Breast Cancer Handbook

Everything you need to know to create a more confident cancer journey.

Brought to you by PearlPoint Cancer Support

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Introduction

Welcome to the Breast Cancer Handbook presented by PearlPoint Cancer Support.

About The Breast Cancer Handbook

Having just been diagnosed with breast cancer, you probably have a lot of questions. The Breast Cancer Handbook from PearlPoint Cancer Support contains everything you need to know to more confidently manage your cancer journey from diagnosis through treatment and survivorship. The Handbook can be your guide.

With the internet and search engines, it’s easy to find information about any breast cancer topic, but not all of it is reliable and trustworthy. But don’t worry! PearlPoint’s Breast Cancer Handbook is a reliable source of information. All of the content in the Breast Cancer Handbook has been reviewed and approved by medical professionals across the U.S. who participate on PearlPoint’s Scientific Advisory Team.

Like the content in the Handbook?
There is more online at mypearlpoint.org. We encourage you to register on the site for a free personal dashboard where you can bookmark, save, and reference articles, videos, and worksheets.

Using the Handbook, you will first learn how to talk about cancer with your healthcare team, family, and friends. As a cancer patient, being able to speak openly and honestly with your healthcare team is important. Communication with your caregiver and loved ones is important as well. You are not alone in your cancer journey.

Next, you will learn about breast cancer and the available treatment options. No two cancer diagnoses are the same. The best treatment for you may not be the best treatment for another patient. Use the information in the Handbook to talk with your healthcare team about your options to create the best treatment plan for you.

Cancer and cancer treatments cause side effects, but most side effects are manageable. Know what to expect. Different treatments have different side effects, and people may respond to treatment in unique ways. The Handbook will walk you through all the possible side effects and tips for managing them.

Nutrition is also a big part of any cancer patient’s journey and a large part of the Handbook. Proper nutrition during your cancer treatment can help you feel better, maintain your strength,
and speed your recovery. After treatment, good nutrition will continue to be an active part of your life in survivorship.

As you likely may imagine, a cancer diagnosis brings with it many practical life concerns—health insurance, finances, transportation, advanced directives. The Handbook contains information and content that will help you learn to manage the practical concerns of cancer during your treatment. But even when treatment ends, the cancer journey is not over. During survivorship, there are many things you can do to promote wellness and help you readjust to life after cancer. The Handbook will provide help and information.

We hope you find the Handbook to be a valuable, frequently consulted tool as you manage your cancer journey. We encourage you to make it your own! Ask your nurse navigator or another member of your healthcare team to highlight the sections that most apply to your specific diagnosis and treatment plan. Use the worksheets in the back to keep track of all your information such as medical history and appointments. And finally, never hesitate to talk with your healthcare team—frequently, proactively, and openly.

**Nurse Navigator**

**What does a nurse navigator do?**

Nurse navigators work directly with cancer patients to help guide them through their cancer care journey. Nurse navigators serve as a constant point of contact for patients to coordinate care, answer questions, and provide resources. Nurse navigators usually specialize in a certain type of cancer to help patients with their specific needs.

As a cancer patient, your healthcare team may include a large number of people including:

- A medical oncologist
- A radiation oncologist
- Surgeon
- Pharmacist
- Dietitian
- Physical therapist
- Other healthcare professionals
- Your caregiver, family, and friends

Your nurse navigator will work closely with every member of your healthcare team to keep the lines of communication open.
Nurse navigators understand the medical, practical, and emotional needs of cancer patients. If you have questions about treatment, medications, appointments, or anything else related to your cancer journey, start by asking your nurse navigator.

**Who is my nurse navigator, and how do I contact him or her?**

<table>
<thead>
<tr>
<th>My Nurse Navigator</th>
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<tbody>
<tr>
<td>Name</td>
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<tr>
<td>Phone Number</td>
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<td>Email</td>
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**Talking About Breast Cancer**

**With Your Healthcare Team**

When going through cancer treatment, your healthcare team is very important. Your healthcare team may include your oncologists, surgeon, nurse navigator, a dietitian, a social worker, or other medical professionals. Every member plays an important role. Use the tips below for talking with your healthcare team:

- Establish your main point of contact.
  - Your main point of contact will probably be a nurse navigator, but it may be another member of your healthcare team. Who should you contact first with questions?
- You need to always be open and honest with your healthcare team about your physical and emotional well-being.
- Do not be afraid to ask questions.
  - Breast cancer is usually not a medical emergency. There is time to ask your healthcare team any questions you may have, and to consider your treatment options.
- Write your questions down before your appointments. Take a pen and paper to write down the answers. You can use the “Appointment Notes” worksheet at the back of the Handbook.
- Before beginning treatment, ask your healthcare team the following:
  - What are all my treatment options?
  - What are the long term and short term side effects of treatment, and how can I manage them?
  - Will my fertility or ability to have children be affected?
Am I eligible for clinical trials?

For more questions to ask your healthcare team, read “Questions for Your Healthcare Team” in this Handbook.

- If you develop any new problems or symptoms during treatment, tell your healthcare team immediately. You are not complaining. This is valuable information for your doctors.
- Do not change your diet, start an exercise program, or take any new medications, including vitamins and supplements, during treatment without talking to your healthcare team first.

With Your Caregiver

Your primary caregiver may be with you when you receive your diagnosis. Your primary caregiver may be your spouse, partner, adult child, parent, or friend. Your primary caregiver is the person who may come with you to appointments, take care of you after surgery or treatment, and support you throughout your cancer journey.

- Everyone reacts to the news of cancer differently. You may feel upset, shocked, or angry. It may take you some time to process the information. Your caregiver may react the same way you do, or your caregiver may not. Even if your caregiver does not react the same way you do, it does not mean that he or she does not care deeply.
- Establish your role and your caregiver’s role early. For example, will your caregiver be the one scheduling most of your appointments, or do you prefer to take an active role? Find what works best for you and your caregiver.
- Be open and honest with each other about how you both feel. Overly positive attitudes may hinder honest communication. It’s okay to be upset.
- Encourage your caregiver to take time to care for his or her own physical and emotional well-being. Being a caregiver comes with its own hardships.
- If your primary caregiver is your spouse or partner, your intimate and physical relationship may change. To learn more about intimacy issues and discussing them with your partner, read the “Intimacy and Fertility” section of the Handbook.

With Your Children

Children are very perceptive, no matter their age. While you may wish to protect your children by not telling them about your diagnosis, even young children may be able to tell that something is wrong. Not knowing what is wrong may cause them more stress and anxiety. Here are some tips to talk to your children and teens about your cancer diagnosis:

- Wait until your emotions are under control and decide what to say ahead of time.
- Tell the truth and answer questions honestly. Depending on your children’s ages, it may not be appropriate to give them all the details, but do be truthful.
• Let them know what to expect. For example, let them know that after surgery you will need a lot of rest and may need to stay in the hospital. If your chemotherapy may cause you to lose your hair, let them know. Keep your children in the loop as much as possible.
• Explain to your children, especially younger children, that they cannot “catch” cancer.
• Let your children know that it is okay to cry or be upset. This may be especially important for your teens to hear.
• Tell teachers, babysitters, and others with responsibilities with and around your kids about your diagnosis in case they see behavior changes you may need to know about.
• Maintain normal schedules as much as possible.
• Let your kids help. Allow them to help with chores, and let them know that their help is important. Teens may want to take an active caregiver role. Let them do so, at appropriate levels.
• Look for support groups in your area. Many places offer support groups for children and teens whose parents have a cancer diagnosis.
• Know when to seek professional help. If your child begins to demonstrate unusual behavior such as angry outbursts, nightmares, or poor grades in school, ask your healthcare team for a recommendation for a counselor.

With Family and Friends

You may choose to keep your cancer journey private, or you may choose to share your story with others. The choice is yours. Remember when family, friends, coworkers, or other acquaintances ask about your diagnosis, they are genuinely concerned about your well-being. You can share with them as much or as little information as you like. These suggestions may help you talk about your diagnosis:

• Decide how much information you want to share before you start telling people about your diagnosis.
• If you chose to keep your journey private, make sure to let people know that you appreciate their concern, but you hope they respect your privacy.
• Choose someone close to you, like your caregiver, to spread the word about updates and treatment progress. After a long day of treatment, you may not feel like calling and texting people, but your friends and family will probably want to know how you are.
• If you want to share your story, consider starting an email chain or a Facebook group. This way you can update everyone with one message instead of needing to answer a lot of emails and phone calls.
  o You can also create your own private website at MyLifeLine.org.
• When people offer to help with things, let them. Your family and friends could cook dinner, drive you to an appointment, or babysit.
If you lose your hair due to treatment or have visible surgical scars, strangers may ask about your diagnosis. Have a response prepared. Again, you may share as little or as much as you like.
Learn About Your Cancer Diagnosis

If you or someone you know has just been diagnosed with cancer, you may have a lot of questions. In the next few pages, you will find basic information about cancer and questions to ask your healthcare team.

Understanding Breast Cancer: What Is Cancer?

To understand breast cancer, it's first important to understand what cancer is: basically, the production of abnormal cells.

The body is programmed to routinely replenish cells in different organs. As normal cells age or get damaged, they die off. New cells take their place. This is what's supposed to happen. Abnormal cell growth refers to a buildup of extra cells. This happens when:

- New cells form even though the body doesn’t need them or
- Old, damaged cells don’t die off.

These extra cells slowly accumulate to form a tissue mass, lump, or growth called a tumor. These abnormal cells can destroy normal body tissue and spread through the bloodstream and lymphatic system.

Benign vs. Malignant: What’s the Difference?

The first thing to understand is that the growth in your breast can be either benign or malignant. You’ve probably heard these terms. Here’s exactly what they mean:

- Benign: means not cancerous. A benign tumor can get larger but does not spread to other tissues or organs.
- Malignant: means cancerous. The cells of a malignant tumor can invade nearby tissues and organs and spread. They are destructive.

Look at the chart below to learn more about the difference in benign and malignant.

<table>
<thead>
<tr>
<th>Benign tumors:</th>
<th>Malignant tumors:</th>
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<tr>
<td>Can be removed</td>
<td>Can often be removed</td>
</tr>
<tr>
<td>Usually don’t grow back</td>
<td>Sometimes grow back</td>
</tr>
<tr>
<td>Are rarely fatal</td>
<td></td>
</tr>
<tr>
<td>Don’t spread to other tissues or body parts</td>
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### Understanding Carcinomas

Breast cancer is almost always a type of carcinoma, because breast cancer often starts in the lining of the breast. Breast cancer can be either a ductal carcinoma or a lobular carcinoma.

Carcinomas are treated based on whether or not they are invasive, or have spread into tissues near the cancer cells. There are two types of non-invasive carcinomas of the breast:

- **ductal carcinoma in situ** (meaning the cancer cells are in the breast ducts) or
- **lobular carcinoma in situ** (meaning the cancer cells are in the breast lobules).

Carcinoma in situ means it is an early stage of cancer and is usually very treatable. The cancerous cells are contained; they have not spread deeper in the breast and they have not spread to other organs in your body.

Since these types of carcinoma in situ have not spread, they are also called non-invasive or pre-invasive breast cancers.

There are two types of invasive carcinomas:

- **invasive ductal carcinoma** (in the ducts) or
- **invasive lobular carcinoma** (in the lobules)

Some breast cancers start in tissue of the glands. A gland is a tissue that produces a substance. Your breast’s ducts and lobules are gland tissues, as they make breast milk. Cancers that start in these gland tissues are called adenocarcinomas.

### The Diagnosis

#### Common Diagnostic Tests

Is your head swimming with the names of tests? What is involved? What are they testing for? Try to move one step at a time. Here is an overview of diagnostic tests you will probably either have to have, or will hear about:

**Biopsy**

Why it is done: A breast biopsy is done to take a small sample of your breast tissue. This is then sent to the laboratory. In this sample, doctors will look for abnormal cells. A breast biopsy is thought to be the first and best way to tell if there is cancer in your breast. There are several
types of biopsies: fine needle aspiration, needle biopsy, incisional and excisional. A breast biopsy will help your doctor know whether your need surgery or treatment.

What you should know: The recovery time for non-surgical biopsies is relatively short. You will be bandaged and need an ice pack to reduce swelling. It’s also recommended that you take a non-aspirin pain reliever with acetaminophen (like Tylenol). After taking it easy for a day, you should be able to return to your normal activities the next day. Recovery is a little different for surgical procedures, like incisional and excisional. See those descriptions later in the Handbook.

BRCA Gene Test
Why it is done: Two genes for breast cancer have been identified: BRCA1 and BRCA2. Women who have inherited mutations in these genes have a higher risk of developing either breast or ovarian cancer. A simple blood test uses DNA analysis to identify mutations (changes) in either of these genes. Your doctor may recommend this kind of testing if you have a family history of breast or ovarian cancer. This test is not routine.

Core Needle Biopsy
Why it is done: A core needle biopsy is performed to analyze a lump. Usually it is a lump that shows up on a mammogram. The doctor uses a hollow needle that is not quite as thin as the one used for fine needle aspiration. The purpose of this test is to remove samples that are tiny—about the size of a grain of rice. These samples will be analyzed to look for features that show the presence of cancer.

Core needle biopsies can be guided either by ultrasound (ultrasound-guided core needle biopsy), MRI (MRI-guided core needle biopsy), or mammogram (stereotactic biopsy).

CT Scan
Why it is done: CT stands for computerized tomography. This type of diagnostic test takes X-ray views from different angles. This allows your doctor to see 3D views of the mass and tissues in your breast and other parts of the body. CT scans are done both in hospitals and outpatient settings. They only take a few minutes and are not painful at all. You will be slid into a donut shaped structure and have to lie very still. Most patients say the worst thing is feeling a bit claustrophobic in the machine. CT scans are commonly called CAT scans.

Estrogen Receptor Test
Why it is done: This test is done from the sample of breast tissue collected to find out if the cancer cells in your breast have estrogen receptors. The outcome of the test can be that the cells are either estrogen receptor negative (ER-) or estrogen receptor positive (ER+). If they are ER+ they may respond well to therapies that deprive them of estrogen.

Fine Needle Aspiration Biopsy
Why it is done: Fine needle biopsy is the simplest kind of biopsy. It is used to assess a lump in your breast. You will be asked to lie on a table, and the doctor will inject a very fine needle into the lump. This allows cells or fluid to be collected from the lump. Your doctor will then be able to determine whether the lump is a fluid-filled cyst or a solid mass.
Lymph Node Dissection
Why it is done: The purpose of this procedure is to see whether the cancer cells have spread to your lymph nodes. In this procedure, you will be given general anesthesia. The surgeon will make a 2-3 inch incision under your arm. Lymph nodes will be removed and sent to a pathologist who will examine them for signs of cancer. It can take a few days to get the report back.

What you should know: You may experience numbness in the back of the arm or the armpit. This is usually temporary. You might also experience weakness, lymphedema (swelling), tingling, or stiffness.

Mammogram/mammography
Why it is done: Traditionally, health care professionals have recommended that annual mammograms be done beginning at age 40—or earlier if there is a family history of breast cancer. A mammogram is an X-ray image of your breast. It does not hurt but may feel uncomfortable. In a mammogram, the technician presses your breasts between two firm surfaces. This spreads out the breast tissue and allows the X-ray machine to get good pictures of your breasts. Your doctor will use these pictures to check for changes in your breast tissue and also to check for cancer. Mammograms are also done once a lump is detected—to show a more detailed picture of the mass.

A new advancement in mammography is breast tomosynthesis, which creates a three-dimensional (3D) image of the breast. Tomosynthesis can be done along with a traditional digital mammogram, but it is not a replacement.

MRI
Why is it done: Magnetic resonance imaging (MRI) can be used to learn more about breast lumps or swollen lymph nodes that did not show up on a normal mammogram. MRIs are similar to CT scans. An MRI scan provides detailed pictures like CT scans. The difference is that MRI scans use radio waves and strong magnets instead of X-rays. The energy from the radio waves produces patterns. A computer takes these and turns them into detailed images of specific parts of your body.

What you should know: An MRI takes up to an hour. You may be placed inside a narrow tube. This can feel confining. There are newer, open MRI machines (not a tube) in many hospitals and clinics around the country.

PET Scan
Why it is done: PET stands for positron emission tomography. A PET scan uses a small amount of radioactive materials to get a picture of your tissues and organs. The radioactive material is injected. A PET scan is not used to diagnose breast cancer. Rather, it is used to assess whether the cancer has spread to your lymph nodes or other parts of your body. It can also determine whether treatment is working on breast cancer that has metastasized.

What you should know: There will be a cold sensation as the radioactive material moves up your arm. You will have to lie very still, and the test will be conducted in the same donut-
shaped mechanism as a CT scan. Many people feel claustrophobic during CT or PET scans, but there is no pain involved in either test.

**Progesterone Receptor Test**

Why it is done: This blood test is done to find out if the cancer cells in your breast have progesterone receptors. The outcome of the test can be that the cells are either progesterone receptor negative (PR-) or progesterone receptor positive (PR+). If they are PR+ they may respond well to therapies that deprive them of progesterone.

**Surgical Biopsy**

Why it is done: There are 2 types of surgical biopsies:

- Incisional: A part of the mass in your breast is removed and sent for analysis.
- Excisional: The entire mass in your breast is removed and studied. This is also called a wide local excision or lumpectomy.

Both types of surgical biopsies are routinely done in an operating room. You will most likely be sedated. You will also be given a local anesthetic to prevent pain.

What you should know: If the mass in your breast can’t be felt, the radiologist may use a wire to direct the path to the mass for the surgeon. This is called wire localization. In this procedure, the tip of a very thin wire is placed within the tumor. Usually this is performed immediately before surgery.

Once the surgeon has removed either the entire mass or a sample, the tissue will be immediately sent to the hospital laboratory. The radiologist will check the edges of the tumor. These are called the margins. Ideally, all margins are clear. This outcome is called negative margins and means that all the cancer has most likely been removed. If the laboratory finds cancer cells in the margins (positive margins), then cancer is probably still in the breast. In this case, more tissue needs to be removed.

When your breast biopsy is done, your surgeon may place a very small stainless steel marker in your breast right at the site of the biopsy. This helps your doctor easily find the area that was biopsied. This helps your doctor monitor you; it also helps the surgeon should another procedure be needed.

**Ultrasound/ultrasonography**

Why it is done: An ultrasound test uses high-frequency sound ways to create very precise images of masses in your body. In the procedure, you will lie on an examination table. The technician will first apply some gel to the outside of your breast. Then the technician will run a small hand-held device over the skin. The images will be transmitted onto a computer screen.
Lymph Node Biopsy

Understanding Lymph and Lymph Nodes

Lymph fluid is a clear liquid that flows through your body and to many tissues of the body. It circulates plasma like fluid in your tissues to clean them and transports white blood cells and other immune cells in this fluid. Lymph fluid is taken away through your body’s lymph system and eventually drains back towards the heart.

Your lymph nodes are the filters for the lymph fluid and immune cells in this system. They are designed to filter out bacteria, viruses, as well as cancer cells that have metastasized in order to prevent illness.

You can see how lymph nodes affect every part of your body. That’s why it is very important to find out if the breast cancer has spread to them.

There are two types of lymph node biopsies used with breast cancer: sentinel lymph node biopsy and axillary lymph node dissection.

Sentinel Lymph Node Biopsy

A sentinel is defined as a watchdog or guard. The sentinel lymph node is the very first lymph node in your breast. In the treatment called sentinel lymph node dissection, the surgeon looks for this sentinel lymph node.

Here’s how the procedure works. A dye and/or radioactive substance is injected close to the nipple making the procedure uncomfortable. This substance goes into your lymph nodes. Your surgeon identifies the first lymph node that the dye reaches as the sentinel lymph node. This is the first node that cancer cells might spread to after the breast. There can be more than one sentinel node. Once your surgeon identifies your sentinel node or nodes, they will be removed and checked for cancer.

This procedure is called sentinel node biopsy.

The advantage to sentinel node biopsy is that the surgeon does not have to remove 10 or more lymph nodes and analyze all of them for cancer. Instead, the focus can be on the node(s) that are most likely to be cancerous. If they are clean, chances are good that other nodes have not been affected. Removal of 10 or more lymph nodes is considered a sentinel node dissection,

Who should have this procedure?

This procedure is recommended for women who have relatively small breast cancers (no more than 2 centimeters) and who have lymph nodes that don’t feel abnormal before surgery.
Sentinel node biopsy is not advised for:

- Anyone likely to have cancer in the lymph nodes.
- Women with previous surgery or treatment that could have changed the lymph drainage system.
- Women who have had chemotherapy before surgery to shrink the size of a large tumor or to treat many lymph nodes.

What to Expect

Prior to surgery, the radiologist will inject a radioactive liquid or a blue dye or both into the area around your areola. Then the surgeon watches to see where the dye travels and concentrates. This will be the sentinel node. Once the sentinel node and a couple of nodes close to it are removed, your surgeon will examine them for cancer. Then they are sent on to pathology to be examined under a microscope.

If the sentinel node does not show any cancer, then most likely the other lymph nodes are clean as well, and the cancer has probably not spread. If the sentinel node does show cancer, you may require additional treatment like:

- Removing more nodes for evaluation during the same procedure
- A second procedure to remove more nodes
- Radiation of the surrounding lymph nodes.

Benefits and Drawbacks

Any lymph node surgery can cause side-effects like numbness and discomfort. For this reason, the fewer lymph nodes removed the better. However, many doctors favor the traditional lymph node approach instead of the sentinel node biopsy. With the traditional approach, there isn't the chance of having to go back in again if the sentinel node shows cancer.

