe a person's overall well-being. Your mental and physical health (including symptoms such as pain and fatigue), ability to perform daily roles, and sexual function are all part of your quality of life. Some treatments may not have lasting effects but some will. Long-term side effects can impact your well-being for months or in some cases, years after treatment. Since long-term effects vary greatly from person to person, it is difficult to plan for any long-term health issues but you can discuss your progress during your follow up visits with your care team. It is important to set realistic expectations for yourself and to allow yourself enough time to recover, which will help your overall sense of well-being.

Long-term issues can include the following:

- Early menopause and symptoms including hot flashes and vaginal dryness
- Fatigue/insomnia/sleeping issues
- Anxiety and depression
- Sexual and intimacy issues
- Lymphedema, and pain related to surgery and radiation
- Heart issues
- Fatigue
- Memory/cognitive issues

As always, discuss any concerns you have with your healthcare team. Even if a condition cannot be completely resolved, often the symptoms can be treated.

What is lymphedema?

Lymphedema is a condition caused by a blockage in the lymphatic system. Lymphedema causes swelling and other problems in the affected area. It is most commonly caused by lymph node removal or damage due to cancer treatment. When axillary lymph nodes are removed during breast surgery (with sentinel node biopsy or axillary dissection) or are treated with radiation therapy, the lymph vessels can become blocked. This blockage prevents lymph fluid from leaving the area, which leads to swelling. It can appear in any area of the upper body on the same side as the breast cancer including the hand, arm, underarm, breast, chest wall, or trunk (front or back).

How can I prevent lymphedema?

In general, avoid any cuts, burns, or damage to the skin of the arm next to your treatment area and take steps to improve circulation.

- Start doing the exercises your physician or physical therapist prescribes as soon as they say you can start.
- Try to avoid infections or burns.
- If at all possible, have blood draws, injections, IV's, and vaccinations in an unaffected limb.
- Have your blood pressure taken in your unaffected arm.
- Moisturize your nails and cuticles often. If you have a manicure, tell them NOT to cut your cuticles.
- Keep your arm and nails as clean and dry as possible. If you have an insect bite, cut, or hangnail, keep the site clean, use an antibacterial cream, and keep it covered.
- Wear gloves when gardening, washing dishes, and for general cleaning.
- Use an electric razor to shave your underarms.
- Use a thimble if you sew.
- Wear sunscreen on your arm to prevent sunburn.
- Wear oven mitts.
- Avoid extreme temperature changes when bathing or washing dishes.
- Avoid tight clothes or jewelry.
- Don't carry heavy objects with your affected arm. Check with your surgeon or physical therapist for sensible weight limits.
- Consider wearing a compression sleeve, especially when flying. You will need to be measured and fitted for a sleeve.

What are the signs of lymphedema?

- Swelling in the arm or hand; you may notice tight rings or watches.
- A feeling of tightness, heaviness, or fullness in the arm or hand.
- Feeling tightness in the skin, a thickening of the skin, and/or pain or redness in the arm and hand.

It is important to seek evaluation and treatment as soon as possible if you do experience swelling, or any of these other symptoms. Contact your physician immediately if you have signs of infection in your affected arm (i.e. redness, warmth, elevated temperature).

For further information and referrals, see your surgeon or oncologist. While there is currently no cure for lymphedema, the treatment focuses on reducing the swelling and controlling the discomfort. Once you have been diagnosed with lymphedema, it is advisable to visit a lymphedema clinic to start your treatment.

Some treatments include:

Exercises: Light exercises can help encourage the lymph fluid to drain, plus they can help prepare for everyday tasks. These are not strenuous exercises but they focus on mild contraction of the muscles in your arm/leg.

Bandaging: Bandages that wrap your entire arm or leg help encourage the flow of the lymphatic fluid towards your trunk. A lymphedema specialist can show you how to wrap your arm with a special bandage (don't use an ACE bandage).

Massage: Lymphatic massage by a lymphedema specialist (see below how to find a specialist) can help encourage the flow of lymphatic fluid and reduce the amount of swelling. This should not be done by someone who has not had the specialized training.

Pneumatic compression: A sleeve is worn over your affected arm or leg that connects to a pump. The pump intermittently inflates the sleeve starting at your fingers or toes that helps to move the lymph fluid up towards your trunk.

Compression garments: These garments are long sleeves or stockings that compress your limb to help move the lymph fluid out of your arm. You need to be measured for your sleeve prior to purchasing a sleeve as there are several different sizes and compression levels. A lymphedema specialist or a medical garment fitting specialist can do this. Some people will require custom-made sleeves.

Surgery: There are new surgical options to treat lymphedema: vascularized lymph node transfer surgery or lymphovenous bypass. These are an intricate microsurgical procedure used to treat patients with advanced lymphedema affecting the skin tissue in the arms or legs. These options are only available at select large medical centers. Research is continuing to investigate new methods of treatment of lymphedema.