Axillary Lymph Node Dissection

Your underarm is known as the “axilla” area. There are 3 general levels of axillary lymph nodes:

- Level I: the bottom level located beneath the lower edge of your pectoralis muscle—part of the chest muscles.
- Level II: located underneath the pectoralis muscle.
- Level III: located above the pectoralis muscle.

An axillary lymph node dissection is a surgery that typically removes the lymph nodes in levels I and II. If you have invasive breast cancer, this procedure will frequently go together with a
mastectomy. It can also be done at the same time as a lumpectomy. In some cases, it can be as a separate surgery after a lumpectomy and with a separate incision.

Your surgeon will typically remove several lymph nodes, often between 5 and 30 lymph nodes during this procedure. These lymph nodes will be analyzed for the presence of cancer. Your doctor will let you know if any lymph nodes show cancer (and, if so, how many). The total number of lymph nodes showing cancer is important.

Keep in mind that:

- Your surgeon will probably remove any lymph nodes that feel or look cancerous.
- Each woman has a different number of lymph nodes located under her arm. Some women may have fewer than 10 and some may have 30 or more.

**What to Expect**

The actual lymph node surgery takes approximately one hour. You will have a 2-3 inch incision in the skin crease under your arm. You will be given general anesthesia. If you are having a modified radical mastectomy, the lymph node surgery will take place at the same time. In the case of a lumpectomy surgery, the lymph node dissection surgery may happen at the same time or as a separate procedure scheduled at another time.

Once the lymph nodes are removed, the pathologist examines them under the microscope for signs of cancer. It can take days before the pathologist’s report is available. This is because the pathologist has to carefully analyze the piece of fatty tissue taken from under the arm in order to find all the lymph nodes and test them.

**Understanding the Risks**

When you have an axillary lymph node surgery, you may encounter:

- Decreased feeling or numbness in the back of your arm or armpit. This is because sometimes the nerve is damaged, cut or stretched during surgery.
- Numbness, weakness, stiffness, tingling or lymphedema on the surgery side is common. Physical therapy and exercise can reduce the chances of these occurring.
- Inflammation of the veins in your arm on the side of the surgery. This is treated with ice and sometimes mild anti-inflammatory medicines like Tylenol to reduce the inflammation.
- Risk of infection in the surgical area. Your doctor will tell you what signs of infection to look for such as redness, drainage, or fever. The infection usually responds well to treatment with medicines.
Breast Cancer Receptors

An important part of breast cancer diagnosis is determining whether the breast tumor has a receptor for either estrogen, progesterone, or both and if the breast tumor is HER2/neu positive.

To understand why this is important, you need to know how the hormones work in your body. Every female has estrogen and progesterone hormones. These hormones travel through your bloodstream. They stimulate both cell division and the growth of new cells.

**Estrogen receptors (ER) and progesterone receptors (PR)** are proteins found in certain cells. These receptors attach to estrogen and progesterone.

Many breast tumors have these receptors. Often they have a lot of them. This means the tumors are hormone-dependent. The hormones estrogen and progesterone cause them to grow.

An early step in the diagnosis process is to test the cancerous tissue to see if it is:

- **HER2/neu positive**: Human epidermal growth factor receptor two is a protein sometimes involved in breast cancer. Too much of the protein on the surface of cancer cells indicates increased aggressiveness.

- **Estrogen receptor positive**: the tumor has estrogen receptors and needs estrogen to grow. An effective treatment strategy may be treating the cancer cells with hormones that block estrogen.

- **Progesterone receptor positive**: the tumor has progesterone receptors and needs progesterone to grow. An effective treatment strategy may be treating the cancer cells with hormones that block progesterone.

Tumors that are progesterone receptor positive or estrogen receptor positive are more likely to respond to therapy. Outcomes are often better.

**About the Progesterone Receptor and Estrogen Receptor Tests**

As explained above, these lab tests determine whether the cancer cells have receptors for either progesterone or estrogen. The first step in taking this test involves getting a sample of the cancer tissue. This can be done through a:

- Fine needle aspiration
- Needle biopsy
- Surgical biopsy

**Another type of breast cancer:**
**Inflammatory breast cancer** is a rare type of breast cancer. In this type, cancer cells block the lymph vessels in the skin of your breast. The breast ends up looking red and swollen. Inflammatory breast cancer is always at least Stage 3B, but it could be more advanced.

**Understanding Your Pathology Report**

**What is a pathology report?**

In order to make a cancer diagnosis, a doctor needs to collect a sample of the tumor cells to be tested and examined in a lab by a pathologist. A pathologist is a doctor who identifies cancer and other diseases by studying cells under a microscope. After the pathologist studies a sample, he or she prepares a pathology report that explains the findings. Doctors use these reports to diagnosis and stage cancer.

**What will be in the pathology report?**

The pathology report provides all the pathologist's findings. Your pathology report may include some or all of the following:

- Your identification information
- Your important medical history
- Details on how the sample or biopsy was taken
- Description of how the sample looked under the microscope
  - Size, color, grade, margins, node status, etc.
- Special tests or markers (hormone receptor status and HER2/neu status)
- A written summary of the full report

**What do the words in my pathology report mean?**

Here is a vocabulary list to help you through your pathology report:

*Abnormal cells*: cells that do not look or behave like healthy cells

*Aggressive*: fast growing

*Benign*: not cancerous

*Biopsy*: a procedure to take a small sample of tissue

*Clean/ clear/ negative margins*: the outer edge of the tissue sample does not contain cancer cells

*Ductal Carcinoma In Situ (DCIS)*: cancer cells in the milk duct that have not invaded surrounding tissue
**ER-negative**: the tumor does not have estrogen receptors.

**ER-positive**: the tumor has estrogen receptors and needs estrogen to grow.

**Florescence In Situ Hybridization (FISH)**: a test used to find genetic mutations

**Grade**: how abnormal the cells look and how quickly the tumor is likely to grow. There are three grades for cancer cells. Grade 1 (low grade) means the cancer cells are only a little different from healthy cells and are slow-growing. Grade 2 (high grade) means the cells look very different from healthy cells and are fast-growing.

**HER2**: Human epidermal growth factor receptor two is a protein sometimes involved in breast cancer. Too much of the protein on the surface of cancer cells indicates increased aggressiveness.

**Histology**: the way the cells look under a microscope

**Inconclusive**: with the current sample and tests, it cannot be determined if cancer is present

**Invasive**: the cancer has spread to surrounding tissues

**Invasive Ductal Carcinoma (IDC)**: cancer cells in the milk duct that have invaded surrounding tissue

**Invasive Lobular Carcinoma (ILC)**: cancer cells in the milk lobules that have invaded surrounding tissue

**In Situ**: abnormal cells have not spread; the abnormal cells are only where they started

**Lobular Carcinoma In Situ (LCIS)**: cancer cells in the milk lobules that have not invaded surrounding tissue

**Lymph node**: lymph nodes filter lymphatic fluid and store white blood cells.

**Malignant**: cancerous

**Metastasis**: cancer that has spread to other parts of the body

**Pathologist**: a doctor who identifies diseases by studying cells and tissues under a microscope

**Positive margins**: the outer edge of the tissue sample does contain cancer cells

**PR-negative**: the tumor does not have progesterone receptors.

**PR-positive**: the tumor has progesterone receptors and needs progesterone to grow.

**Stage**: how advanced the cancer is (see the next section on staging)
**Stains**: used to color the tissues and cells so the pathologist can see them better

**Tissue Block**: the sample of tissue removed during a biopsy or surgery

**Vascular invasion**: cancer cells are in the blood vessels

For a more complete glossary, visit mypearlpoint.org/glossary.

Use your pathology report and ask your nurse navigator to fill out the “My Diagnosis” worksheet included in the Handbook.

## Stages of Breast Cancer

The TNM staging system is used for all types of cancer, not just breast cancer. The letters TNM describe the amount and spread of cancer in your body:

- **T**: indicates how big the tumor is and whether the cancer has spread into surrounding tissue.
- **N**: indicates whether the cancer has spread to surrounding lymph nodes.
- **M**: indicates metastasis, which means that cancer has spread to other body parts.

Using TNM, your doctor will diagnose your cancer according to one of the following stages:

<table>
<thead>
<tr>
<th>Stage 0</th>
<th>This is an extremely early stage. Abnormal cells are present. For example, there may be abnormal cells in the lining of a breast duct (ductal carcinoma in situ) but there has been no spread.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>This is a very early stage. Cancer cells are in the breast tissue but have not spread beyond the breast. The tumor is not more than 2 centimeters across.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Breast cancer is called Stage 2 when either:</td>
</tr>
<tr>
<td></td>
<td>• The tumor is no more than 2 cm. in size but has spread to the lymph nodes under the arm.</td>
</tr>
<tr>
<td></td>
<td>• The tumor is between 2 cm. and 5 cm. but has not spread.</td>
</tr>
<tr>
<td></td>
<td>• The tumor is between 2 cm. and 5 cm. and has spread.</td>
</tr>
<tr>
<td></td>
<td>• The tumor is over 5 cm. but has not spread.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>This stage is called locally advanced cancer. The cancer has spread from where it began into nearby tissue and lymph nodes. Stage 3 is divided into 3</td>
</tr>
<tr>
<td>Types: A, B and C</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Stage 3A</strong></td>
<td></td>
</tr>
<tr>
<td>Stage 3A refers to breast cancer in which the tumor has spread to lymph nodes under your arm. It’s also possible for the cancer to have spread to lymph nodes behind your breastbone. The tumor can be either:</td>
<td></td>
</tr>
<tr>
<td>- Not over 5 cm.</td>
<td></td>
</tr>
<tr>
<td>- More than 5 cm.</td>
<td></td>
</tr>
<tr>
<td><strong>Stage 3B</strong></td>
<td></td>
</tr>
<tr>
<td>This stage refers to any size tumor that has grown into the chest wall or breast skin. It can be accompanied by breast swelling and nodules (lumps) in the skin on your breast. Also in this stage the cancer may have spread to lymph nodes under the arm, or to lymph nodes behind the breastbone.</td>
<td></td>
</tr>
<tr>
<td><strong>Stage 3C</strong></td>
<td></td>
</tr>
<tr>
<td>This stage refers to a tumor of any size. It has spread either:</td>
<td></td>
</tr>
<tr>
<td>- To the lymph nodes behind the breastbone and under the arm.</td>
<td></td>
</tr>
<tr>
<td>- To the lymph nodes above or below the collarbone.</td>
<td></td>
</tr>
<tr>
<td><strong>Stage 4</strong></td>
<td></td>
</tr>
<tr>
<td>This stage refers to a tumor of any size that has spread to other parts or areas of the body beyond the breast and nearby lymph nodes. These areas may include lungs, distant lymph nodes, bones, or brain.</td>
<td></td>
</tr>
</tbody>
</table>

**How Breast Cancer Spreads**

Before you can understand how breast cancer cells can spread, it’s important to have a clear picture of the anatomy of your breasts.

**The Breasts**
Inside a woman's breast are 15 to 20 sections called lobes. Each lobe is made of many smaller sections called lobules. Lobules have groups of tiny glands that can make milk. After a baby is born, a woman's breast milk flows from the lobules through thin tubes called ducts to the nipple. Fat and fibrous tissue fills the spaces between the lobules and ducts.

The breasts also contain lymph vessels. These vessels are connected to small, round masses of tissue called lymph nodes. Groups of lymph nodes are near the breast in the underarm, above the collarbone, and in the chest behind the breastbone.

Cancer cells break away from where the tumor is. These cells then go into your blood vessels or lymph vessels. From there they can enter all tissues of your body. As they travel, cancer cells can attach to other tissues and grow to form new tumors.

This spread is called metastasis.

**Choosing and Oncologist and Treatment Center**

If you’ve been diagnosed with breast cancer, it’s important to explore all options related to breast cancer treatment. Below, learn what’s next, what questions to ask the doctor, and what treatments are available.

**Finding an Oncologist**

The first step on the breast cancer treatment journey is to find an oncologist (medical or surgical) who inspires trust. It may seem overwhelming to choose an oncologist. First, start with referrals from your primary care physician, specialist, or insurance carrier. Talk to family and friends who may have recommendations.

Here are some things to consider when choosing an oncologist:
• Is the oncologist board certified?
• How much experience does he or she have in treating breast cancer?
• Do you feel comfortable talking with this doctor? Does he or she listen well?
• Is the staff compassionate? Is the environment a good one or do you feel rushed?
• What hospital(s) does this oncologist see patients in?
• What are the office hours?
• What if you have an emergency? Can you call?
• Can this doctor be contacted after hours?

You will be spending a lot of time with the oncologist and staff nurses and technicians, so it’s important to feel comfortable with them.

As you and your doctor explore the treatment options open to you, make sure you find out the answers to the following:

• What are the chances my cancer will come back after this treatment?
• What do we do if the cancer comes back or the treatment doesn’t work?
• Will I lose my hair?
• Will it hurt?
• Will there be scars?

Choosing a Cancer Center

Choosing where to receive treatment is just as important as selecting an oncologist. It’s good to know the differences between hospitals. Here are some guidelines:

• Academic cancer centers: These are affiliated with medical schools. At these locations, high priority is put on research. They are usually located in large cities.
• Community cancer centers: The main focus is on patient care.
• Cancer centers: These are noted for a high quality of science and research.

Some questions to ask before choosing where to get your treatment include:

• Volume: How many breast cancer surgeries does the surgeon do annually?
• Travel: How far do you want to travel? Would there be extra costs?
• Cost: Is the hospital covered by your insurance plan?
• Accreditations: What accreditations does the hospital hold?

Specific Questions To Ask Your Doctor

I found a lump. What questions should I ask?
• What else could cause a lump besides cancer?
• How common are lumps in the breast?
• What kind of test do I need? A mammogram or ultrasound? What’s the difference?
• Will I definitely know something once I get further testing? Can the test be inconclusive?
• What is an MRI?
• I’ve heard that a lump can be aspirated. What does this involve? Who does this?

The diagnosis is breast cancer. What questions should I ask?

• What kind of breast cancer do I have? What stage is it?
• How big is the tumor?
• Has the cancer spread to my lymph nodes or other parts of my body? If so, what affect does that have on my treatment options?
• What kinds of tests will be done on the tumor?
• How will these tests determine my options for treatment?
• Who is in charge of my care now?
• What do you recommend for treatment?

I’m supposed to have a biopsy. What do I need to know?

• Where will I have the biopsy done? Will the whole lump be removed or just part?
• Can the lump be aspirated?
• How long does the procedure take?
• Will the procedure be done outpatient? Will I be awake, and will I feel anything?
• Should I take my regular medications before the biopsy?
• Will the biopsy leave a scar?
• What is the recovery like from a biopsy? Will I be sore?
• When will I be able to resume my normal activities?
• After the biopsy, how long will it be before I know the results?
• If the biopsy shows cancer, who will recommend the treatment?

The diagnosis is cancer. What questions do I ask about treatment options?

• Will I need chemotherapy?
• Is it possible to do a lumpectomy and save my breast? Will I need radiation afterwards?
• After my surgery, will I need more treatment? Radiation? Chemotherapy?
• What is hormonal therapy, and will I need it?
• If I need a mastectomy, can reconstruction be done at the time of the surgery? Is it better to wait until later?
• If I choose not to have reconstruction, what options do I have in terms of prostheses?
• Will my insurance cover my specific type of treatment?
• Is there a clinical trial for people with my type of breast cancer? Where can I learn more about clinical trials?

The diagnosis is cancer and surgery is recommended. What questions should I ask?

• What type of surgery am I going to have? Why is it recommended?
• How long will I be in the hospital?
• What care or help will I need once I go home from the hospital?
• How will I feel after the surgery? How long will it be before I can resume my normal activities?
• Are there some common side effects after this type of surgery?
• Where will the surgical scar be? Will it fade over time?
• If I’m having a lumpectomy, will my breast feel different after surgery?
• What risks are associated with this surgery?
• What treatments will I need after the surgery?
• When will I find out the results of the surgery?
• How long before I have a follow-up appointment?
• What is lymphedema and how can I reduce the possibility of getting it?
• Where can I find a breast cancer support group?

Treatment Options

It’s helpful to understand the possible treatments for breast cancer. Following are overviews of the most common treatments. Reading these should help you know what to expect, what the potential side effects are, and what the advantages are to each.

In the following pages, you will learn more about each of the following treatment types:

• Lumpectomy or Segmentectomy
• Mastectomy
• Chemotherapy
• Radiation
• Hormonal Therapy
• Biologic Therapy

Surgery

When surgery is possible, surgery is often the best way to remove cancer cells from the body. For breast cancer there are a multiple surgical options, including lumpectomy, which preserves the breast, and mastectomy, which removes the breast. After surgery for breast cancer, some
women also choose to undergo reconstructive surgery. Type of surgery needed depends on tumor size, staging, hormone status, genetics, and other factors. Speak with your surgical oncologist about which surgery type is best for you.

**Lumpectomy or Segmentectomy**

Lumpectomy is a type of breast cancer treatment in which your breast is preserved. For this reason it's called a breast conserving or breast preservation surgery. In a lumpectomy, the surgeon removes only the breast tumor and some surrounding normal tissue. Technically, a lumpectomy is a partial mastectomy, because part of the breast tissue is taken out. The amount of tissue taken varies from patient to patient.

**What to Expect in a Lumpectomy**

If your tumor cannot be seen or felt, the surgeon will call for a mammogram or ultrasound. These tests will help the surgeon locate and mark the tumor. The surgeon or a nurse may draw with a felt tip marker on your breast to show where the incision will be.

In cases where the tumor cannot be seen or felt, the surgeon may also use a technique called needle localization or wire localization. The surgeon will insert a thin, hollow needle into the breast. A mammogram is conducted to make sure the needle is positioned properly. If it is, a fine wire is threaded through the hollow needle to mark the area. The needle is removed, leaving the wire behind. The surgeon will use the wire as a guide to remove the tumor and surrounding tissue.

In the anesthesia room, a nurse will insert an intravenous infusion (IV) line into your hand or arm. It will be taped in place. This is not painful but may feel cold or uncomfortable. You'll be given relaxing medication through this IV line.

You will have a local anesthetic to numb the incision area. Some people get general anesthesia as well.

The actual surgery takes about 15-50 minutes. Most surgeons make curved incisions (like a smile or frown). This way, the incision follows the natural curve of your breast.

Sometimes it is necessary to insert a rubber tube called a drain into your breast area or armpit. This collects extra fluid that can build up in the space where the tumor was.

**Recovery**

When the surgery is over, you'll be moved to a recovery room. Nurses will monitor your vital signs—your heart rate, body temperature and blood pressure. Usually you don’t have to stay overnight in the hospital with a lumpectomy.
You may be given pain medication in the recovery room. You will have a prescription to take home with you. It’s a good idea to get it filled on your way home. You might ask a friend or family member to get it filled for you as soon as you are home. You may not need the medication, but you should have it in case you do.

Before you leave, your surgeon or nurse will instruct you in caring for the lumpectomy bandage. Sometimes, you will need to do nothing to the bandage until your follow-up visit. If you have a drain in your armpit or breast area, it might be removed before you go home. Sometimes a drain stays in until the first follow-up visit with the doctor. This appointment is usually 1-2 weeks after surgery. In that case, you’ll need to empty the fluid from the detachable drain bulb several times a day. You will need to record the amount of fluid in the bulb. You can use the “Drain Bulb Log” worksheet included in the back of the Handbook. Your surgical team will give you instructions on caring for the drain.

Most surgeons use stitches that dissolve over time. Some surgeons still use surgical staples. These are removed during your first follow-up visit.

You will need someone to drive you home from the hospital.

**Once You’re at Home**

With your surgeon’s permission, you will need to exercise the side where you had the lumpectomy. This will prevent stiffness in your arm or shoulder. Your surgeon or a nurse will show you these exercises. Generally, you will start on them the morning after surgery. Your surgical team will also tell you what signs of infection to look for in your incision.

You’ll need to stay home and rest for a few days after your lumpectomy. Make sure to get enough rest so you can return to your normal routine. It is normal to feel fatigued after the procedure.

You may feel pain or numbness around the incision. Take pain medication, if needed, according to your doctor’s directions.

Do not bathe until your doctor has removed your drains and/or sutures. Take sponge baths until then.

It’s important to wear a good sports bra that provides support. Wear it both day and night for a while to restrict movement that could cause pain. If you have large breasts, you may want to sleep on the side not operated on and support your healing breast under a pillow.

When you’ve had a lumpectomy, your nerves will need to regrow. As they do, you might feel a crawling sensation. You may itch or be sensitive. You can take acetaminophen or NSAIDs like ibuprofen for relief.

**Questions to Ask**
Here are some questions to ask your surgeon as you plan for lumpectomy surgery:

- How many lumpectomies have you performed?
- What are the risks?
- How should I prepare in advance?
- How long does the surgery take?
- How much tissue will be removed?
- How will you decide how much tissue to remove?
- Will you remove any lymph nodes under my armpit?
- Will I have anesthesia? If so, what kind?
- Should I donate my own blood before surgery? Will I need blood transfusions?
- How will my breast look after the lumpectomy?
- Will I need to stay in the hospital overnight?
- How long is the recovery process? When can I resume my normal activities?
- What exercises do I need to do after surgery?
- What precautions should I follow once I go home?
- How much pain medication can I take?
- Will I be at risk for lymphedema after surgery?
- What signs of infection should I watch for?

SEGMENTECTOMY

A segmentectomy is similar to a lumpectomy. However, in a segmentectomy, more of the surrounding breast tissue is removed with the lump. Usually, some lymph nodes are also removed at the same time.

Who should not have it?

Radiotherapy is required after segmentectomy. For this reason, pregnant women and other people who can’t tolerate radiation should not have segmentectomy.

What to Expect

After a segmentectomy, you should not do any moderate lifting for several days. Other activities may be restricted as well. You may be instructed to wear a well-fitting support bra both day and night for about a week after surgery. If you feel pain, it can usually be well-controlled with pain medication that your doctor gives you.

Radiation therapy starts 4 to 6 weeks after surgery. It continues for 4 to 5 weeks. The exact timing is different for each patient.
Mastectomy

A mastectomy is a procedure where your entire breast (nipple, areola, lymph nodes, and some of the surrounding tissue) is removed. You may not realize that there are actually 6 different kinds of mastectomy:

- Simple (or total) mastectomy
- Radical mastectomy
- Modified radical mastectomy
- Partial mastectomy
- Subcutaneous (nipple sparing) mastectomy
- Skin sparing mastectomy

Let’s look at each of the 6 types.

**Simple (total) mastectomy**

In some mastectomies, it’s necessary to remove lymph nodes under your arms. This is called axillary lymph node dissection. However, in a simple mastectomy, usually no lymph nodes under your arms are removed. The only lymph nodes that are sometimes removed in a simple mastectomy are nodes that are located within the breast tissue itself. In addition, the surgeon removes no muscles from beneath your breast. This makes recovery a bit easier.

**When is a simple mastectomy called for?**

Your doctor may recommend a simple mastectomy if you:

- Have many or large areas of ductal carcinoma in situ (DCIS); or
- Want a prophylactic mastectomy—in other words, one that prevents breast cancer from occurring in the future.

**Radical mastectomy**

This is the most extensive kind of mastectomy. In this procedure, the surgeon removes your whole breast. In addition, the surgeon removes:

- Three levels of your underarm lymph nodes.
- The chest wall muscles under your breast

**When is a radical mastectomy called for?**

Radical mastectomies were common in the past. However, today, a radical mastectomy is only recommended when the cancer has spread to your chest muscles. For most people, modified radical mastectomy is just as effective as radical mastectomy. However, it is less disfiguring.
**Modified radical mastectomy**

In this procedure, the surgeon removes both the breast itself and two levels of lymph nodes. This process is called axillary lymph node dissection. The surgeon removes no muscles from under your breast.

**When is a modified radical mastectomy called for?**

If you have invasive breast cancer and are going to have a mastectomy, your surgeon may recommend a radical mastectomy. This way, the lymph nodes can be removed and examined. This tells your doctor whether cancer cells have spread beyond your breast.

**Partial mastectomy**

In a partial mastectomy, the surgeon removes the cancerous part of the breast tissue. Some normal tissue around it is also removed. Technically, a lumpectomy can be considered a partial mastectomy. However, more tissue is removed in a true partial mastectomy.

**When is a partial mastectomy called for?**

If you have stage 1 or 2 breast cancer, you may consider a partial mastectomy. In many cases, a partial mastectomy plus radiation therapy is as effective as a total mastectomy.

**Subcutaneous ("nipple-sparing") mastectomy**

If you have a subcutaneous ("nipple-sparing") mastectomy, the surgeon will remove all of your breast tissue, but leave your nipple alone. There are some possible disadvantages to this procedure:

- More breast tissue is left behind that could develop cancer.
- Breast reconstruction after the mastectomy can cause distortion and numbness in your nipple.

Because of these potential problems, many doctors still recommend a simple mastectomy instead.

**Skin-sparing mastectomy**

A skin-sparing mastectomy leaves as much of your breast’s skin as possible. During this procedure the surgeon removes the skin of your nipple, areola and the original biopsy scar. This creates an opening. Then the surgeon removes the breast tissue through this opening.

What remains is a pouch of skin that offers the best shape to house an implant or reconstruction.
When is a skin-sparing mastectomy called for?

Many women think this procedure gives them the most realistic reconstruction. Most women can have skin-sparing mastectomies. However, it may not be right for you if:

- You are not planning to have immediate breast reconstruction.
- There’s a chance that tumor cells are close to the skin. If this is the case, they need to be removed to prevent the spread of cancer.

Is Mastectomy Right for You?

It’s important to discuss your treatment options with your doctor. Together you can make the right decision about treatment. Mastectomy may be the right choice if:

- The tumor is larger than 5 centimeters. Stage and other factors weigh in here also. Your doctor may advise a mastectomy for some tumors less than 5 cm. Others less than 5 cm. may require only a lumpectomy.
- Your breast is small. This would mean that a lumpectomy would leave you with very little breast tissue.
- Your surgeon has tried multiple times to remove the tumor with a lumpectomy but has not been able to completely remove it and get clear margins.
- You have a small tumor (under 4 cm.) but lumpectomy plus radiation is not an option for you. Reasons why it would not be an option include that you’ve already had radiation to that breast; you are pregnant; or your have a disease like lupus or rheumatoid arthritis.
- You feel that a mastectomy would give you greater peace of mind than a lumpectomy.

If I have a mastectomy, will I need radiation? If so, what does that involve?

Mastectomy Plus Radiation

You may need radiation after your mastectomy if:

- Your tumor is larger than 5 centimeters
- The tissue removed during mastectomy does not have clear margins
- Your surgeon finds cancer cells in 4 or more lymph nodes
- The cancer was found in multiple locations within your breast

In these cases, radiation will typically follow chemotherapy.

Mastectomy: What to Expect

Before your mastectomy, your surgeon or a nurse will draw on your breast with a felt-tip marker. This will show you where the incision will be. You will be sitting up when this is done so that the natural crease of your breast can be followed.
You will be given anesthesia. A nurse will insert a needle connected to a long tube. This is called an intravenous infusion (IV) line. It will be either in your hand or your arm and will be taped into place. The nurse will give you medication to relax you through this IV line. Once you are in the operating room, you will be given general anesthesia.

How long does the surgery take and how long will I be in the hospital?

About the Surgery

On average, a mastectomy can take 2-3 hours. If you're having reconstruction at the same time, the surgery will take longer.

Usually the surgeon will make the incision in the shape of an oval around the nipple. It will run across the width of your breast. If you are having a skin-sparing mastectomy, the incision will be smaller.

In a mastectomy, the surgeon separates the breast tissue from the overlying skin. The breast tissue is also separated from the chest wall muscle underneath unless you are having a full radical mastectomy.

All of the breast tissue is removed. Some lymph nodes may be removed as well, if your surgeon suspects the cancer has spread to them.

If you are having immediate breast reconstruction, then that will begin as soon as all breast tissue is removed.

The final step is for the surgeon to insert surgical drains. These are long tubes inserted in your breast area or armpit. This is necessary because extra fluid can build up in the space where the tumor was. These tubes help the fluid leave your body. After the drains are put in, your surgeon will stitch the incision closed. Then the surgeon will cover your chest with a tight bandage.

You'll stay in a recover room right after surgery. Nurses will monitor all your vital signs. You can be given medication if you are in any pain.

Typically, you will stay in the hospital for up to 3 days. The stay may be a little longer if you have had reconstruction at the same time.

You will need someone to drive you home from the hospital. You may also want your caregiver to be present when you receive your instructions for post-surgery care.

Recovering from a Mastectomy

**Bandage:** Before you leave, your surgeon or nurse will instruct you in caring for the bandage or dressing. Sometimes, you will need to do nothing to the bandage until your follow-up visit.
**Drain Bulbs**: After a mastectomy, the drain in your armpit or breast area usually stays in until the first follow-up visit with the surgeon. This appointment is usually 1-2 weeks after surgery. You will need to empty the fluid from the detachable drain bulb several times a day. You will also need to record the amount of fluid collected in the bulb. You can use the “Drain Bulb Log” worksheet included in the back of the Handbook. For the first few days, the drainage will be red because of blood cells, but it will change color. It’s important to drain this fluid away so it does not collect in the surgical incision. Your surgical team will teach you how to care for your drain before you leave the hospital.

**Arm Exercises**: It’s important to begin exercising the morning after your surgery. Your doctor or nurse will show you simple exercises. This will keep your arm and shoulder from getting stiff. There are some exercises that will need to be avoided until drains are removed.

Don’t worry that you’ll forget how to do the exercises once you’re at home. You will be given written, illustrated instructions that remind you how.

Before you leave the hospital, you will receive information about recovering at home. The instructions should cover the following:

- Taking pain medicine
- Caring for your bandage
- Caring for the surgical drain
- Your stitches and staples
- Recognizing signs of infection
- Recognizing signs of lymphedema
- When you can start wearing a prosthesis or bra

If you have any questions, contact your healthcare team immediately.

**Your Recovery at Home**

Be prepared for it to take your body a few weeks to recover from a mastectomy. It can take longer if you had reconstruction. Make sure you give yourself adequate time to heal. Here are some ways to plan for your recovery at home:

- Rest. Don’t make too many plans for the first few weeks after surgery. Realize that you’re going to need extra rest.
- Get help from friends and family. You’ll need help with meals, laundry, and childcare. Accept offers of help from family and friends graciously. Don’t feel as if you’re imposing. How would you feel if a relative or friend were in your shoes? Wouldn’t you be very happy to help out?
- Take pain medication if you need it. Most people report some numbness and pain after a mastectomy. If you’re in pain, take medication. Always follow your doctor’s instructions regarding pain medication. Make sure to get any pain medications filled as
soon as you leave the hospital. Perhaps a friend or relative can do this for you. That way, the pain medication is on hand if and when you need it.

- Make sure to do arm exercises every day. These will prevent stiffness.
- Expect “phantom” sensations or pain in the months to come. This is normal. The reason for these sensations is that your nerves have to regrow. Taking analgesics and NSAIDs like acetaminophen (Tylenol) and ibuprofen can help relieve this discomfort.

Questions to Ask Your Surgeon About Mastectomy

If you are considering a mastectomy for your breast cancer treatment, here are some questions to ask your surgeon:

- How many mastectomies have you performed?
- What are the risks of mastectomy?
- How long will surgery take?
- How long will I stay in the hospital?
- Will I need to have any underarm lymph nodes removed?
- Will I need blood transfusions? Should I donate my own blood before surgery?
- Am I a good candidate for immediate breast reconstruction?
- What are the risks of having reconstruction surgery?
- If I have immediate breast reconstruction, how will my breast look after surgery?
- If I don’t have immediate reconstruction, how will my chest look after surgery?
- Will I be at risk for lymphedema after surgery?
- Will you give me written instructions to follow as I recover?
- Are there exercises I need to do after surgery?
- When can I return to my normal routine and activities?
- What are signs of infection I should look for?
- Whom should I call if I have questions?
- What is the best way to get in touch with your office?
- When will I need to come in for a follow-up visit?

Breast Reconstruction

Some women choose to have their breasts reconstructed after surgery. There are two main types of breast reconstruction surgery:

- Implants
- Tissue flap procedures (tissues taken from another part of the body)

Implants and Expanders

Breast implants can often be done at the same time as a mastectomy. When implants take place at the same time as a mastectomy, it is called “immediate reconstruction.” This is a good option for some women. However, this is not a good option for women with high-risk tumors. It
may also not be a good option for women with lower-risk tumors who are going to do radiation therapy after surgery. This is because radiation may alter the appearance or feeling of the reconstructed breasts. For this reason, many women choose to do reconstructive surgery at a later time in their cancer journey.

Implants are either silicone or saline. Alternative types of breast implants may be available through clinical trials. Reconstructive surgery involving implants is usually a two-step process.

1) The first step is to insert expanders under the skin and chest muscle. The expanders create space for the implant. Over 6-10 weeks, your surgeon will gradually inject more saline into the expanders to stretch the skin and tissue. While this process can be uncomfortable, you will still be able to go about most of your daily activities. Ask your surgeon about your need to limit your physical activities.

2) The second step is to remove the expanders and insert the saline or silicone implant. Recovery is generally 3-4 weeks.

What are the benefits?

Compared to other breast reconstruction options, implants have the following benefits:

- Less extensive surgery
- Shorter recovery time
- Fewer scars

What are the risks?

- Implants can rupture or leak. You may need regular breast MRIs to check for ruptures or leaks.
- Implants will likely need to be replaced at some point in your lifetime.
- Implants may feel less like natural breasts than breasts reconstructed from your own tissues.
- With any surgery, there are risks of infection.

Tissue Flap Procedures

Tissue flap procedures use tissues from your own body to reconstruct breasts. Tissues may be taken from the abdomen, back, thighs, or buttocks. The two most common flaps used are the TRAM (transverse rectus abdominis) flap and the latissimus dorsi flap (see below for more information). Recovery time can be 4-6 weeks or longer for some procedures.

Here is a chart explaining the different options for tissue flap procedures:

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRAM (transverse rectus abdominis) flap</td>
<td>Uses skin, fat, and muscle from the lower abdomen to reconstruct breasts</td>
</tr>
</tbody>
</table>
Latissimus dorsi flap | Uses skin, fat, and muscle from the upper back to reconstruct breasts
---|---
DIEP (deep inferior epigastric artery perforator) flap | Uses skin and fat only from the lower abdomen to reconstruct breasts.
TAP or TDAP (thoracodorsal artery perforator) flap | Uses skin and fat only from the upper back to reconstruct breasts.
GAP (gluteal artery perforator flap) | Uses fat and skin from the buttocks to reconstruct breasts. Can be taken from superior/upper buttocks (S-Gap) or inferior/lower buttocks (I-Gap).
TUG (transverse upper gracilis) flap | Uses muscle and fat from inner thigh to reconstruct breasts.

The options for tissue flap procedures vary by location and surgeon. Your surgeon can discuss all your options with you.

**What are the benefits?**

- Breasts reconstructed with your own tissue are more likely to feel and look like natural breasts.
- With tissue flap procedures there is no risk of ruptures or leakage, and after healing, tissue flaps will never have to be replaced.

**What are the risks?**

- Longer recovery time
- Scars where the tissue flap is removed
- Flap necrosis (The tissues flap could die. This is rare.)
- With any surgery, there is a risk of infection.

**Nipple and Areola Reconstruction**

Nipple and areola reconstruction is another optional part of breast reconstruction. Usually, it is a separate surgery that occurs 4-5 weeks after the reconstructed breasts have healed. Nipples can be constructed from your own tissue from breasts, thighs, buttocks, or other areas. Nipples can also be tattooed onto the skin. Both of these are outpatient procedures.

For women with early stage breast cancer, a nipple-sparing mastectomy may be possible. In this procedure, only the breast tissue under the nipple is removed.

**Questions To Ask Your Surgeon About Breast Reconstruction**

Discuss all your options with your surgeon to choose which type of breast reconstruction (if any) is right for you. Use these questions to begin the conversation:

- Which type of reconstruction would you recommend? Why?
• What are my other options?
• What are the risk and benefits of each of my options?
• If I choose to do an implant, what type of implant would you recommend?
• What are my options for nipple and areola reconstruction?
• What is the recovery time? When will I be able to return to my normal activities?
• What can I expect my breasts to look like after surgery? Do you have pictures of any past patients?
• Will I have feeling in my breasts?
• Will my health insurance cover the costs?

Chemotherapy

Chemotherapy treatment (usually called “chemo”) involves using medicines that prevent cancer cells from growing and spreading. Chemotherapy medicines do this by destroying cancer cells altogether or preventing them from dividing. Chemo affects your whole body because it goes through your bloodstream.

When is chemotherapy used?

• In early-stage invasive breast cancer to get rid of any cancer cells that may be left behind after surgery. Chemo helps decrease the risk of the cancer coming back.
• In advanced-stage breast cancer to destroy or damage the cancer cells as much as possible.
• In some cases, chemo is used before breast cancer surgery in order to shrink the cancer. This is called neoadjuvant chemotherapy. It is used when a tumor is inoperable at its current size or to make breast sparing surgery a possibility.
• It is relatively common for chemo treatment to begin after surgery and recovery.

Chemotherapy not only weakens and destroys cancer cells at the site of the tumor, but throughout the body as well. Unfortunately, this means that chemo can unintentionally harm the development of normal cells like your hair, nails, mouth, and digestive tract.

Chemo doesn’t refer to one treatment but many, because there are lots of different chemotherapy medicines. Brand names for common chemotherapy medications for breast cancer include:

• Carboplatin (Paraplatin)
• Capecitabine (Xeloda)
• Cyclophosphamide (Cytoxan)
• Daunorubicin (Cerubidine, DaunoXome)
• Docetaxel (Taxotere)
- Doxorubicin (Adriamycin, Doxil)
- Epirubicin (Ellence)
- Eribulin (Halaven)
- Fluorouracil (Adrucil)
- Gemcitabine (Gemzar)
- Ixabepilone (Ixempra)
- Methotrexate (Folex, Mexate)
- Mitomycin
- Mitoxantrone (Novantrone)
- Paclitaxel (Abraxane, Taxol)
- Thiotepa (Thioplex)
- Vincristine (Oncovin, Vincasar PES, Vincrex)
- Vinorelbine (Navelbine)

Sometimes, your doctor may combine two or more medicines to treat your breast cancer. These combinations are called chemotherapy regimens. Common regimens include:

AT: Adriamycin and Taxotere
AC + T: Adriamycin and Cytoxa, with or without Taxol or Taxotere
CMF: Cytoxan, methotrexate, and fluorouracil
CEF: Cytoxan, Ellence, and fluorouracil
FAC: Fluorouracil, Adriamycin, and Cytoxan
CAF: Cytoxan, Adriamycin, and fluorouracil (Note: the difference in the CAF and FAC regimens is not in the medicines but in the doses and frequencies)
TAC: Taxotere, Adriamycin, and Cytoxan
GET: Gemzar, Ellence, and Taxol

Your doctor may refer to specific groups of chemotherapy medicines:

Anthracyclines: In terms of their chemistry, these are similar to an antibiotic. They make the cancer cells die by damaging their genetic material.

Taxanes affect the way cancer cells divide.

**What to Expect with Chemotherapy**

Chemo medicines come in different forms and can be given in different ways:
• Intravenously (IV): As an infusion, the medicine comes through a thin needle (IV) in a vein in your hand or lower arm. An oncology nurse will insert the needle before each infusion and take it out afterwards.

• Injection: As a single shot into a muscle in your leg, arm, hip, or under the skin in the fatty part of your stomach, leg or arm.

• By mouth: As a pill or capsule. You may take this yourself at home.

• Through a port: This is inserted in your chest during a short outpatient surgery. It is about the size of a quarter and sits right under your skin. A port is a small disc made of plastic or metal. A catheter (soft thin tube) connects the port to a large vein. The chemo medicines are delivered through a thin needle right into the port. You can also get your blood drawn through the port. Once you have finished chemo, the port is removed in a brief outpatient procedure.

• Through a catheter in your chest or arm. This is a soft thin tube that is inserted into a large vein. This is done in a short outpatient surgery. The other end of the catheter stays outside your body. This is similar to having a port.

If you have a catheter or port, you will need to watch for infection. Your healthcare team will tell you signs of infection.

What’s the advantage to a port or catheter?

Many doctors recommend getting a catheter or port because it makes chemotherapy easier and more comfortable each time, as you won’t have to be restuck each time, as you do with an IV or injection. Also, a port may be a good idea if you are having problems with arm lymphedema.

Some breast cancer patients have a portable pump attached to the port or catheter. This controls how much and how fast the chemotherapy medicine goes in. The pump can either be internal (implanted under the skin during a short outpatient procedure) or external (carried with you). Once your rounds of chemo are done, the pump is taken out.

Setting Your Schedule

Your oncologist will set your treatment regimen. Every chemo regimen is made up of cycles. This means a period of treatment followed by a period of recovery. For example, you may get chemo one day and then have a few weeks of recovery with no treatment. That would be one cycle. Or you may get chemo for several days in a row and then have a recovery period. Several cycles make up a complete chemotherapy regimen.

The number of cycles in a regimen and the length of each regimen varies from patient to patient. A lot depends on the medicines used. However, most regimens take 3 to 6 months to complete. A typical routine is treatment every 3 weeks.
For some patients, the doctor recommends a “dose-dense” chemo schedule. This means the chemo medicines are given every 2 weeks. Research has shown that dose-dense chemo can improve results and reduce the risk of breast cancer recurrence.

A disadvantage to dose-dense chemotherapy is that it doesn’t allow much time for your immune system and red blood cells to recover between cycles. Doctors sometimes prescribe medicines that strengthen your immune system if you’re going to have dose-dense chemo.

You can get chemotherapy in a variety of settings: at a hospital, in a doctor’s office, in a clinic, or at home if you are taking chemo in a pill form or you have a portable pump.

If you take chemo in a clinic, hospital or doctor’s office, you usually go home between treatments. In some cases, you may stay in the hospital to be monitored. This is especially true if your immune system isn’t working as well as it should be. Your doctor will explain where you’ll be getting your treatment.