Additional resources

- Cancer Resource Center of the Finger Lakes - (607) 277-0960 www.crcfl.net
- How to find a lymphedema specialist - <https://lymphaticnetwork.org/living-with-lymphedema/lymphedema>
- YouTube videos - What is Lymphedema? <https://www.youtube.com/watch?v=d0cT3A9pYRo>
- Lymphedema Surgery - <https://www.youtube.com/watch?v=3npraA2UYRY>

- Q&A Johns Hopkins Medicine - <https://www.hopkinsmedicine.org>
- Lymphedema FAQ's - <https://lymphaticnetwork.org/living-with-lymphedema/lymphedema>

What can I do to help my survival?

It is well established that lifestyle choices can impact your risk for cancer and some data supports that changes in lifestyle improves treatment outcome.

1. Eat a healthy diet

Although making healthy food choices can't guarantee preventing or impacting cancer, it might reduce your risk and support better treatment outcome. Consider these guidelines:

Eat plenty of fruits and vegetables. Base your diet on fruits, vegetables and other foods from plant sources - such as whole grains and beans.

Avoid refined sugars. Some strategies to help you eat less sugar include:

- switch sodas for flavored sparkling water without added sugar
- opt for unsweetened tea
- add colorful fruit like berries, melon and citrus to your water
- sprinkle cinnamon or cocoa on your coffee beverages and skip the sugar
- carry healthy snacks, like nuts or whole-grain crackers and cheese instead of sugary snacks

Avoid excessive fat from animal sources and limit processed meats. A report from the International Agency for Research on Cancer, the cancer agency of the World Health Organization, concluded that eating large amounts of processed meat can slightly increase the risk of certain types of cancer.

Generally, a Mediterranean diet has been shown to be a healthy approach. The Mediterranean diet focuses mostly on plant-based foods, such as fruits and vegetables, whole grains, legumes, and nuts. People who follow the Mediterranean diet choose healthy fats, such as olive oil over butter, and fish instead of red meat.

2. Reduce or eliminate alcohol

Cancer risk, including breast cancer, increases with the amount of alcohol you drink and the length of time you've been drinking regularly. If you choose to drink alcohol, do so only in moderation, with 3 or fewer drinks per week.

3. Maintain a healthy weight

Being overweight can increase the risk of the breast cancer coming back (recurrence) in women who have had the disease. This higher risk is because fat cells make estrogen so more fat cells mean more estrogen in the body, and estrogen can make hormone-receptor-positive breast cancers develop and grow.

Research has shown that for post-menopausal women, it is especially important to maintain a healthy weight to reduce breast cancer risk and recurrence.

4. Be physically active

Research data on the benefits of exercise continues to mount for improving health and for impact on cancer survival. At least 20 studies of people with breast, colorectal, prostate, and ovarian cancer suggested that physically active cancer survivors have a lower risk of cancer recurrence and improved survival compared with those who are inactive.

Numerous benefits for the cancer survivor include increased energy, better sleep, decreased muscle wasting and bone loss, and improvement in overall quality of life.

As a general goal, include at least 30 minutes of physical activity in your daily routine. For substantial health benefits, strive to get at least 150 minutes a week of moderate aerobic activity or 75 minutes a week of vigorous aerobic activity. A combination of moderate and vigorous activity also works well.

5. Avoid using tobacco

Using any type of tobacco puts you at higher risk for cancer. Smoking has been linked to various types of cancer - including cancer of the lung, mouth, throat, larynx, pancreas, bladder, cervix and kidney. Chewing tobacco has been linked to cancer of the oral cavity and pancreas. Even if you don't use tobacco, exposure to secondhand smoke might increase risk of lung cancer.

If you need help quitting tobacco, ask your doctor about stop-smoking products and other strategies for quitting.

For more information about survivorship, please visit:

<https://www.cancer.net/survivorship/survivorship-resources>

Should I join a clinical trial?

Research is ongoing to improve all areas of breast cancer care, including survivorship. After discussing the benefits and risks with your healthcare provider, we encourage you to consider joining a clinical trial.

BreastCancerTrials.org in collaboration with the Susan G. Komen Foundation offers a custom matching service to help you find a clinical trial that fits your health needs, including clinical trials on quality of life issues.

Another good site for clinical trials info: <https://www.cancer.gov/about-cancer/treatment/clinical-trials>

References:

American Cancer Society www.cancer.org

ASCO <https://www.asco.org>

Beyond Breast Cancer <https://www.lbbc.org/>

Breast Cancer Foundation www.breastcancer.org

Breast Cancer Treatment Handbook by Judy C Kneece, RN, ONC <https://www.breastcancer.org>

Cancer Resource Center of the Finger Lakes www.crcfl.net

Dr. Susan Love Foundation <https://drsusanloveresearch.org/>

Genomic Health

http://www.genomichealth.com/en-US/oncotype_iq_products/oncotype_dx.aspx

Living Mayo Clinic

<https://www.mayoclinic.org/diseases-conditions/breast-cancer/symptoms-causes/syc-20352470>

Lymphatic Network <https://lymphaticnetwork.org/living-with-lymphedema/lymphedema>

MSKCC <https://www.mskcc.org/cancer-care/types/breast>

Moffitt Cancer Center <https://moffitt.org/>

MD Anderson Cancer Center www.mdanderson.org

NBBC <http://www.breastcancerdeadline2020.org/breast-cancer-information/>

NIH <https://www.nlm.nih.gov/>

Susan Komen Foundation <https://ww5.komen.org/>