**Passing Time During Chemotherapy**

A chemotherapy treatment at a hospital or clinic can take anywhere from one to several hours. Although many chemo treatment areas have televisions and magazines, you may want to bring something to help pass the time. Ideas include:

- A laptop
- Knitting, needlepoint or crochet
- A thick novel
- Crossword or other puzzle book
- Sketchbook and pencils
- Cards or board games (if you have someone to play with)
- MP3 Player or portable CD player to listen to music
- Paper and pens to keep a journal or write letters

**Planning Ahead for Chemotherapy**

Chemotherapy treatment can drain most of your energy. This is a major process your body is going through. There are some things you should take care of before you start chemo:

- Get your teeth cleaned and get a dental check-up. Chemo weakens your immune system, so you may be more vulnerable to infections caused by bacteria that are dislodged during teeth cleaning.
- Get any heart tests (like an EKG) that your doctor recommends.
- Get a Pap smear, if you’re overdue. Chemo can alter the results of your Pap smear, so get one beforehand.
Find someone to help around the house. Chemo causes extreme fatigue. Line up someone to help with your daily chores: cleaning, grocery shopping, carpooling, and cooking to name a few. Don’t be afraid or embarrassed to ask for help. Friends and family members will be happy to do something that helps you during this treatment phase. Ask yourself: wouldn’t you be willing to do it for someone else?

- Join a support group if that sounds helpful.
- Find out ahead of time what you should and shouldn’t eat or drink on treatment days.
- Tell your doctor all the vitamins, supplements, over-the-counter and prescription medicines you take.
- Talk to your doctor about hair loss. Most chemo medicines cause some amount of hair loss. If you plan on wearing a wig, you might want to go ahead and get it so you can match it to your hair color and style.

Radiation

Radiation therapy is also called radiotherapy or simply radiation. This is a very effective way to destroy cancer cells that may remain after the breast surgery. Radiation can pinpoint the cancer cells very well. Estimates are that radiation can reduce the risk of breast cancer coming back by about 70%.

In addition, radiation therapy is relatively easy to tolerate, because its side effects are mostly limited to the treated area. Fatigue is the most common full-body side effect. Fatigue usually starts at week two and worsens until week five. For tips on managing fatigue, read the “Side Effect Management” section of the Handbook.

A radiation oncologist will oversee your radiation treatments. There are 3 major types of radiation:

**External Radiation:** The most common type of radiation is external radiation. It is usually given after lumpectomy. It may also be given after a mastectomy.

**Internal Radiation:** A less common method is internal radiation. It is primarily used after a lumpectomy.

MammoSite Radiation Therapy System (RTS) is a type of high dose internal radiation therapy used specifically after a lumpectomy. A member of the healthcare team will insert a balloon catheter into the breast at the site of the lumpectomy. The catheter will then be expanded, and a tiny bead is inserted into the area. This bead will deliver the radiation therapy. Since this type of radiation targets one small area, it protects surrounding healthy tissue from the damage caused by radiation.

**Intraoperative Radiation:** A relatively new type of radiation is intraoperative radiation therapy (IORT). This is given during lumpectomy surgery once the cancer has been taken out.
Is radiation necessary for me?

Radiation therapy is appropriate for all stages of breast cancer because it is relatively safe and very effective. Radiation can also be given to people with stage IV cancer that has spread to other parts of the body.

Radiation is never safe for pregnant women.

**Lumpectomy with Radiation**

Radiation is designed to destroy any cancer cells that are left in the breast after the tumor has been removed.

Usually a doctor will recommend that you have radiation after your lumpectomy if the cancer is:

- Early stage
- 4 centimeters or smaller in size
- Located in one site
- Removed with clear margins

**Mastectomy with Radiation**

During a mastectomy, it’s hard to remove every cell of breast tissue. It’s especially hard to remove the tissue behind the skin in front of your breast or along the muscle behind your breast. It’s possible for some breast cancer cells to remain in these places. This is why there could be a risk for recurrence in the area where your breast was.

Your doctor may recommend radiation if you have any of the following risk factors after your mastectomy:

- Cancer has invaded the lymph channels and blood vessels in your breast.
- The cancerous tissue that was removed has a positive margin.
- At least 4 lymph nodes were involved.
- You are premenopausal, and at least, 1 lymph node was involved.
- Cancer has invaded your skin.
- The tumor is 5 centimeters or larger.

It is estimated that 20 to 30% of people with these risk factors are a higher risk of recurrence. This is why radiation can be an important treatment, because it reduces the risk of recurrence.

Radiation is not appropriate for you if:

- You are pregnant.
- You have already had radiation to that part of your body.
- You have a connective tissue disease, like vasculitis.
• You cannot commit to the daily regimen of radiation therapy.

**When is radiation given?**

For some people, radiation is given right after surgery. Sometimes, however, it is given after another treatment, like chemotherapy or hormonal therapy. Every patient’s cancer is different. Your doctor will discuss the specific treatment routine you’ll need. As a rule of thumb, if you need chemotherapy, that will come before radiation.

**What to Expect**

Most side effects of radiation involve the skin of the area being treated. When you’re first undergoing radiation, you’ll notice your skin color change from pink to red. It will look like sunburn. You will probably also have itching, burning, soreness or peeling.

Some areas of your skin may react more than others. Problem areas often include:

• Skin along the fold under your breast
• Skin of your armpit
• Skin in the upper corner of your breast

Some skin has a more dramatic reaction to radiation. This is likely if:

• You have large breasts.
• Your complexion is fair and you get sunburns more easily.
• You have recently had chemotherapy.
• You are receiving radiation after mastectomy, and the treatment delivers a high dose to the skin.

Just like with a sunburn, your skin may be dry, sore, and more sensitive to touch. You skin may start to peel. If this happens, it tends to be toward the end of your treatments or later. Watch for signs of infection. Your oncologist will tell you what to look for.

The good news is that skin irritation caused by radiation is temporary. Your doctor can also give you salves, medications and prescriptions to ease the discomfort.

**After the Treatment**

Once you finish radiation, your skin may continue to get worse for another week or so. Then it will start to get better. There are things you can do to prevent irritation before and after treatments:

• Wear loose-fitting cotton shirts.
Avoid letting shower water fall directly on your breast.
Shower in warm instead of hot water.
Avoid harsh soaps; use fragrance-free soaps with moisturizers.
Wear a good support bar with no underwire to keep your breasts separated and lifted.

If your skin becomes very irritated, you can take several steps to minimize the irritation:

- Moisturize your skin with an ointment like Eucerin, A&D, or Radiacare.
- Apply an aloe vera ointment or 1% hydrocortisone cream. Use the cream 3 times a day.
- Blow on the area with a hair dryer set to cool or air (no heat).
- If your skin forms a blister, leave it alone. It is designed to keep the area clean while the new skin grows back.

Regarding sun exposure:

- Keep the treated area out of the sun.
- Wear a cover-up when you’re not in the water—like an oversized cotton shirt.
- Avoid chlorine because it’s very drying.
- Use a sunscreen that is at least SPF 30 on the area that was treated.
- Re-apply sunscreen every few hours.

**Hormonal Therapy**

To understand hormonal therapy you must first know that many breast cancers are hormone-receptor-positive. This means that the estrogen hormone makes the cancer cells in your breast grow. Hormonal therapy treats hormone receptor positive breast cancers. This kind of therapy only affects the action of estrogen in breast cancer cells, not progesterone. It is not used, then, if your breast cancer is progesterone receptor positive.

Hormonal therapy medicines treat hormone receptor positive breast cancers by:

- Blocking the activity of estrogen in your body.
- Lowering the amount of estrogen in your body.

Your ovaries are the main source of estrogen before menopause. Therefore, if you are premenopausal and diagnosed with estrogen receptor positive breast cancer, you may choose to shut down your ovaries through medicine or surgery.

Two option treatment options include:
- Tamoxifen: Tamoxifen prevents the action of estrogen in breast tissue by preventing estrogen molecules from reaching the hormone receptors.
- Aromatase inhibitors: Aromatase inhibitors help lower the amount of estrogen in your body.

Hormonal therapy is also used to decrease the risk of early-stage, hormone receptor positive breast cancer coming back after surgery. It is also used to treat advanced/metastatic hormone receptor positive breast cancer. Pre-menopausal women can use hormonal therapy.

Hormonal therapy can be given before, at the same time as, or after other breast cancer treatments.

Hormonal therapy is never safe during pregnancy.

**Which hormonal therapy is right for me?**

You and your doctor will consider several factors when identifying the best hormonal therapy medicine for you:

- Your breast cancer stage
- Your stage of menopause
- Whether you’ve had any blood clots
- Your bone density
- Whether you’ve had any arthritis

If you have side effects from one therapy, you may be able to switch to another.

**How do I take hormonal therapy?**

All the hormonal therapy medicines except one, Faslodex (fulvestrant) are pills. They are taken once a day. The medicines can be taken with or without food. Faslodex is a liquid that is injected into your muscle once a month. Most hormonal therapies are taken long term, 5 years or longer. Some women begin taking tamoxifen then switch to an aromatase inhibitor after the first 2-3 years.

**Questions to ask your doctor about hormonal therapy**

I have just been diagnosed with hormone receptor positive breast cancer. What questions should I ask?

- What are the benefits and risks of aromatase inhibitors for me?
- For me, what are the benefits and risks of tamoxifen?
- Does an aromatase inhibitor or tamoxifen make more sense for me?
- How long will I need to take hormonal therapy?
- Do I need a bone density test?

I have taken tamoxifen for 2 to 3 years. What questions should I ask?

- Would there be any benefits to switching to an aromatase inhibitor?
- If I don’t switch to an aromatase inhibitor, how much longer will I take tamoxifen?
- How long would I take an aromatase inhibitor if I did switch?
- Will I have different side effects if I switch to an aromatase inhibitor?

I have finished 5 years of tamoxifen or an aromatase inhibitor. What questions should I ask?

- Should I now take a different type of hormonal therapy for an additional 5 years? If so, what are the benefits?
- Should I keep taking my current hormonal therapy medicine for longer than 5 years? If so, what are the benefits?
- How many years would I take an aromatase inhibitor? How many years would I take tamoxifen?
- What side effects are possible with an aromatase inhibitor? With tamoxifen?

**Biologic Therapy**

Biological therapy is a treatment that works with your immune system. This therapy takes advantage of the body’s own immune system to act on cancer cells while leaving healthy cells relatively intact. All the parts of your immune system help protect you from getting diseases and infection. Your immune system includes the:

- Spleen
- Lymph nodes
- Tonsils
- Bone marrow
- White blood cells

White blood cells are particularly important to your immune system. Here are some terms you might hear:

- Neutrophils, monocytes, and lymphocytes are types of white blood cells.
- B cells, T cells, and natural killer cells are types of lymphocytes.

Your immune system is able to tell the difference between good cells that keep you healthy and bad cells that make you sick.
Biological therapy can serve 2 purposes. First, it can help fight cancer by:

- Stopping or slowing the growth of cancer cells.
- Making it easier for your immune system to destroy cancer cells.
- Keeping cancer from spreading to other parts of your body.

One form of biological therapy is cancer vaccines. There have been many vaccines studied in breast cancer to stimulate the immune system to destroy cancers. Many non-cancer vaccines are given before you get sick, but most cancer vaccines are given once you have a diagnosis of cancer. These vaccines help your body fight the cancer and keep it from returning.

Another strategy to attack breast cancer cells is to use antibodies. Antibodies are proteins that can attach or stick to other specific proteins in the body or on the cancer. Antibodies can be natural or made by the body's own immune system or made artificially.

There are two approved antibodies for breast cancer:

- Herceptin (trastuzumab)
- Perjeta (pertuzumab)

These antibodies only work if the tumor expresses the human epidermal growth factor receptor 2 (HER2) protein on its surface. Breast tumors that have this protein are said to be HER2+. The treatment antibodies work by sticking to the cancer and cause them to stop growing. They can also stick to the cancer cell and flag or signal the body's own immune system to attack the cancer cells. Most of these are given by injection.

There are many types of other biological therapies. One uses drugs that interrupt the pathways in the cell that tell cancer cells to grow. Some are combined with chemotherapy and some with hormonal therapies. Some of these block signals inside the cancer cell that tells the cancer cells when to divide. Afinitor (everolimus) has recently been approved for advanced hormone receptor positive breast cancer. Most of these drugs are taken by mouth.

Another type of therapy uses antibodies to inhibit the growth of new blood vessels and cuts off the nutrients to the cancer cell. Many trials in different cancers have reported improvements in disease control and survival with these agents. For breast cancer, many trials are underway evaluating their benefit.

Questions for Your Healthcare Team

If you’ve just been diagnosed with cancer, you may be confused and overwhelmed. You probably want answers, but you may not even know what questions to ask. As a cancer
patient, being able to talk openly and honestly with your healthcare team is very important. Use these must-ask questions as a guide to start talking with your healthcare team.

**What is my diagnosis?**
This question may seem like a no-brainer, but in the rush of appointments, you may not receive a clear answer. If you are unsure of your diagnosis, ask your oncologist. Sometimes more specific tests are needed to make an exact diagnosis.

**What is my prognosis? What stage is my cancer?**
Knowing your prognosis can help you better prepare for the future and select your best treatment plan. In order to know the stage of your cancer, your doctor will need to do tests. These may include scans, genetic testing, and/or a biopsy. The answer to these questions may be difficult to hear. You may consider having a family member or friend with you at this appointment.

**What are my treatment options? What would you recommend?**
Ask your oncologist to explain all your treatment options, including possible side effects and cost. Ask your oncologist which treatment he or she recommends. If you are unsatisfied with your options, do not be afraid to seek a second opinion.

**Am I eligible for a clinical trial?**
Clinical trials help improve the standard of care for all cancer patients. Based on your situation, a clinical trial may also be your best treatment option. Each trial has its own eligibility requirements. Ask your healthcare team about your options.

**What are the possible short-term and long-term side effects of treatment? How will these affect my normal activities?**
Always ask about short-term and long-term side effects before beginning treatment so you are prepared. You should also consider short-term and long-term side effects when deciding which treatment plan is best for you.

**How can I manage these side effects?**
Some side effects can be easily managed through diet, exercise, or over-the-counter medication. Other side effects may require prescription medication, occupational therapy, or physical therapy which your oncologist can prescribe as needed.

**Will my ability to have children be affected? Is there anything I can do to preserve my fertility?**
Some cancers and cancer treatments can affect your fertility, but you do have options. Before treatment, you may be able to freeze eggs or embryos. There may be steps you can take during treatment to protect your reproductive system as well. For more information, visit Fertile Hope at http://www.fertilehope.org/ or read the “Fertility” section of the Handbook.

**How can I keep myself as healthy as possible during treatment?**
Your own immune system plays a big part in your fight against cancer. It is important to stay as healthy as possible while undergoing cancer treatment.
Where can I find help with financial concerns?
Evaluate your financial situation as soon as possible. You will not want to deal with financial stress in the middle of treatment when you may not feel well. See the “10 Financial Assistance Tips for Cancer Patients” section in the Handbook.

Where can I find help with lodging or transportation?
When beginning cancer treatment, planning ahead is key. Some treatment centers have lodging coordinators or social workers to help you with the logistics of treatment. See the “Practical Concerns” section of the Handbook.

What will my follow-up care plan include?
After you finish treatment, make sure you and your oncologist create a follow-up care plan. You will need to check for recurrence. You may also need follow-up care for long term side effects. See the “Screening Recommendations and Follow-Up Care” section of the Handbook.

When can I call myself a survivor?
According to the National Cancer Institute’s definition of a cancer survivor, “a person is considered to be a survivor from the time of diagnosis until the end of life.”

All About Genetic Counseling

What is genetic counseling?
Genetic counseling helps people determine their risk for hereditary cancers. Genetic counselors are medical specialists who help people do the following:

- identify their risk for hereditary forms of cancer and
- develop a personalized plan to manage risk.

What happens during genetic counseling?
First, you will provide your family medical history. From the history, your genetic counselor determines the likelihood that cancer in your family is hereditary. Your genetic counselor will discuss with you the following:

- your need for genetic testing
- any inheritance patterns in your family
- your surveillance and risk reduction options

If you choose to do testing, your genetic counselor will coordinate the testing. After testing, your genetic counselor will interpret the results for you to come up with the best surveillance and risk reduction plan for you. Your genetic counselor will also tell you if other members of your family need to be tested.

What are the most common hereditary cancer syndromes?
Genetic testing for hereditary breast and ovarian cancer and Lynch syndrome are the most common reasons for referrals to genetic counselors.

**What are BRCA mutations?**

The BRCA1 and BRCA2 gene mutations make up the majority of hereditary breast and ovarian cancers.

Women who carry mutations in the BRCA genes have a 55-85% risk of developing breast cancer and a 15-60% risk of developing ovarian cancer. For women who do not carry mutations in the BRCA genes, the risk is 12-13% for breast cancer and 1-2% for ovarian cancer. Men who carry mutations in the BRCA genes have a slightly increased risk for prostate cancer. Men who carry BRAC2 mutations have an increased risk for male breast cancer, pancreatic cancer, and perhaps melanoma.

**What is Lynch syndrome?**

Lynch syndrome is also known as Hereditary Non-Polyposis Colorectal Cancer. Lynch syndrome can be due to mutations in one of five genes: MLH1, MSH2, MSH6, PMS2, and EPCAM. People with Lynch syndrome are at an increased risk for the following cancers:

- Colon
- Uterine
- Ovarian
- Urinary tract
- Gastrointestinal
- Brain
- Sebaceous adenomas or carcinomas

The risks for each of these cancers vary depending on which gene carries the mutation.

**Should I do genetic testing?**

If one or more of these apply to you, talk to your healthcare team about genetic testing.

- Multiple family members on the same side of the family with the same cancer
- Multiple family members on the same side of the family with related cancers (breast/ovarian/pancreatic or colon/uterine/ovarian)
- Cancer at early ages (under 50)
- More than one diagnosis of cancer in the same person
- Rare cancers
- A known family history of altered genes that increase cancer risk
- Triple negative breast cancer diagnosis before 60
- Jewish ancestry
- A personal or family history of breast, ovarian, or pancreatic cancer
- If you have a pheochromocytoma or a paraganglioma tumor

If you are concerned about hereditary cancers, speak to your healthcare team or find a genetic counselor.

**Where can I find a genetic counselor?**

You can find a genetic counselor using the National Society of Genetic Counselors website at www.nsgc.org. You can also ask your healthcare team for a referral.

**Will my insurance cover genetic testing?**

Most insurance companies now cover genetic testing for people with a family history that suggests a hereditary cancer syndrome. Your genetic counselor can help you verify your coverage.

If you are uninsured or genetic testing is not covered by your insurance, your genetic counselor can help you locate local and national resources.

**I've decided to meet with a genetic counselor. How should I prepare?**

You need to give your genetic counselor as much accurate and detailed information as possible. Your genetic counselor will want to know about:

- Your personal and/or family history of cancer
  - Who was diagnosed? Which side of the family?
  - What was the diagnosis?
  - What was his or her age at diagnosis?
  - Pathology reports
  - Death certificates
- Age and cause of death of all family members
- Your ethnic background
  - Any Jewish ancestry

Even if you have little or no information about your family history, you can still speak with a genetic counselor.

**I tested positive for a hereditary cancer syndrome. Now what do I do?**

Your genetic counselor will help you come up with the best surveillance and risk reduction plan based on your risk. You may be referred to a doctor who can advise you about how to prevent the cancer identified, sometimes through surgery to remove the organ that could develop
cancer. Be sure always follow your recommended screening schedule. Cancer is easier to treat when caught early.

Your genetic counselor can help you share your test results and coordinate testing for family members. Your family needs to know about surveillance and risk reduction options. Some family members may not carry the same mutation.

Genetic counseling can cause anxiety. You may also wish to seek emotional support. There are support groups available. Ask your genetic counselor about ones in your area. Read the “Emotional Support Programs” section of the Handbook for more information.
Clinical Trials

Clinical trials are medical research studies that test new ways to prevent, screen, diagnose, or treat a disease. Cancer clinical trials determine if a treatment shows an improved way of caring for patients. Clinical trials improve cancer care for all patients. Talk to your doctor about clinical trials. Depending on your specific diagnosis, a clinical trial may be your best treatment option.

All About Cancer Research

Cancer research involves very highly trained doctors and scientists trying to figure out how cancer works. Research is always done by a set of rules, called the scientific method, that ensures the information will be valid. Researchers begin by looking for answers to questions like these:

- What causes cancer?
- What makes cancer cells keep growing?
- What destroys cancer cells?
- What stops cancer cells from growing?

By studying how cancer cells behave in animals, researchers can develop theories, or ideas, about potential treatments for humans with cancer. Once a treatment is ready to be tested on humans, researchers conduct clinical trials.

What are clinical trials?
A clinical trial is a medical research study that tests new ways to prevent, screen, diagnose, or treat a disease. The word “clinical” means related to examining and treating patients.

Cancer clinical trials help to determine if a treatment, drug, or procedure shows a better way of treating a particular cancer, or provides a way to treat a condition for which there wasn’t a treatment before.

It takes years of thought and planning to have a clinical trial accepted by the U.S. Food and Drug Administration (FDA). The FDA must approve the trial before researchers can recruit patients. Clinical trials allow patients access to the latest research treatments before they are available to the public.

Who sponsors clinical trials?
Medical or research institutions, pharmaceutical and biotechnology companies, the government, and nonprofit groups who want to improve current cancer treatment can all sponsor clinical trials. Some trials are "investigator initiated," which means a researcher or doctor created the trial, but these trials face the same strict requirements.
What do the phases of clinical trials mean?

**Phase I** trials answer the questions: Is the drug or treatment safe? What is a safe dose? What are the side effects? Phase I trials are small, each only involving 20-80 participants. These trials are usually the first time a drug or treatment has been tested in humans.

**Phase II** trials tell researchers if the drug or treatment is effective in a larger group (100-300 participants) and help identify safety concerns.

**Phase III** trials determine within a large group (1,000 – 3,000 participants) if the experimental drug or treatment works better than what is currently used and if there are additional side effects. Most Phase III trials are randomized, meaning some participants will receive the experimental drug or treatment while others will receive the standard drug or treatment currently accepted by the medical community as best for their cancer type (standard of care).

**Phase IV** trials allow researchers to learn more about the drug or treatment and its risks, benefits, and best use.

Usually FDA approval comes after large phase III trials. However, sometimes special consideration is given to treatments that show great promise in early trials.

After enough data is gathered to prove that the new treatment is effective or more effective than current treatments, the FDA will investigate the findings and approve the treatment for use. After FDA approval, doctors can prescribe treatments to their patients without enrolling patients in clinical trials.

**For a participant, what happens in a clinical trial?**

Each clinical trial recruits and screens participants through participating treatment centers. In order to learn if a drug is effective, the participants must be similar in the type of diagnosis and other factors. Trials are designed to be very specific so researchers can know that the drug or treatment being studied is causing changes. For example, a clinical trial may be designed to answer a specific question, such as this: “Is this treatment effective for BRCA positive breast cancer in patients who have not received previous treatment?”

Participants must be eligible in order to qualify for the trial. Some possible requirements for eligibility include:

- Cancer type
- Stage
- Specific tumor types or genetic markers
- Treatment history
- Age
- Other medical conditions

If you qualify for a trial, your healthcare team will provide you with all the information about the trial. They will tell you, in a process called informed consent, how the trial will be conducted and the possible risks and benefits of the trial. You will then sign a document stating that you understand the details of the trial and that you are willing to participate. Even after signing the document of informed consent, you may withdraw from the trial at any time for any reason.
The way you receive treatment depends on the specific clinical trial. Clinical trial treatments can come in many forms. These include but are not limited to the following:

- Intravenous (IV) medications given through a port or IV line
- Shots
- Oral medications
- Surgery
- Radiation

As with any cancer treatment, clinical trial treatments may come with side effects. Your healthcare team will help you manage these side effects. It is very important to report to your healthcare team any side effects that you experience. Part of what researchers are studying is how the treatment affects the whole body, not just the cancer cells.

**How is a clinical trial treatment different from other treatments?**

Patients who decide to participate in clinical trials receive excellent care and attention. Throughout the trial, your healthcare team will closely monitor you for improvements and adverse side effects.

Researchers want to control as much about your care as they can to make sure it is the treatment that is helping your cancer improve, and not something else. Because of this, you may have restrictions on what you can eat and what other medicines you can take.

Although you should always follow your treatment plan and not miss appointments, doing so is especially important with a clinical trial. Clinical trials must have consistency among the participants to know if the treatment really is working.

**Are clinical trials a “last resort” for cancer patients?**

Patients who are no longer helped by existing standard of care treatments may find that a clinical trial provides hope, but many patients begin their treatment program with a clinical trial because the treatment best suited to their situation is still being tested. Some clinical trials even exclude patients who have already received another form of treatment.

When participating in a clinical trial that evaluates if a new treatment is better than the current standard treatment for your cancer type, you will always receive treatment – either the standard of care or the new treatment being studied. By being in a clinical trial, you may receive the added benefits of a new treatment before it is available to the public.

In many cases, cancer research moves at a faster pace than the FDA treatment approval process. Researchers have made important discoveries about biomarkers and mutations that affect how cancers respond to treatment. Because of the long time it takes for a treatment to be tested through the clinical trials process, many of these breakthrough treatments are still only available through participating in a clinical trial.

**Why Should I Consider A Clinical Trial?**

A clinical trial is a medical research study that tests new ways to prevent, screen, diagnose, or treat a disease. The first step is to speak with your oncologist to find out if a clinical trial is right for you.
for your cancer journey. The National Comprehensive Cancer Network (NCCN), an alliance of 21 leading cancer centers, believes that “the best management for any patient with cancer is in a clinical trial.”

**Why should I consider a clinical trial?**

Here are the top reasons why you should consider a clinical trial:

**Complete care**

The "standard of care" is what the medical community agrees is the treatment for a specific type of cancer given the patient's overall health. Clinical trials ALWAYS provide treatment that is the standard of care or better. For example, in a randomized Phase III trial for a promising new chemotherapy drug, some patients would get the treatment under study while others get the standard of care. Or some patients would get the current standard of care plus the treatment under study while others get just the current standard of care.

**Personalized Medicine**

Many of the newest clinical trials focus on very specific tumor types such as tumors that carry specific genetic mutations, markers, or DNA sequencing. Basically, these treatments are tailored to individual cancer diagnoses. Many of these treatments are only available through clinical trials.

**Careful monitoring**

Because the promising new treatment is being carefully studied, patients are also carefully monitored by healthcare professionals to see how they are doing and to watch for side effects. So, patients enrolled in clinical trials tend to talk with their health care professionals more often and are watched more carefully than patients not involved in a trial.

**Safety first**

Requirements for clinical trials are strictly managed by the Food and Drug Administration. Before a drug is approved for testing in humans, the FDA ensures that it has gone through strict testing protocols in laboratory animals.

**Close to home**

Most people are familiar with the tremendous research being conducted all over the country at research institutions, but in fact, many community cancer centers offer opportunities for their patients to participate in clinical trials. Depending on the type of clinical trial you seek, you may have many options that do not require you to travel.

**Scientific advancement**

Without clinical trials, there is no progress toward cures for cancer. By participating in scientific research through a clinical trial, you can help future cancer patients access new, better treatments. You can play a more active role in your own health care. People who are treated through clinical trials have access to the best new treatments before the general public.

**Now that I know the benefits of clinical trial, what are the risks?**

There are risks involved with the treatment for any life-threatening illness, including treatment offered through clinical trials:
• There may be difficult side effects from medications or treatments.
• The treatment may not be effective.
• The clinical trial may require extra time for trips to the study site, treatments, hospital stays, or complex dosage requirements.

However, through the process of "informed consent," your medical team will make sure you understand all the risks and benefits.

How can I find a clinical trial?
If you are interested in participating in clinical research, your first conversation should be with your doctor. He or she may be able to suggest trials or help you search for appropriate options.

My PearlPoint’s Clinical Trial Locator (my.pearlpoint.org/clinical-trials/search) uses clinicaltrials.gov for our search data, as all clinical trials have to be registered with them. Be aware that the information may not be up-to-date. Your best source of information will be with the facility that is conducting the clinical trial. Their contact information will be clearly noted.

How To Talk to Your Doctor About the Latest Cancer Research
If you are interested in participating in a clinical trial, the first step is to talk to your healthcare team.

How To Start the Conversation
Here are some tips for talking to your doctor about clinical trials:

• Don’t be afraid to ask. Your doctor may not bring up clinical trials, but you are the person being treated so you should be involved in planning your treatment.
• Do not feel that you are second-guessing your doctor. Your doctor should be willing to discuss options with you and answer all your questions without feeling insulted.
• Do not be afraid to seek a second opinion if necessary.
• If possible, talk to your doctor about clinical trials before you begin treatment. Some trials require that participants have not received any other treatments.
• Write down your questions and what you want to talk about before your appointment. Organize your thoughts and your notes so you don’t forget anything.
• You may wish to have your caregiver go with you to your appointments. Your caregiver can take notes or ask any additional questions if you happen to forget.
• Search My PearlPoint’s Clinical Trial Locator (my.pearlpoint.org/clinical-trials/search) to find possible trials on your own. If you’ve done some research, beginning the conversation with your doctor may be easier, especially if your treatment location is not a large research center.
• Keep in mind that while a clinical trial may be one patient’s best option, there may not be a clinical trial option for your diagnosis. You should discuss ALL your treatment options with your healthcare team to create the best treatment plan for you.
What To Ask Before Starting a Trial

Once you find a trial and meet the eligibility requirements, you will go through a process called informed consent. During this process, your healthcare team and members of the research team conducting the trial will tell you all you need to know about the trial. Make sure you receive answers to the questions below:

- What is the purpose of the trial?
- How will the trial treatment be better for me than other treatment options?
- How will the healthcare team learn if I am eligible for the trial?
- Where will I receive treatment?
- What type of treatment will the trial involve?
- What will happen at my appointments? (For example, will I have scans, blood tests, and/or examinations?)
- During the treatment, who should I contact with questions and concerns?
- What are the risks and benefits of this trial?
- Will my insurance cover the cost of the trial?
- Will I receive any financial assistance for travel and lodging?
- What will my follow-up care be?
Most cancer patients experience some side effects as a result of their diagnosis or treatment. The type of side effects depends on your diagnosis, treatment type, and overall health. Some of the most common side effects for cancer patients include: fatigue, loss of appetite, nausea, pain, and weight loss. Talk to your healthcare team about your risk for side effects—which side effects are you most likely to experience?

Side effects can be managed a variety of ways with lifestyle changes, nutrition, exercise, and medication. Read through the following sections to learn tips for managing your side effects to help improve your cancer journey.

Changes in Taste and Smell

Changes in taste and smell can interfere with maintaining good nutrition during treatment. Here are some ways to manage changes in taste and smell.

- Note which foods and liquids taste and smell different.
  - Any or all of the four tastes — salty, sweet, bitter, and sour — may be affected.
  - It is common for meats to taste especially bitter.
  - Sometimes one taste is specifically more pronounced. For example, everything may taste really salty, or sweets may taste so sweet they are not appealing.
  - Pay attention to changes in taste to be able to apply these tips appropriately.
- Take care of your mouth and teeth.
  - Dental issues may affect taste, so visit your dentist prior to treatment.
  - Rinse mouth thoroughly before eating using plain water or a baking soda/salt water mixture (¼ tsp. of baking soda and 1/8 tsp. salt with 1 cup warm water).
  - Sometimes medications, chemotherapy drugs, and radiation cause a film to form inside the mouth, affecting the taste buds. Rinsing may help to clean away this film.
  - After meals, rinse with an alcohol-free mouthwash or the baking soda/salt water mixture.
- If meats taste bitter or are not appealing, try alternative protein sources such as eggs, beans, cheese, or nuts.
  - If beef tastes bitter, try chicken, turkey, or fish.
  - Marinades that are sweet are often able to counter the bitter flavor of some meats.
  - Other sources of protein to try are eggs, cheese, nuts, or beans.
  - It is important to find high protein foods that are palatable to best meet the body’s protein needs.
- Try to keep odors to a minimum.
  - Do not cook anything with a long cooking time in the house where the person who is in treatment spends most of his/her time.
Use cups that have lids and use straws to limit the odor of any liquids that are not appealing.
Serve foods at room temperature. Hot foods tend to have a stronger smell than cold foods.
- Limit exposure to metal.
  - Eat using plastic utensils instead of metal.
  - Prepare and store food in glass pans and containers.
  - Between meals, sour flavors such as lemonade or candy may help. Mint candy or gum may also give some relief.
  - Tart or bitter flavors may be more palatable. Try citrus and vinegar based foods. Seasoning food differently and more heavily may help to mask the metallic flavor. Try barbecue sauce, salad dressings, ketchup, mustard, relish, onion, garlic, rosemary, ginger, chili powder, basil, oregano, tarragon, curry, and cumin.
- Don’t be afraid to try some new foods.
  - Sometimes foods you didn’t like before cancer treatment become more appealing as tastes change.
  - Do not be surprised if favorite foods do not taste the same as they did before.
  - Be patient as these changes are usually temporary.
  - Try to make good nutrition a priority and stock your home with a variety of healthy foods.

“Chemo Brain” (Cognitive Issues)

Many cancer patients report issues during and after cancer treatment including:

- memory loss
- forgetfulness
- loss of concentration
- confusion

These side effects result from changes in the cognitive (thinking) processes of the brain. Even though these side effects are commonly referred to as “chemo brain,” factors other than chemotherapy can lead to cognitive side effects such as:

- brain cancer or brain metastasis
- brain surgery
- radiation to the brain
- medications
- fatigue
- anemia
- hypothyroidism
- stress and anxiety
Cognitive side effects can be short term or long term. This depends on the cause of the side effects, the age of the patient, and the overall health of the patients. If the cause is medication, once the medication is stopped, cognitive issues should improve. If surgery or radiation damages the brain or nervous system, the side effects may not improve over time. Delirium is a severe cognitive issue indicated by loss of awareness and memory, drastic changes in behavior and judgment, and lack of muscle control. Delirium can be dangerous if the person is left alone. Delirium is most likely to occur in advanced cancer patients or near end of life.

Cognitive issues present many challenges. Because the direct cause of cognitive issues can be unclear, they are difficult to treat. Healthcare professionals are still researching cognitive issues as they relate to cancer and cancer treatment.

Changes in memory and brain function can be distressing, but many patients share the same experience. There are some things you can do to manage cognitive side effects.

**Plan Ahead**

- Write to-do lists.
- Keep a detailed calendar of appointments and other important dates.
- Leave notes around the house to remind yourself to do things.
- Track your medications and use a weekly pill box.
- Lay out everything you need for the day the night before.
- Use your phone to set reminders.

**Get Organized**

- De-clutter your home and your workspace.
- Make sure everything has a place.
  - Put keys in bowl by the door every day.
  - Leave your cell phone on your nightstand.
- Use labels for storage areas and boxes.

**Minimize Distractions**

- Avoid multitasking; focus on one task at a time.
- Put your phone and other unnecessary electronic devices away when working.

**Exercise Your Brain**

- Do “brain exercises” by taking free online quizzes or playing along with game shows.
- Try Sudoku or crossword puzzles.
- Read.
- Learn a new hobby such as painting or writing.

**Exercise Your Body**
• Exercise is not only good for your body. It can make you feel better mentally, too. Exercising releases mood-boosting endorphins.
• Exercise also combats fatigue, which can contribute to cognitive issues.
• Try going for a daily walk or taking an exercise class.
• Ask your healthcare team before beginning any exercise program.

Eat Well

• Choose foods that promote healthy brain functioning such as fish (omega-3 fatty acids), dark leafy greens, fresh fruits and vegetables, and whole grains.
• Avoid alcohol and other substances that alter cognition.

Get Plenty of Rest

• Being tired can make you less focused.
• Fatigue and insomnia are common side effects of cancer treatment.

Check Red Blood Cell Counts

• Anemia is a condition that occurs when the body does not have an adequate amount of red blood cells.
• Anemia can cause cognitive issues.
• Ask your healthcare team to check your red blood cell counts if they are not doing so already.

De-Stress

• Anxiety and stress can cause or worsen cognitive issues.
• Try to relax in a way that works for you. Consider trying:
  o Deep breathing
  o Meditation
  o Taking a warm bath
• Your doctor may be able to prescribe medication to help with anxiety and depression.
• Try seeking emotional support from a support group or one-on-one partnering organizations.

Ask for Help

• Be honest with your friends and family about your “chemo brain.”
• If you explain what you are going through, they can be more understanding.
  o They can also help you manage your side effects by sending you friendly reminders or helping you organize your space.
• As always, talk to your healthcare team about your side effects and ways to manage them.
Constipation

Constipation is common during cancer treatment. It can be caused by many factors such as cancer type, food and liquid intake, surgery, or medications. Follow these tips to manage constipation and promote regularity.

- Soluble and insoluble fiber are both important for overall health and nutrition.
  - Soluble fiber is found in oats, beans, sweet potatoes, and fruits.
  - Soluble fiber is completely digested by the body. Soluble fiber reduces cholesterol, stabilizes blood sugar, and rids the body of toxins.
  - Insoluble fiber is found in wheat, nuts, seeds, and fruit and vegetable skins.
  - Insoluble fiber is not digested by the body and is excreted as waste. Insoluble fiber promotes regularity.
- Drink plenty of liquids.
  - Fluid helps your body process fiber without discomfort. A good starting goal is eight 8-ounce glasses of fluid per day.
- Gradually increase your fiber intake.
  - Your daily goal should be between 25-35 grams daily.
  - Fiber is mostly found in plant foods, such as fruits and vegetables, beans, legumes, whole grain cereals, breads, and oatmeal.
- Eat 3-5 servings of fruits and vegetables daily.
  - Choose whole fruit instead of juice.
  - Eat the skins and seeds for extra fiber.
  - Try to have a fruit or vegetable with each meal or snack.
- Choose foods that promote regularity.
  - Eat cereals, breads, and pastas that are made with 100% whole grain.
  - Have brown or wild rice in place of white rice or potatoes.
  - Choose hot cereals like oatmeal or cold cereals with at least 5 grams of fiber.
  - Choose whole wheat breads, whole corn or wheat tortillas, and whole grain crackers instead of refined products.
  - Eat more beans, lentils, and peas. Add them to soups and casseroles, or have them as a main entrée.
  - Beans are also a great source of protein, so you can use them as a substitute for meat at mealtimes.
  - Beans can be gas forming, so add them gradually. If you experience bloating or discomfort, you may want to limit them in your diet.
- Try plum or prune juice.
  - Start with a small amount such as a ½ cup.
  - Eating dried prunes may also help relieve constipation.
- Try to include exercise or physical activity in your daily routine.
Physical activity is a natural way to help constipation.
Always discuss any exercise or physical activity with your healthcare team before making changes.

- Talk to your healthcare team about medication or supplements to help with constipation.
  - There are over the counter medications that may help with constipation but you should always check with your doctor first before taking anything.

## Diarrhea

Diarrhea occurs when foods pass through the body too quickly. The body cannot absorb enough nutrients, vitamins, minerals, and water. Follow these tips to carefully manage diarrhea and prevent dehydration and malnutrition.

- Contact your healthcare team for advice managing diarrhea.
  - If you have sudden diarrhea, have diarrhea for more than 24 hours or are experiencing pain, cramping, or blood in your stools, call your healthcare provider immediately.
  - Take medications or supplements only if they are recommended by your healthcare team.
  - Always ask your healthcare team first before taking anti-diarrhea medications.
  - Always talk to your healthcare team or a dietitian before taking any supplements.

- Stay hydrated to replace fluid losses.
  - Be sure to drink plenty of clear liquids (water, ginger ale, sports drinks, or electrolyte replacement drinks) for 12 to 24 hours after a sudden bout of diarrhea.
  - Make a homemade electrolyte replacement drink by mixing the following ingredients: ¼ teaspoons salt, 8 teaspoons sugar, 3 tablespoons orange juice concentrate, and 4 cups water.
  - Let carbonated drinks lose their fizz before you drink them.
  - Drinking clear liquids helps the bowel rest and replaces lost fluids.
  - Healthy people need a minimum of 8 cups of liquid per day. You may require more to replace fluids lost with diarrhea.

- Eat 5 or 6 small meals per day instead of 3 larger meals.
  - Eating smaller meals may put less stress on your bowels and will make it easier for your body to digest food.

- Choose foods and drinks carefully.
  - Very cold foods and very hot foods can make diarrhea worse.
  - If your diarrhea gets worse after eating a certain food, stop eating that food until you recover.
  - Avoid foods and drinks that can make your diarrhea worse. High fiber foods, raw fruits and vegetables, full-fat dairy products, foods and drinks that contain caffeine, and spicy or high-fat foods can make diarrhea worse.
  - Choose foods that help manage diarrhea, like white rice, puffed rice cereal or other low-fiber grains, soft fruits like bananas and applesauce, cooked soft vegetables, and low-fat meats and dairy products.
Difficulty Swallowing

Treatment to the head and neck can make swallowing difficult and painful. This may make it hard to eat well and maintain a healthy weight. Follow these tips to make swallowing easier.

- Chemotherapy or radiation to the head and neck can harm the cells that line the throat and cause discomfort.
  - Higher doses of radiation can cause more discomfort.
  - Chemotherapy and radiation treatment at the same time may make side effects worse.
  - Drinking alcohol or using tobacco can make side effects worse.
- Use mealtime tactics to make swallowing easier.
  - Eat 5 or 6 small meals each day instead of 3 large meals. It may be easier to eat a smaller amount of food at one time.
  - Cook foods until they are soft and tender.
  - Moisten and soften foods with gravy, sauces, broth, or yogurt.
  - Consume liquids with meals.
  - Sip drinks through a straw; this may make them easier to swallow.
- Avoid foods that are hard to swallow or irritating.
  - Avoid coarse foods that do not soften in the mouth.
  - Avoid sharp and crunchy foods like potato and tortilla chips.
  - Avoid spicy foods.
  - Avoid acidic foods like lemons, lime, oranges, and tomatoes.
  - Be careful eating hot foods to reduce the risk of burning your mouth. Cold foods may be soothing.
  - Avoid alcohol.
- Choose foods that are easy to swallow.
  - Try breakfast foods like instant oatmeal, grits, pancakes, waffles, and cold cereal that has been softened in milk.
  - For a main dish, try chicken, tuna or egg salad, soups and stews, soft cooked fish, tofu, and meatloaf.
  - Pick side dishes like cottage or ricotta cheese, macaroni and cheese, mashed white or sweet potatoes, and rice or risotto.
  - Try desserts like custard, tapioca pudding, ice cream, milkshakes, and sherbet.
  - Choose snacks like creamy nut butters, applesauce, gelatin, smoothies, and yogurt.
Dry, Itchy Skin

When cancer treatments fight cancer cells, they can also affect healthy cells. This can result in certain side effects including skin changes. Side effects of the skin commonly occur with two cancer treatments: external beam radiation therapy and new targeted therapies.

**External Beam Radiation Therapy**

With external beam radiation therapy, high-energy radiation rays from outside the body are used to kill and shrink cancerous tumors. The radiation is targeted at a specific area of the body. This therapy usually consists of daily treatments over several weeks.

Skin side effects, such as the following, do not usually appear until about the third week of treatment and may continue after finishing treatment:

- The skin at the treatment area may become red, dry, and tender like a mild to moderate sunburn.
- The skin may also become very itchy, which is a condition called pruritus.
- In some cases, the skin may even darken, swell, blister, or peel away.
- If the skin becomes moist or cracked, you are at risk for an infection.

If side effects become too severe, your radiation oncologist may stop or delay treatment to allow your skin to rest.

**Targeted Therapies**

Targeted therapies focus on or “target” a specific type of cell or molecule. Common types of targeted therapy drugs attack the epidermal growth factor receptor (EGFR) to stop cancer cells from continuing to grow. Because EGFRs are also important to normal skin cell growth, this may cause skin side effects.

The most common skin side effects with targeted therapies are rashes, dry and itchy skin, hair loss, redness, and inflammation around fingernails and toenails. These side effects most commonly appear after the second or third treatment.

The following are targeted therapies (drugs) that commonly cause skin changes:

<table>
<thead>
<tr>
<th>Drug</th>
<th>Type of Cancer</th>
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<tbody>
<tr>
<td>Erlotinib, Gefitinib, Cetuximab, Panitumumab</td>
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<td>Everolimus and Temsirolimus</td>
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Source: American Society of Clinical Oncology

**How can I manage my skin side effects?**
First, always tell your healthcare team about any skin changes you notice. Some side effects can be easily managed with prescription creams or oral medications. Here are some tips to help take care of your skin while undergoing cancer treatment:

**Avoid irritants.**

- Use unscented bath and household products including soap, shampoo, lotion, detergent, and dryer sheets.
- Do not use bath products containing alcohol. Alcohol dries the skin, making irritation worse.
- If your facial skin is affected, avoid using makeup, or switch to a sensitive skin brand.
- Always wear gloves when cleaning, and avoid skin contact with cleaning products.
- Do not shower or bathe with extremely hot or extremely cold water.
- Stay out of the sun, or wear protective clothing and sunscreen if you must be outside.
- Do not use tanning beds.
- Do not use chlorinated pools or hot tubs.

**Let your skin rest.**

- Do not scratch or pick at your skin.
- Do not pop blisters.
- Wash skin with care.
- Use a mild, fragrance-free soap.
  - Do not scrub the skin.
  - Let warm (not hot) water gently run over the affected area.
- Do not wear tight clothing over the affected areas.
- Do not use adhesive bandages.

**Moisturize.**

- Keep skin well moisturized.
- Use petroleum-based skin protectants or unscented lotions.
- Look for moisturizers specifically for sensitive skin.
- Ask your doctor which over-the-counter moisturizer is best for you.
- Use a humidifier while you sleep, and keep the temperature cool.
- If you are having radiation treatment, do not apply moisturizers right before treatment. It’s better for your skin to be clean and clear during actual treatments.

**Watch for signs of infection.**

- Signs of infection include:
  - swelling, redness, or warmth
  - cloudy drainage or pus instead of clear
  - fever
  - bad smells
• Tell your doctor immediately if you notice signs of infection. You may need an antibiotic. If left untreated, infections can become very serious and spread to other parts of the body.

Dry Mouth

Dry mouth is common during and following cancer treatment. Symptoms of dry mouth are thirst, sore mouth or throat, difficulty swallowing, and changes in taste. Follow these tips to manage dry mouth.

• Chew gum or suck on ice chips, hard candy, or popsicles to help relieve dry mouth.
  o Keeping gum, ice chips, candy, or popsicles in the mouth helps keep the mouth moist.
  o Choose sugar-free or low-sugar gum or candy for prevention of cavities.
  o In place of ice chips, try frozen grapes.
  o Use lip balm if your lips become dry.

• Choose foods that are easier to chew and swallow.
  o Choose soft foods like scrambled eggs, puddings, and ice cream.
  o Avoid dry foods.
  o Cut your food into small pieces to make it easier to chew and swallow.
  o Soups and stews are good options, as long as meats are soft or cut into small pieces.
  o Try mashed potatoes and rice instead of crackers or breads.
  o Choose canned fruits or applesauce instead of raw fruits.
  o Puddings, ice cream, and sorbet are also good options.
  o Serve foods with gravy, broths, or sauces. This will make them easier to chew and swallow.
  o Season your food with citrus and herbs instead of salt or hot spices.

• Drink at least eight to ten 8-ounce cups of liquid each day.
  o Drinking liquids with meals can make it easier to swallow foods.
  o Sip cool drinks in between meals to ensure adequate fluid intake.
  o Tart drinks in small amounts, such as lemonade, may help your mouth produce more saliva.
  o Keep a glass of water next to your bed at night. Drink when you wake during the night.

• Eat small meals, and eat more often.
  o Eating small, frequent meals will ensure that you are meeting your nutritional needs.
• Try to have a good source of protein with meals and snacks. Eggs, cottage cheese, yogurt, beans, lentils, and smoothies are good soft food choices that also provide protein.

• Promote a moist mouth.
  • Rinse your mouth every 1-2 hours.
  • Mix ¼ tsp. of baking soda and 1/8 tsp. salt with 1 cup warm water. Rinse with plain water after using this mixture.
  • Do not use a mouthwash that has alcohol. Alcohol makes a dry mouth worse.
  • Ask your doctor if an artificial saliva product might help. Radiation and some medications can decrease saliva production.

• Avoid things that make dry mouth worse.
  • Alcoholic drinks can worsen dry mouth.
  • Do not smoke or use other tobacco products.
  • If you do smoke, talk to your healthcare team about quitting.

• Tell a doctor or nurse if you have white patches in your mouth.
  • White patches can be evidence of an infection.

Fatigue

Fatigue impacts quality of life and can make it hard to eat healthy meals. The body needs proper nutrition to function. Improper nutrition can make other side effects worse. These tips can help manage fatigue.

• Cancer-related fatigue primarily occurs because the body requires additional energy to heal.
  • Other side effects, medications, and stress can make fatigue worse.
• While rest is important, too much rest can make you feel more tired so stay as active as possible.
  • Try going for a daily walk.
  • Talk to your healthcare team before beginning any exercise program.

• Go no longer than 4-5 hours without eating throughout the day.
  • Try to eat a balanced breakfast every day.
  • Try to eat small meals and snacks rather than large meals.

• Eat foods that provide sustainable energy; avoid foods that do not.
  • Try to include a source of protein at every meal to sustain energy released from food.
  • Try to limit sweets and sugary foods.
  • Avoid alcohol, caffeine, and chocolate in the evening.

• Stay hydrated by drinking liquids throughout the day.
• Stock your kitchen with easy-to-prepare foods and meals.
- Ask your family and friends to help you shop for food and prepare meals.
- Prepare food when you feel your best, and save it for later.
- Prepare large amounts of your favorite meals then freeze meal-sized portions for later.
- Try keeping a food and fatigue journal to find patterns that trigger fatigue.
- Discuss fatigue with your healthcare team.
  - Ask your doctor to check for nutrient deficiencies, such as protein, iron, B vitamins, and vitamin D.
  - Talk to your healthcare team about other side effects such as anemia, pain, or vomiting.

**Feeling Full Quickly**

Feeling full too quickly is a common side effect, especially after abdominal surgery. This can cause weight loss. Not eating enough weakens the body and delays healing. Below are some tips to ensure proper nutrition.

- Eat small, frequent meals throughout the day.
  - Smaller meals are easier to digest and will allow you to better meet your needs throughout the day.
  - Keep healthy snacks on hand to eat between scheduled meals.
- Avoid foods and actions that may cause gas or bloating.
  - High-fat foods take longer to digest. They can make you feel fuller between meals. Avoid fried or greasy foods.
  - Gas-forming foods include: broccoli, cauliflower, Brussels sprouts, cabbage, corn, turnips, onions, peas, garlic, cantaloupe, watermelon, apples, avocado, beans, lentils, and nuts.
  - Stop behaviors that involve swallowing extra air. Do not suck on ice or candy, chew gum, drink carbonated drinks, or drink through a straw.
- Drink liquids between meals rather than during meals.
  - Drinking with your meals and snacks can fill you up more quickly.
  - Avoid carbonated drinks. Carbonated drinks can make you feel fuller.
- Keep your head up after meals.
  - Lying down after meals will only make your discomfort worse.
- If you are underweight or losing weight too quickly, choose foods that are rich in nutrients and calories.
  - Try to have a source of protein with each meal and snack. Some examples of protein-rich foods include eggs, chicken, fish, meat, milk, yogurt, cheese, beans, nuts, and peanut butter.
o Add extra calories, protein, and healthy fats to foods you already eat to help prevent weight loss. Try adding olive oil, nuts, nut butters, seeds, non-fat powdered milk, or protein powder to recipes.

o Drinking nutrient-rich liquids like smoothies or milkshakes can provide nutrition without making you feel full. Liquids leave the stomach more quickly than solid foods.

o Ask a registered dietitian if drinking a liquid nutrition supplement is needed to provide necessary calories and protein. If needed, a specific liquid nutrition supplement can be recommended that meets your needs.

## Gas and Bloating

Excess gas is a common side effect, especially for colorectal and stomach cancer patients. Foods, drinks, behaviors, and medications contribute to gas. These tips may help with the pain, bloating, and discomfort that come with excess gas.

- Avoid gas-forming foods.
  - Avoid broccoli, cauliflower, Brussels sprouts, cabbage, corn, turnips, onions, peas, peppers, radishes, garlic, cantaloupe, watermelon, apples, avocados, beans, lentils, and nuts.
  - Avoid dairy products such as milk cheese or yogurt.
  - Avoid carbonated beverages.

- Avoid behaviors that cause you to swallow extra air.
  - Eat slowly.
  - Do not suck on ice or candy.
  - Do not chew gum.
  - Do not drink through a straw.
  - Drink liquids slowly with small sips.

## Hypothyroidism

### What is hypothyroidism?

Hypothyroidism means your body is not making enough of the thyroid hormone. The thyroid hormone regulates your metabolism. Metabolism is the internal process that allows your body to use food and nutrients and produce and use energy. Hypothyroidism may occur for many reasons, including as a result of cancer treatment or surgery that affects or removes the thyroid gland.

### What are the side effects of hypothyroidism?

The side effects of hypothyroidism include:
Fatigue
 Difficulty sleeping
 Sleeping too much
 Puffiness (often in the face) and bloating
 Loss of concentration, memory loss, absentmindedness.
 Weight gain
 Anxiety, irritability, mood swings
 Depression
 Dry eyes and mouth
 Dry or flaky skin
 Inability to process nutrients used by the body, such as calcium
 Hair loss or thinning
 Changes or interruptions to menstrual cycle
 Joint pains and stiffness
 Muscle cramps
 Intolerance to cold
 Constipation
 Nausea
 Tingling or numbness in fingers or toes (neuropathy)

Remember, these side effects are temporary. Once you begin taking a thyroid hormone (levothyroxine, sold under the brand names Synthroid and Levoxyl), your side effects will gradually improve. Your doctor will need your help to know if you are getting the right dosage; use the “Treatments and Side Effects Log” later in the Handbook to keep track of your symptoms and side effects.

What can I do to manage hypothyroidism?

• Take your medication as directed.
  o It is important to take your thyroid hormone as directed by your doctor, usually on an empty stomach at the same time every day.
  o It is usually recommended that you not take supplements for a period of time after taking thyroid hormone. Antacids, iron, and calcium supplements, dietary fiber, soy, and even walnuts can affect your body's absorption of the hormone. Check with your doctor or pharmacist for more specific recommendations.

• Eat a healthy diet.
  o Proper nutrition will help you fight fatigue, prevent unwanted weight gain, and promote healthy hair and skin.
  o Your calorie needs may change as your thyroid hormone levels change, and therefore you may find it helpful to talk with a Registered Dietitian for guidance.

• Get active.
Physical activity can improve quality of sleep, increase energy, treat constipation, prevent unwanted weight gain, and alleviate feelings of depression or anxiety.

- Ask your healthcare team before starting any exercise program.
  - Go easy on yourself.
    - You may feel frustrated by fatigue and absentmindedness, but remind yourself that these side effects won’t last forever.
    - Once you begin taking levothyroxine, it may take months for the body to re-regulate itself; try not to get discouraged.

**Insomnia and Difficulty Sleeping**

Many cancer patients report that they occasionally have trouble sleeping or that they can’t sleep at all (insomnia). Lack of sleep can lead to other issues such as fatigue, loss of concentration, headaches, and irritability.

To minimize the impact of insomnia, focus on these three possible solutions: managing other side effects of cancer or treatment, creating a good sleep routine, and talking to your healthcare team.

**Manage other side effects.**

Some side effects of cancer treatment can lead to difficulty sleeping. If you can minimize those side effects, then your sleep may improve.

**Nausea**

Nausea may make it difficult for you to go to sleep, and vomiting may wake you up at night.

- Sleeping with your head slightly elevated may help you get more comfortable.
- If your doctor has prescribed medication for nausea, make sure you take it as recommended, especially before bedtime.

**Pain**

Any type of pain can keep you up at night and make it difficult to be comfortable.

- Make sure you take pain medication as recommended, especially before bedtime.
- For more information on managing pain, read the pain management section of this handbook.

**Weight Gain**

If you gained weight as a result of cancer treatment, you may have trouble falling asleep and staying asleep. The extra weight can make it difficult to get comfortable. It can also make sleeping more difficult because your body has to work a little harder to function normally, such as regulating breathing.
- Try using a body pillow to give you more sleeping positions.
- Read the weight gain section of the Handbook for more information on how to maintain a healthy weight.

Hormonal Changes
Hormonal changes, such as menopause for women, can disrupt sleep, especially with side effects such as hot flashes and night sweats. Talk to your healthcare team about the best ways to manage hormonal changes. Your doctor may be able to prescribe medications to help manage hormonal changes.

- Cool temperatures can help promote sleep. Make sure your bedroom thermostat is set low and that your pillowcase feels cool to your skin.
- If night sweats are a problem, buy wicking sleepwear to keep you dry at night.

Stress and Anxiety
Stress and anxiety can keep you up at night. It may feel difficult to “turn off your brain.” Finding ways to cope with your stress and anxiety is very important.

- Enjoy a relaxing activity every night before bed to take your mind off cancer. Try working on a crossword puzzle, reading a book, or listening to music.
- Try simple stretches, yoga, or meditation to clear your mind.

At any point in your cancer journey, you may wish to seek emotional support. Support groups, peer matching programs, or individual counseling may help relieve stress and anxiety.

Create a good sleep routine.
Try to create a comfortable and relaxing sleep routine. For example, every night before bed take a hot bath or read a few chapters of a good book. If you do this every night, it will signal to your body that it is time for sleep. The most important thing is that this routine works for you. Here are some tips to get you started:

Tips for creating relaxing sleep environment:

- Make sure your mattress, bedding, and pillows are comfortable for you.
- Pleasant smells, like lavender, may help you sleep. Try an aromatherapy mist on your pillow.
- Buy a fan or white noise machine to drown out other distracting noises.
- Turn out all the lights, and use blinds or curtains to cover the windows.
- Do not leave the TV or computer on while you are trying to fall asleep.
- Silence all call, email, and text alerts on your phone.

Tips for sleeping through the night:

- Try to go bed and wake up at the same time each day.
- Choose a small snack, not a large meal, before bed.
o Digestion may wake you up, but a small snack will keep you from getting hungry during the night.

- Use the restroom right before going to bed.
- Exercise during the day, but do not exercise right before bed.
- The buildup of adrenaline and endorphins from exercise makes it difficult to wind down.
- Limit daytime naps to no more than 30 minutes.
- Avoid caffeine, alcohol, and tobacco products.

**Talk to your healthcare team.**
Always talk to your healthcare team if you are having insomnia or difficulty sleeping. Your doctor may recommend prescription medications or over-the-counter sleep aids to help you fall asleep and stay asleep. Do not take any medications without consulting your healthcare team first. Some sleep aids can be habit-forming so only take these medications as directed by your doctor.

**Lactose Intolerance**
Lactose intolerance occurs when the body cannot digest milk sugar (lactose). Some patients experience lactose intolerance, with symptoms like diarrhea, gas, and stomach cramps after having dairy. These tips may help to relieve symptoms.

- Avoid dairy products and foods containing lactose and instead choose lactose-free or reduced lactose milk products.
  - Most grocery stores sell lactose-free milk and ice cream.
  - Consider trying products made with soy or rice instead after checking with your healthcare team. Soy milk, rice milk, and almond milk are available at most grocery stores.
  - Yogurt with live active cultures and hard cheeses such as parmesan and aged cheddar are lower in lactose. You may find these to be better tolerated and less likely to cause symptoms.
  - Avoid using butter, margarine, cream, or soft cheeses when cooking or preparing foods.

- Read labels carefully.
  - Avoid foods that have been prepared with milk, butter, milk solids, cream, casein, or whey.
  - Avoid products with ingredient lists that say “May contain milk”.

- Talk to your doctor about using over-the-counter enzymes.
  - Lactase enzyme products are available in capsule, liquid, or pill form.
  - Taking these enzymes with your meal may help you to digest the lactose in milk and prevent symptoms.

- Choose other calcium-fortified or high-calcium foods.
o Read labels to find foods that have been fortified with calcium to ensure you are meeting your calcium needs.
o There are many ways to meet your calcium needs from foods other than dairy products. Other good sources of calcium include leafy green vegetables, broccoli, fortified orange juice, fortified cereals, canned salmon, tofu, almonds, soy beans, and white beans.
o Talk with your physician or a registered dietitian about whether you could benefit from taking a calcium supplement.

• Symptoms of lactose intolerance may improve overtime after treatment ends, but sometimes it can be a long-term problem.

Loss of Appetite

Loss of appetite interferes with good nutrition before, during, and after treatment and can contribute to dangerous weight loss. The following are some tips to optimize nutrition while dealing with appetite loss.

• Manage any other nutrition related side effects that may contribute to appetite loss.
o Nausea, vomiting, diarrhea, constipation, dry mouth, sore mouth, swallowing difficulty, and heartburn may lead to loss of appetite.
o Talk to a registered dietitian and your healthcare team for assistance with any of these side effects. It is important to get help managing any of these side effects to increase appetite.

• Take note of when your appetite is best.
o For some people this is in the morning and appetite diminishes throughout the day. For other people it may be the opposite.
o When you feel well, eat as much nutritious food as possible in case you do not feel well later.
o Do not limit or restrict food intake when appetite is good.

• Eat 5-6 small meals per day and snack anytime.
o Small amounts of food are typically easier to digest and are easier on the stomach. It is often easier to better meet nutrition needs while battling appetite loss with smaller amounts of food more frequently.

• Keep healthy snacks around, and do not go more than three hours without eating.
o Pack a cooler or insulated lunch bag to take on longer trips or to appointments when the wait time is variable.
o Keep small containers of fruit, dried fruit, trail mix, small bottles of juice, yogurt, cheese, whole grain crackers, cereal, granola bars, and other portable food items that are easy to eat and require little to no preparation.
Always keep snacks visible and available as a reminder that it is important to eat to get the body the nutrients it needs.

- If food is not appealing, have a nutritious beverage instead.
  - A high-protein shake or smoothie can have as many calories as a small meal or large snack.
  - Have a ready-to-drink liquid nutrition supplement when food is not appealing.
  - Milkshakes, smoothies, or protein shakes can be made with yogurt, milk, ice cream, protein powder, fruit, and other ingredients using a blender. Have these ingredients available for times when a drink sounds better than a meal.

- Drink liquids between meals.
  - Sometimes drinking liquids with meals causes the stomach to get full faster. This prevents eating enough and maximizing nutrition from food sources.
  - If an early feeling of fullness is a problem, try waiting to drink any liquids until after a meal and do not drink any liquids for at least 30 minutes before a meal.

- Add calories and protein to foods to give their nutrient content a boost.
  - There are ways to add protein and calories to foods that are already eaten regularly.
  - Add a scoop of protein powder to a shake or smoothie.
  - Add healthy fat such as olive oil, nuts, or nut butter to recipes and other dishes to boost the calorie content.
  - Ask a registered dietitian for other suggestions on how to increase the protein and calorie content of foods.

- Exercise or do some physical activity at least an hour before a meal.
  - Check with your healthcare team first before adding exercise to your routine.
  - Regular exercise may help increase appetite.
  - Go for a 20-minute walk before sitting down to a meal.

- Get in the habit of having a bedtime snack.
  - An easy-to-digest snack such as yogurt and fruit, cheese and crackers, or peanut butter and crackers is an easy way to get some additional nutrition and will not impact appetite for the next meal.
  - If reflux or heartburn is an issue, have this snack at least one hour before lying down.

- Emotions are often related to appetite. Talk to your healthcare team about managing your emotional well-being.
  - Depression, anxiety, fear, and stress can all affect appetite.
  - Trained health professionals such as social workers and psychologists can assist in managing these emotions.
  - Support groups are another resource that may help in processing these emotions.
**Lymphedema**

Lymph nodes are part of your body's immune system. The immune system helps your body fight infection and disease by circulating lymph fluid throughout the body. Lymph nodes carry lymph fluid from node to node through this web-like system.

Cancer may affect the lymph nodes, making it necessary to remove those nodes. When lymph nodes are removed, it changes the flow of the lymph fluid.

Lymph fluid may build up in parts of the body where lymph nodes have been removed or damaged. This causes lymphedema, a swelling that can be very painful. It is important to learn if you are likely to suffer from lymphedema, as you can take steps to avoid or lessen its impact.

**Who is at risk for lymphedema?**

- Breast cancer patients whose surgery required removal of lymph nodes under the arm
- Other cancer patients whose treatment also required the removal of lymph nodes under the arm
- Cancer patients whose surgery required removal of lymph nodes in the neck (head and neck cancers, thyroid cancer)
- Cancer patients who have had lymph nodes removed from the groin area (testicular cancer)
- Cancer patients who had radiation treatment that damaged lymph nodes

**What are the symptoms of lymphedema?**

- Swelling (pressing the skin with your finger may leave a dent or impression)
- Pain
- Numbness
- Loss of ability to move the affected area
- Hardened skin
- Ulcerations/tears in swollen skin

**How can I avoid lymphedema or avoid making my lymphedema worse?**

- If you had lymph nodes removed from under your arm, do not have your blood pressure taken from that arm, especially if you have had the symptoms of lymphedema.
- Similarly, do not have blood drawn or receive shots or IVs in an area where lymph nodes have been removed.
- Avoid sunburns by staying out of the sun and always wearing at least SPF 30 sunscreen.
- Use insect repellent when outside to help avoid bites that could lead to infection.
• Avoid trauma or injury to the area where lymph nodes have been removed.
• Avoid heavy lifting with the affected arm.
• No tattoos on the affected arm.
• Do not wear tight clothing, bands, shoes, or jewelry on the affected area.
• Wear a compression sleeve or stocking if ordered by your doctor.
  o The snug way a compression sleeve or stocking fits on your arm or leg helps lymph fluid move though the system instead of getting blocked.
  o Compression sleeves for lymphedema need to fit correctly. An ill-fitting compression sleeve may make lymphedema worse.
  o Your healthcare team can help you find the correct compression sleeve for you.
  o Compression sleeves and stockings are often not covered by health insurance, including Medicare and Medicaid plans.
    ▪ Ask your case manager or representative if lymphedema sleeves and treatments are covered by your plan.
    ▪ Ask your healthcare team about free or reduced-cost resources in your area or at your treatment center.
    ▪ Seek financial assistance.
      • CancerCare: (800) 813-HOPE (4673)
      • Patient Advocate Foundation: (800) 532-5274
• Keep your skin moisturized and healthy to avoid cracks that may lead to infection.
• Maintain a healthy body weight.
  o Eat a variety of fruits and vegetables.
  o Choose whole grains.
  o Choose lean proteins.
  o Limit sugar and sweets.
  o Drink eight glasses of water a day.
• Exercise.
  o Ask your healthcare team which exercises are right for you. Some exercises may make lymphedema worse.
  o Talk to your healthcare team before beginning any new exercise program.

How can I manage lymphedema?

• Tell your healthcare team as soon as you notice the symptoms of lymphedema.
• If your lymphedema is moderate to severe, your doctor may recommend you to a lymphedema therapist or a physical therapist for complex decongestive therapy (CDT).
  o Complex decongestive therapy involves a few different strategies, as follows:
    ▪ Massage
    ▪ Skin care
    ▪ Special exercises
    ▪ Compression bandages
- The massage is called manual lymphatic drainage (MLD). This massage style helps move lymph fluid through the system to decrease pain and swelling.
- Your lymphedema therapist may also recommend a pneumatic compression sleeve.
  - These sleeves have an attached pump that inflates and deflates the sleeve around the affected arm or leg.
  - The pump helps move lymph fluid through the system.
- Follow the same guidelines for avoiding lymphedema listed above.
- Lymphedema can make it easier to have infections in the affected area.
  - Tell your healthcare team immediately if you notice any of the signs of infection:
    - Fever
    - Redness or red streaks
    - Warmth or heat at the swelling area
    - Cloudy pus or drainage

Nausea

Nausea and vomiting are common side effects of cancer treatment that can cause dehydration, poor nutrition, and weight loss. Follow these tips to control nausea and vomiting.

- Take anti-nausea medications as prescribed by your healthcare provider.
  - It is important to take anti-nausea medications as prescribed.
  - Do not wait until the onset of nausea to take medication.
  - It is best to attempt to keep nausea managed with medication to allow for consistent eating and optimal nutrition.
  - Call your healthcare provider if you are taking the medication as prescribed and it is not providing any relief. A different medication may be needed.
- Track nausea to determine causes and trends.
  - Some nausea may be directly related to chemotherapy.
  - It is beneficial to know how soon after chemotherapy the nausea begins. Sometimes it is immediate and other times the onset is delayed.
  - Tracking may help to identify other triggers or causes of nausea.
- Keep odors to a minimum.
  - Odors can lead to nausea so it is best to choose foods with little or no odor such as oatmeal, cereals, canned fruit, shakes, and smoothies.
  - When preparing food at home, opt for foods with short cooking times and minimal odor such as pancakes, scrambled eggs, reheated soup, or other prepared foods that just require reheating.
  - Cool and room temperature foods usually have fewer odors than hot food.
Avoid cooking foods that have long cooking times such as casseroles, meats, and slow cooked meals.
Ask friends or family members to cook these items in an alternative location like a neighbor’s kitchen.

- Eat several small meals or snacks during the day.
  - Eating small meals or snacks 5-6 times per day instead of 2 or 3 larger meals may help with nausea management. This keeps the stomach from getting too empty and prevents excess stomach acid.
  - Chew all foods very well. The digestion process begins in the mouth.
  - Keep bland, odorless snacks on hand for easy meals and snacking. Some examples are crackers, cheese, canned fruit, yogurt, toast, rice, and pasta.
  - Not all foods are appealing to everyone. The key is to find the foods that are tolerable and stock up on those.

- Create a relaxing environment for eating and snacking.
  - Lighting, temperature, and other external cues may make nausea worse.
  - Dim lighting and cooler temperatures tend to be better for nausea management.
  - The use of a fan or ceiling fan may also make a difference.
  - It is important to be removed from situations that contribute to anxiety when attempting to enjoy a meal or a snack. (i.e. loud voices, arguing, loud music, or non-relaxing television programs).
  - Soft relaxing music, a relaxing television program or another activity that is relaxing in a cool, dim room may be the best environment for meals and snacks.
  - Rest after meals but do not lie flat as this may trigger nausea.

- Experiment with different foods.
  - Everyone is an individual and not all foods work for everyone when nausea is an issue. Try to be patient and experiment with different foods.
  - Start with bland foods with minimal odor and introduce them one at a time.

- Avoid foods and behaviors that tend to trigger nausea.
  - Some foods are triggers for nausea for unexplained reasons. Some of these reasons may be psychological. It is best to avoid these foods for optimal nutrition. The time that it takes to recover from an episode is time that the body is missing out on good nutrition.
  - Foods that are harder to digest and stay in the stomach longer can be triggers for nausea. These foods are usually higher fat foods such as fried foods and foods prepared with a lot of butter or oil.
  - Spicy foods are usually not tolerated well.
  - Some behaviors such as eating in a restaurant may trigger nausea. If this is the case, order food to carry out and eat it in a more relaxing environment.
  - Caffeine and smoking contribute to nausea.
  - Limit or avoid smoking, and drink only decaffeinated beverages.
• Try foods and drinks containing ginger.
  o Ginger is a spice that has shown some promise for relief from nausea.
  o Ginger snaps, ginger ale, ginger gum, or ginger tea may be options that can help
    manage nausea.
  o Ginger is also common in some Asian recipes.
  o Ginger supplements are available; however, they have not been studied
    extensively to determine an effective dose.
• Avoid drinking while eating.
  o Sometimes excess liquid in the stomach contributes to nausea.
  o It is best to drink any beverages at times other than meal times.
  o The best beverages to choose are water, 100% fruit juices without added sugar,
    and caffeine-free soda that no longer has carbonation.
  o Ginger ale specifically may help with nausea.
• Wear loose-fitting, comfortable clothing.
  o Clothing that is tight especially around the midsection can trigger nausea.
  o Soft, comfortable fabrics tend to be more relaxing as well.
• Stay hydrated if vomiting occurs.
  o Continue to drink clear liquids including water and other electrolyte containing
    beverages like sports drinks.
  o Attempt to eat bland foods such as crackers or toast.
  o If vomiting is continuous and cannot be controlled, contact your healthcare
    provider immediately.

Pain

Cancer and Pain
Pain related to cancer comes in many different forms. Pain can be caused by the cancer itself,
or it can be a side effect of treatment.

For the best pain management, you and your healthcare team will first need to find out the
cause of your pain. Be prepared to answer these questions:

• How severe is your pain?
• Is there anything that makes it better?
• Is there anything that makes it worse?
• What does it feel like—an ache or a sharp pain, dull, throbbing, or tingling?
• Is the pain in only one part of your body?
• How does the pain interfere with your daily life?

Keeping a pain journal can be helpful. Use the “Treatment and Side Effects Log” included in
the Handbook.
Is the pain a side effect of treatment?

Chemotherapy, radiation, and surgery are the three most common cancer treatments, and pain is a potential side effect for all three. However, the type of pain caused by each is different.

Chemotherapy can cause the following types of pain: muscle and joint aches, mouth sores, headaches, and neuropathy. Neuropathy is an unpleasant tingling or numbness, usually in the hands or feet. Damage to nerve endings causes this feeling.

Radiation causes the skin at the treatment site to become dry, red, and painful like a mild to moderate sunburn. Sometimes these burns blister. Depending on the location of radiation, there may be other side effects. For example, radiation to the brain may cause headaches.

Surgery causes pain at the incision site. Depending on the extent and location of the surgery, this pain could be mild to severe. Surgery can damage muscles and tissues leading to range of motion problems. Surgery can also damage nerves and cause neuropathy. Amputations and mastectomies can lead to “phantom” pains where the removed limb or breast used to be.

Is the pain a side effect of the cancer itself?

Depending on size and location of the tumor, pain could be from the cancer itself. If the tumor is pressing on nerves, joints, or bones, it can cause pain. This type of pain is more common with advanced or metastatic cancer, especially when the cancer spreads to the bones. Tumors in the bones can cause fractures as the tumors continue to grow.

Pain Management Plans

Your healthcare team can help create the best pain management plan for you. If the first plan you try does not work, tell your healthcare team. You may need to try a different plan. Open and honest communication with your healthcare team is very important. Pain is a difficult side effect to treat. It may take a few tries to find the best plan for you. Do not be afraid to seek a second opinion if needed.

Your pain management plan may include:

Pain Medications

Your doctor may prescribe pain medications or suggest over-the-counter pain medications. Ask your doctor before taking any over-the-counter medications. Some pain medications can cause nausea or constipation. Your doctor may be able to suggest additional medications to help with these side effects. You may have to try a few different types of medications or dosages to find what works for you.

Physical Therapy

Physical therapy uses exercises to help improve strength and motion. If your pain is related to loss of range of motion or difficulty doing physical activities such as walking, physical therapy may help ease pain.

Exercise

Regular exercise, even something as simple as a daily walk, may also help with pain. Exercising is good for the body. It can also make you feel better mentally too. Exercising releases endorphins, natural chemicals that make you feel happier. Exercising also combats
fatigue which is a common side effect along with pain. Always ask your doctor before beginning an exercise plan.

**Complementary and Alternative Medicine**

Some cancer patients find success at relieving pain with complementary and alternative medicine (CAM) such as acupuncture, guided imagery, massage, supplements and vitamins, or yoga. The phrase “complementary and alternative medicine” means treatments outside the standard scope of what you would find at a hospital or treatment center. Complementary medicine is used along with standard treatment. Alternative medicine is used instead of standard treatment.

Always discuss the pros and cons of each treatment you consider with your healthcare team. If you are considering a complementary treatment, inform your medical team BEFORE you are treated to make sure it will not negatively interact with your standard treatment. If you are considering quitting standard treatment for an alternative treatment, remember: standard treatments go through a long and careful research process to ensure that they are safe and effective, but less is known about most types of CAM.

For more information on CAM, visit the National Center for Complementary and Alternative Medicine website.

**Palliative Care**

Palliative care provides relief from pain and other symptoms, but it does not provide a cure. For cancer patients, common palliative therapies include surgery, radiation, or chemotherapy as a method of shrinking tumors that are causing pain. Palliative care is most commonly used for advanced or metastatic cancers.

**Emotional Support**

Taking care of your emotional well-being can also help manage pain. There are a number of ways to find emotional support—peer partnering programs, support groups, and one-on-one counseling.

Your doctor may even prescribe antidepressants, which have been shown to help with nerve pain as well as emotional well-being.

**Managing Other Side Effects**

Other side effects of treatment, such as fatigue, nausea, or loss of appetite, may be making your pain worse. You may be able to manage many of these side effects with simple nutrition and habit changes.

**Reflux, Heartburn, and GERD**

Heartburn, reflux, and GERD (gastroesophageal reflux disease) may occur during cancer treatment. Cancer treatments or medications may affect parts of your digestive tract and cause the food and liquids in your stomach to reflux (travel back) into your esophagus (food pipe). If
you have reflux, you may have symptoms such as swallowing difficulty, a sore throat, sour taste in your mouth, heartburn and painful digestion.

Talk with your healthcare team for the best care for reflux. Here are some tips and guidelines to help control reflux:

**Go small.**

- Eat 5-6 small meals or snacks throughout the day. Smaller amounts of food are easier for the body to digest and absorb.
- Smaller amounts of food also mean there is less food that can travel back up the food pipe.

**Choose lean.**

- Avoid fried and fatty foods. These foods are hard to digest and stay in your stomach for a long time. Time increases risk for reflux.
- Choose baked, broiled, or grilled foods instead.

**Dress for comfort.**

- Wear loose-fitting clothes, especially clothes that are not tight around your stomach.
- Clothes that are tight around the stomach can trigger reflux.

**Avoid smoking and alcohol.**

- Smoking cigarettes (including e-cigarettes) and drinking alcohol can trigger reflux.
- Instead of after-dinner drinks and cigarettes, chew sugarless non-mint gum for 30 minutes after meals. This encourages food to move through your digestive system.

**Sit up.**

- Pay attention to your posture.
- Sit up at least 1 hour after eating.
- Good posture helps your breathing and may reduce fatigue during eating.
- Raise the head of your bed 6 to 9 inches by putting wooden blocks under the legs of the head of your bed.

**Slow down.**

- Eat slowly and chew food really well. Digestion begins in the mouth.
- Smaller food pieces are much easier to digest and are less likely to cause discomfort.
- Meals eaten in calm, relaxed place seems to be better digested.
- Added stress from treatment can also trigger reflux; try to eat when you are feeling most relaxed.
Choose well.

- Some specific foods and drinks may cause reflux symptoms.
- Some common problem foods and drinks may be: chocolate, cocoa, mint, whole milk, caffeine, pepper, some fruits/juices, pastries and other high-fat desserts.

Write it down.

- Record in a log the times you eat, the foods and drinks you consume, and any reflux symptoms.
- If you eat a large portion of a problem food, you may have symptoms. Try a small portion and take notes in your log. Use your log to eliminate items that cause reflux symptoms.
- Avoid "problem foods" for a couple of days to see if symptoms disappear.

Avoid eating before bed.

- Avoid eating too close to bedtime.
- Have your last food or drink 1-3 hours before you recline.
- If still having trouble sleeping due to reflux, you may need to raise the head of the bed so that gravity helps keep food down in the stomach.

Ask for help.

- Consult a local registered dietitian for specific recommendations based on your level of food tolerance.
- Talk to your healthcare team if symptoms persist or get worse.

Sore Mouth, Throat, and Tongue

Some cancer treatments can cause mouth sores, ulcers, and tender gums, leading to dehydration, poor eating, and weight loss. Follow these tips to manage sore throat, mouth, and tongue.

- Choose soft, bland foods.
  - Softer foods will be easier to chew and swallow.
  - Soups and stews are good options, as long as meats are soft and tender.
  - Try breakfast foods like instant oatmeal, grits, pancakes, waffles, and cold cereal that has been softened in milk.
  - Pick side dishes like cottage or ricotta cheese, macaroni and cheese, mashed white or sweet potatoes, and rice or risotto.
  - Try desserts like custard, tapioca pudding, ice cream, milkshakes, and sherbet.
  - Choose snacks like applesauce, gelatin, smoothies, and yogurt.
• Prepare foods in ways that make them easier to eat.
  o Cut foods into small pieces. You may consider using a blender or food processor to puree foods.
  o Cook foods until they are soft and tender.
  o Serve foods with gravy, broths, or sauces.
  o Choose soft or canned fruits or applesauce instead of raw fruits with tough skins.
• Avoid foods and drinks that make mouth sores worse.
  o Avoid citrus fruits and juices, salty or spicy foods, and acidic foods like tomatoes.
  o Do not drink carbonated or caffeinated drinks.
  o Refrain from having beer, wine, liquor, or any other type of alcohol.
• Avoid very hot foods.
  o Hot foods can cause mouth and throat discomfort.
  o Choose room temperature or cold foods that are soothing.
  o Allow soups and hot foods to cool to room temperature before serving.
  o Try freezing fruits, and suck on frozen fruit pops, fruit ices, or ice chips.
• Choose foods that are good sources of protein to combat weight loss.
  o Aim to have a good source of protein with meals and snacks.
  o Ground meats, eggs, cottage cheese, yogurt, custard, beans, lentils, and smoothies are good soft food choices that also provide protein.
  o Eat small, frequent meals. You may find it easier to eat smaller amounts at a time.
• Drink at least 8-10 eight-ounce glasses of water each day.
  o Drink liquids with your meals as this will make it easier to swallow foods.
  o Sip cool drinks in between your meals.
  o Drink with a straw. This can help push the foods past the painful sores in your mouth.
  o Avoid caffeinated or/and carbonated beverages.
  o Avoid alcohol. Alcohol can irritate the mouth.
• Use good mouth care.
  o Rinse your mouth several times a day. Mix ¼ tsp. of baking soda and 1/8 tsp. salt with 1 cup warm water to make a rinse that removes food and promotes healing.
  o Do not use a mouthwash that has alcohol. Alcohol makes a sore mouth worse.
  o Use a toothbrush with soft bristles.
  o Remove dentures (except during eating) if your gums are sore. Keep dentures clean.
  o Avoid cigarettes, cigars, and tobacco products.
  o Ask your doctor about special mouthwashes and sprays that can numb the mouth and throat.
  o Tell your doctor if your gums are bleeding or if you have white patches in your mouth. Both can be signs of infection.
Weight Gain

Weight gain is common among cancer patients. This can be for a variety of reasons. The following tips help maintain a healthy weight before, during, and after cancer treatment.

- Know the factors that can cause weight gain.
  - Medication, hormone therapy, or chemotherapy can lead to weight gain.
  - Fatigue and other side effects can cause decreased physical activity.
  - Stress, fear, or depression can lead to changes in eating habits.
  - Fluid retention causes swelling.
- Eat a variety of fruits, vegetables, whole grains, and beans.
  - All of these foods are high in fiber and low in calories.
  - Fiber helps you feel fuller longer.
- Choose whole grain foods.
  - Whole grains also contain fiber and are a lasting energy source.
  - Whole grain foods include whole grain breads, cereals, pasta, crackers, and brown rice.
- Choose lean proteins.
  - Protein foods also help you feel fuller longer.
  - Lean proteins include eggs, fish, skinless chicken, turkey, lean beef, lean pork, beans, and soy products.
- Choose low-fat or fat-free dairy products.
  - Low-fat and fat-free dairy products contain the same amount of protein as regular dairy products.
  - Low-fat and fat-free dairy products include 1% or skim milk, low-fat yogurt and reduced-fat cheese and cottage cheese.
- Limit foods high in fat and calories.
  - High-fat foods like regular butter, creamy dressing and sauces, sour cream, mayonnaise, fried foods, and dessert contain more calories and can contribute to weight gain.
  - Limit frequency and portions of high-fat foods and choose reduced-fat items when possible.
  - Avoid high-fat cooking methods, such as pan or deep frying. Broiling, steaming, grilling, and roasting are recommended.
- Avoid high-calorie beverages.
  - Avoid drinking large amounts of sugar-sweetened beverages such as sodas, sports drinks, sweetened teas, lemonade, and sweetened fruit juice.
  - Choose low-calorie, low-sugar beverage options such as water and unsweetened tea.
  - Limit or reduce alcohol consumption. If alcohol is consumed at all, it is best to limit to no more than one drink per day for women and two drinks for men.
• Avoid eating when you are not physically hungry.
  o Listen to your body. Don’t confuse boredom or stress for hunger.
  o Try making a list of alternate activities you can do when you have the urge to eat when not hungry.
• Watch your portion sizes.
  o Try measuring out your portions so you know exactly how much you are eating.
  o Check the nutrition label to determine serving sizes.
  o Choose to eat all meals and snacks off of a plate rather than out of the package so you can keep track of how much you are eating.
• Limit eating out.
  o Restaurants often serve large portions of higher calorie and higher fat foods.
  o Limit eating out so you are not tempted with large portions of these foods as often.
• Write down your intake.
  o Studies show that those who record all of their food and drink intake eat less calories than those who do not.
  o Keeping a food journal could help keep you mindful about appropriate portion sizes and urges to eat when not hungry.
• Try exercise.
  o Aim for 30 minutes of exercise every day if able.
  o Always discuss any changes in exercise with your physician.
• Always discuss weight gain with your physician.
  o A physician can help determine the cause of weight gain and can give recommendations for how to appropriately manage weight gain.
  o Do not go on a diet to lose weight without discussing with your physician first.

Weight Loss

During cancer treatment, the body needs more calories and protein, especially when side effects can make it difficult to eat. Follow these tips to increase intake.

• Eat small, frequent meals (5-6 a day) instead of 3 large meals.
  o Eat every 2 to 3 hours even if you do not feel hungry.
  o Set a timer to remind you it is time to eat. Eat the most when you feel hungriest.
  o Eat protein foods like chicken, fish, meat, eggs, nuts, and beans first.
• Use smoothies and shakes to get in calories and protein.
  o Liquids can be easier to consume than solid foods.
  o Smoothies or shakes can serve as a small meal replacement.
Add ingredients such as whole milk, powdered milk, protein powder, peanut butter, ice cream, or yogurt to smoothies or shakes to add calories and protein.
Premade liquid nutrition supplements are available at grocery and drug stores. Ask a registered dietitian which type is best for you.
Ingredients such as whole milk, peanut butter, ice cream, yogurt, or fruit can be added to liquid nutrition supplements.

- **Add more fats to foods to increase the calories.**
  - Fat has more calories per gram than carbohydrates or protein.
  - Use butter, oils, mayonnaise, sour cream, and salad dressings liberally.
  - When cooking, use oil or butter instead of a nonstick spray.
  - Add mayonnaise to sandwiches and tuna or chicken salad.
  - Add peanut butter or cream cheese to toast or crackers.

- **Drink most liquids between meals instead of with meals.**
  - Liquids such as water, juice, or soda while you eat can make you feel full faster.
  - Drink only small amounts with meals.
  - Drink higher calorie liquids like juice and milk between meals.
  - Drink smoothies, shakes, and nutrition supplements with or in place of a meal.

- **Snack regularly throughout the day.**
  - Keep quick and easy snacks with you.
  - Try granola bars, trail mix, peanut butter crackers, nuts, and dried fruit.
  - Keep your favorite snacks around so you will eat more.
  - Eat a bedtime snack. It will not affect your appetite at your next meal.
  - Peanut butter crackers, half a sandwich, yogurt, and cereal are good bedtime snacks.
Many cancer patients experience sexual dysfunction, fertility issues, or changes in their sex lives after a cancer diagnosis. These changes can be physical or mental. Many are not comfortable discussing these issues with their healthcare team or with their partners, but being able to speak openly is important.

Managing Sexual Side Effects

Each type of cancer treatment—chemotherapy, radiation, surgery, and hormonal therapy—can cause possible sexual side effects. Side effects may vary depending on the type of cancer, the specific mode of treatment, and the individual’s response to treatment. Talk to your healthcare team about what you should expect from treatment.

Following are some of the most common sexual side effects and tips for managing each.

Lack of Desire

During and after cancer treatment, many women report a lack of sexual desire. Lack of desire may come from hormonal changes such as early menopause or other side effects, making sex unenjoyable.

- Rethink what sex and intimacy mean.
  - Do not expect sex after cancer to be exactly the same as sex before cancer. Your body has been through a lot of changes.
  - Be patient. It may take some time to discover what is comfortable and pleasurable for you.
- Ask your doctor about estrogen therapies to increase estrogen and if they are safe for you to use.
  - Low levels of estrogen can cause female sexual dysfunction.
  - Estrogen therapies can help with lack of desire and dryness.
  - Estrogen therapies come in pills, creams, patches, and vaginal rings.
  - If your cancer is hormone driven, estrogen therapy may not be safe for you.
- If you are taking anti-depressants or pain medication, talk to your doctor about adjusting your dosage.
  - Both these medications can cause lack of desire.
- Manage other side effects such as dryness, pain, nausea, or fatigue that may be causing your lack of desire.
Dryness

Early menopause, triggered by chemotherapy, adjuvant therapies, or surgery, can cause vaginal dryness. Radiation to the pelvic region can also cause dryness.

- Use a water-based lubricant during sex.
  - Stay away from scented and warming lubricants. These can irritate the vagina, actually making dryness worse.
  - Do not use petroleum jelly based lubricants.
- Try vaginal moisturizers to improve overall dryness.
  - Vaginal moisturizers are different from lubricants. You do not use them only during sex. If used regularly, they improve overall dryness and vaginal health.
- As mentioned above, ask your doctor about estrogen therapies and if they are safe for you to use.

Pain

Pain during intercourse may occur for a few reasons such as dryness or scar tissue. Radiation to the pelvic region may cause minor burns as well as scarring that causes the vaginal canal to shrink. Gynecological surgery can damage or result in the removal of sex organs.

- After surgery, ask your doctor if and when it is safe to have sex.
- If the shape of the vagina has changed from treatment, you may need to adjust the way you have sex by trying new positions or new activities.
- After gynecological surgeries that affect the vagina, reconstructive surgery may be an option.
- A vaginal dilator can be used to stretch the vaginal canal. Vaginal dilators are smooth plastic cylinders of different widths. By beginning with the smaller ones and inserting them into the vaginal canal regularly, the vagina begins to stretch, making intercourse less painful. Vaginal dilators also make medical pelvic exams more comfortable.
- Pain may come from dryness. If you are also experiencing dryness, try the tips above.

General pain in other parts of the body can also make sex uncomfortable and decrease your desire to be intimate. To learn more about pain management unrelated to sex, read the “Pain” section of the Handbook.

Difficulty Reaching Climax or Orgasm

Surgery and other treatments that directly affect the pelvic region can result in loss of sensation if nerves are damaged. This can make achieving an orgasm difficult for some women. Actions that worked before treatment may no longer feel the same. Other side effects mentioned in this article such as pain, lack of desire, and emotional issues can also make achieving orgasm difficult.
• Work on managing all of side effects that may be affecting your sex life.
• For most women, vaginal penetration does not provide enough stimulation for orgasm. Extended clitoral stimulation may be needed.
• Use your mind. Make sure you are comfortable and in the right mindset for sexual activity. Try imaging sexual fantasies to get in the mood.
• Try using a vibrator to increase stimulation. Vibrators can be purchased at a drug store or discreetly online.

Managing Non-Sexual Side Effects

Other treatment side effects, such as nausea and fatigue, may interfere with your sex life. Manage these side effects by using the tips in the Handbook.

Self-Esteem and Body Image

How you feel about yourself can affect your sex life. Cancer and cancer treatment can cause significant changes to your body. You may have hair loss, weight loss, weight gain, or scars. With these changes, you may not feel the same way about your body. This is all normal. Do not be critical of yourself. Your body battled cancer.

Below are tips for managing issues related to self-esteem and body image.

Hair Loss

• Hair usually grows back after treatment ends.
• In the meantime, try wigs, hats, and scarves.
• When your hair does begin to grow back, use a gentle shampoo such as baby shampoo.

Weight Changes

• Talk to your healthcare team about reaching and maintaining a healthy weight.
• Ask your healthcare team if it is safe for you to start an exercise program.
  o The endorphins released during exercise can also make you feel better emotionally.

Surgical Scars

• Most surgeries leave some scars. Try using over-the-counter lotions and gels to help minimize incision scars. Moisturizers made with cocoa butter also minimize scars.
• After surgery for breast cancer, some women choose to wear a breast prosthesis.
  o Insurance companies often cover a prosthesis.
• After surgery for breast cancer, some women choose to have breast reconstructions surgery.
Talk to your healthcare team about your options.

**Emotional Support**

You have to care for your mental health as well as your physical health. If you are struggling with anxiety or sadness, you probably don’t feel like having sex. Some options for emotional support include: peer partnering programs, support groups, and one-on-one counseling. Look the emotional support section of the Handbook for more information.

**Talking to Your Partner About Sex**

Being able to talk openly with your partner about sex is very important. What worked for you both before cancer may not work now. You may need to try different things to find what works for you both. If it has been a while since you’ve been intimate, start slowly with simple kissing and touching. Here are some basic guidelines for talking to your partner:

- Be honest.
- Always tell your partner if something hurts or is uncomfortable.
- If something feels good, let your partner know.
- Be patient with yourself and your partner.
- Set the scene by going on a romantic date or watching a movie together at home.

**Talking to Your Healthcare Team About Sex**

Your healthcare team is made up of health professionals. You should feel comfortable telling them anything. There is nothing embarrassing about sexual dysfunction, as it can happen following cancer and its treatment. After fighting cancer, you deserve to have a healthy sex life.

You may wish to talk to healthcare professionals who specialize in areas related to sexual dysfunction including:

- Gynecologist
- Endocrinologist
- Sex therapist
- Psychologist or counselor

Talking about sexual dysfunction can be difficult. Here are some sample questions to begin your conversation with your doctor:

- How will treatment affect my sex life?
- What can I do to manage sexual side effects?
I have pain and dryness during sex. What can I do to manage this?
I no longer feel any desire to have sex. What can I do to feel like myself again?
Could you recommend a specialist?
Will treatment affect my fertility?

**Fertility**

Cancer treatments can lead to infertility or make it difficult to have children. Gynecological surgery can cause infertility. Chemotherapy and adjuvant therapies can trigger early menopause in women. Even though this process sometimes reverses in young women, it can still make conceiving difficult. Chemotherapy can also damage reproductive organs. Radiation to the pelvic area can damage reproductive organs.

Women do have options to preserve their fertility. However, it is important to talk to your healthcare team about fertility and your options before you begin treatment. Many fertility-preserving options must be done before the damage caused by treatment occurs.

Before beginning treatment, some women freeze and bank eggs or embryos (fertilized eggs). Fertility preservation can be a long process so you will need to factor this into your timeframe for treatment. Some fertility treatments require that you take hormones before the procedure. For women with certain types of cancer, taking these hormones is not safe.

Some steps can be taken to protect reproductive organs during treatment. For example, during radiation treatment, depending on the area receiving radiation, you may be able to use a shield.

If you continue to have sex during treatment, be sure to use proper protection. Pregnancy during chemotherapy or radiation is not safe for the mother or the child. Even if your periods stop during treatment, you may still be able to conceive so always use a form of birth control. Some cancers may affect your ability to use hormonal birth control methods, such as oral medication and devices such as IUDs and hormone rings. Make sure you ask your doctor before resuming any birth control you used before your diagnosis. Since cancer treatment can compromise your immune system, be sure to always use condoms to protect against sexually transmitted diseases (STDs).

Talk to your healthcare team as soon as possible about your fertility status and options.

For more information, visit www.fertilehope.org or www.myoncofertility.org.
When you are faced with a cancer diagnosis, nutrition can be an important part of your journey. Eating a well-balanced diet before, during, and after cancer treatment can help you feel better, maintain your strength, and speed your recovery. Use these tips about nutrition written by registered dietitians.

I Have Breast Cancer. What Should I Eat?

How do I make the best food choices throughout cancer treatment?

When you are faced with a breast cancer diagnosis, nutrition can be an important part of your journey. Eating a well-balanced diet before, during, and after cancer treatment can help you feel better, maintain your strength, and speed your recovery.

- **Maintain a healthy weight.** Depending on what breast cancer treatment you undergo, you may experience weight gain or weight loss. Aim to maintain a healthy weight during treatment, avoiding excess gain or loss. Strict dieting during treatment is not recommended. Many breast cancer patients gain weight as a result of treatment as well.

- **Eat small, frequent meals throughout the day.** Eating frequent small meals will ensure your body is getting enough calories, protein, and nutrients to tolerate treatment. Smaller meals may also help to reduce treatment-related side effects such as nausea. Try eating 5-6 small meals or “mini” meals about every three hours.

- **Choose protein-rich foods.** Protein helps the body to repair cells and tissues. It also helps your immune system recover from illness. Include a source of lean protein at all meals and snacks. Good sources of lean protein include:
  - Lean meats such as chicken, fish, or turkey
  - Eggs
  - Low fat dairy products such as milk, yogurt, and cheese or dairy substitutes
  - Nuts and nut butters
  - Beans
  - Soy foods

- **Include whole grain foods.** Whole grain foods provide a good source of carbohydrate and fiber, which help keep your energy levels up. Good sources of whole grain foods include:
  - Oatmeal
  - Whole wheat breads
  - Brown rice
  - Whole grain pastas
• **Eat a variety of fruits and vegetables every day.** Fruits and vegetables offer the body antioxidants, which can help fight against cancer. Choose a variety of colorful fruits and vegetables to get the greatest benefit. Aim to eat a minimum of 5 servings of whole fruits and vegetables daily.

Fresh fruits and vegetables may need to be cooked for patients in treatment with a weakened immune system.

• **Choose sources of healthy fat.** Avoid fried, greasy, and fatty foods, Choose baked, broiled, or grilled foods instead. Healthy fats include:
  - Olive oil
  - Avocados
  - Nuts
  - Seeds

• **Limit sweets and added sugars.** Foods high in added sugars like desserts and sweets provide little nutritional benefit and often take the place of other foods that are better for you.

• **Stay hydrated.** Drinking enough fluids during cancer treatment is important for preventing dehydration. Aim to drink 64 ounces of fluid daily. Avoid drinking large amounts of caffeinated beverages. Too much caffeine can lead to dehydration.

• **Use good mouth care.** Chemotherapy and radiation to the head or chest can irritate the lining of the mouth, throat, and esophagus. This irritation can make eating and swallowing difficult. Good mouth care is very important if you have mouth soreness. Brush teeth with gentle toothpaste after eating and floss daily.

• **Practice good food safety.** Wash your hands often while preparing food. Use different knives and cutting boards for raw meat and raw vegetables. Be sure to cook all foods to their proper temperature and refrigerate leftovers right away.

• **Talk to your healthcare team before taking any vitamins or supplements.** Some medications and cancer treatments may interact with vitamins and supplements. Choose food first as the main source for nutrients.

• **Drink alcohol in moderation, if at all.** Alcohol may contribute to dehydration, can lower the abilities of your immune system, and provides no beneficial nutrients.

• **Most importantly, know that your cancer journey is unique to you and your treatment.** You may experience side effects that affect your ability to follow these suggestions. If you are struggling with any side effects, such as loss of appetite, nausea, diarrhea, vomiting, or any other nutrition concerns, your needs may be different. A registered dietitian can suggest nutrition guidelines that will be appropriate for your cancer journey.
Nutrition and Surgery Guidelines

The outcomes of a surgery are directly related to nutrition status prior to and after surgery. It is very important to eat a well-balanced diet prior to surgery including fruits, vegetables, whole grains, and an adequate amount of protein. Vitamins, minerals, and protein are vital to the healing process. A single nutrient deficiency can impair the immune system causing significant delays in the healing process and a decrease in ability for the body to fight an infection. Follow these guidelines beginning at least three weeks prior to surgery or as long as possible prior to surgery to optimize your nutrition for a faster recovery:

Eat 3-5 servings of fruits and vegetables every day. Choose a wide variety of colors.

One serving of fruit is one piece of fruit (such as a medium orange or apple) or ½ cup of canned or frozen fruit. One serving of vegetables is ½ cup cooked or 1 cup raw. Fruits and vegetables are excellent sources of B vitamins as well as antioxidants (vitamins A, C, and E). The vitamins in fruits and vegetables support the body’s immune system before, during, and after surgery. Frozen vegetables and fruit are good to have available when shopping frequently is not possible.

Eat 6-11 servings of whole grain foods every day.

One serving is considered one slice of 100% whole wheat bread, ½ cup cooked brown rice, ½ cup whole wheat pasta, or ½ cup of whole grain cereal. Whole grains also contain B vitamins essential to building the immune system and aids the healing process.

Eat a variety of protein containing foods at meals and snacks.

Protein contains essential amino acids that are vital to the healing process. The body’s protein status prior to surgery also influences the recovery time. Good sources of protein include meat, fish, eggs, cheese, beans, nuts, tofu, and dairy products.

Use fats, oils, and sweets sparingly.

Choose healthier fats such as canola and olive oil. Avoid fried foods. Excess fat and sugar contain empty calories that do not provide the body with any nutrients. Too many empty calories and not enough nutritious food may have an effect on the immune system.

Drink plenty of water in the 3 weeks prior to surgery.

Staying well hydrated will help in the recovery process. It will also help during the period of time right before surgery that water is not allowed. A general goal for daily water consumption is eight to ten 8-ounce glasses per day.

Establish consistent eating habits.

Eat a good breakfast everyday including a good source of protein like eggs, peanut butter, or Greek style yogurt. Lunch should include a protein source, whole grains, vegetables, and fruit. The evening meal should be similar to lunch. Remember to include healthy snacks like fruit, trail mix, hummus and carrot sticks or whole grain crackers with cheese or peanut butter.
Goes grocery shopping the week before surgery.

If you are not able to go to the grocery store yourself, send someone with a list to shop for you. Shopping for healthy foods right before surgery will allow you to keep up your healthy eating plan after surgery during the recovery period. Focus more on shelf-stable items, and buy fewer perishable items. Shelf-stable items such as peanut butter, canned fruit in its own juice, and low-sodium canned soups are good to have available when you return home from the hospital.

Get some exercise.

Walking is not only good for the body it is also good for the brain. Exercise may help in “clearing your head” when you begin to get anxious. It will also help you to maintain lean body mass (muscle). Muscle loss may occur after surgery due to physical inactivity. It is important to try to get back to doing some exercise as soon as possible after recovering. Your surgeon can advise you as to when it is safe for you to resume or begin exercising.

Tell your doctor about any vitamins, minerals, herbs, or other over-the-counter products and medications you take.

Some of these may be harmful during surgery and it is best to stop taking them prior to surgery. Examples of herbal supplements to discontinue as soon as your surgery is scheduled are: echinacea, ephedra, garlic, ginger, ginkgo biloba, ginseng, kava, licorice, saw palmetto, St. John’s wort, and valerian root.

Follow the pre-surgery instructions given by your doctor.

The pre-surgery instructions given by your doctor are meant to help minimize complications before and after surgery. Follow these instructions carefully. Most likely there will be some restrictions on food and beverage intake as the surgery date approaches.

Talk to a registered dietitian if you have lost weight or have any eating problems that are keeping you from eating healthy.

A registered dietitian will assess you and make recommendations for you to optimize your nutrition prior to surgery. Sometimes a liquid nutrition supplement may be beneficial.

Food Safety

The immune system is weakened during all types of cancer treatment. Unfortunately, chemotherapy medications are not able to tell the difference between healthy cells and cancer cells. For this reason, perfectly healthy red and white blood cells are damaged or killed during treatment and shortly thereafter. The result of this is that body is not as good at fighting illness and infection. A common term used to refer to a very low neutrophil (white blood cell) count is neutropenia. Paying special attention to food safety during cancer treatment to reduce the risk of exposure to food borne illness may also be referred to a neutropenic diet.
following are some simple tips to reduce exposure and avoid unnecessary infection and/or illness during the time the immune system is compromised.

**Keep EVERYTHING Clean**

- Wash hands often and thoroughly especially before handling any food as well as after. Be sure to wash hands with warm water and soap for at least 20 seconds. Pay special attention to finger nails and the backs of the hands.
- Keep raw and cooked foods separate. Do not reuse any utensils, cutting boards, plates, dishes, etc. once they have been touched by raw meat or eggs. Utensils, cutting boards, plates, dishes, etc. that have been used for preparing raw meats or eggs should be washed in hot, soapy water. It is best to keep a separate cutting board for meat and fruits/vegetables. Have an extra clean cutting board available for additional preparation as well.
- When shopping for and storing raw meats, keep them away from other foods and cover the packages with extra plastic wrap or use plastic bags. This will prevent any liquids from leaking onto other foods or surfaces. Store meats and eggs toward the bottom of the refrigerator to prevent any dripping on other foods below.

**Cook Food Thoroughly**

- Avoid raw meat such as sushi, undercooked eggs (make sure eggs are at least “over easy” and not “sunny side up”), and other meats that have not been cooked to a proper internal temperature.
- Cook all eggs until both the white and the yolk are firm.
- Use a meat thermometer to make sure that all meats are cooked to the proper internal temperature prior to eating. Here is a chart for reference:

<table>
<thead>
<tr>
<th>Meat</th>
<th>Internal Minimum Temperature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ground Beef</td>
<td>165º F</td>
</tr>
<tr>
<td>Turkey</td>
<td>165º F</td>
</tr>
<tr>
<td>Chicken</td>
<td>165º F</td>
</tr>
<tr>
<td>Steak or other cuts of beef</td>
<td>160º F</td>
</tr>
<tr>
<td>Whole chicken, turkey, duck, or goose</td>
<td>180º F</td>
</tr>
<tr>
<td>Pork</td>
<td>170º F</td>
</tr>
<tr>
<td>Egg dishes</td>
<td>160º F</td>
</tr>
<tr>
<td>Casseroles</td>
<td>165º F</td>
</tr>
<tr>
<td>Reheated leftovers</td>
<td>165º F</td>
</tr>
</tbody>
</table>
Foods To Avoid

- Raw or undercooked meats
- Unpasteurized milk and juices
- Soft cheeses made with unpasteurized milk such as feta, blue cheese, Roquefort, Stilton, brie, or farmer’s cheese
- Processed meats such as luncheon meats as well as anything else from a deli counter
- Refrigerated meat spreads or paté
- Smoked fish or precooked shrimp or crab meat
- Sprouts such as bean sprouts, alfalfa sprouts, or broccoli sprouts
- Pre-cut fresh fruit and vegetables. Buy them whole, wash, and cut them yourself using proper sanitary techniques as outlined above.
- Unwashed fresh fruits and vegetables
- Unroasted or raw nuts and seeds
- Raw tofu or tempeh
- Food from salad bars of buffets
- “Fresh” salad dressings, salsas, sauces, etc. sold in the refrigerated section of the grocery store.
- Raw apple cider
- Raw honey
- Unrefrigerated cream-filled pastries

The guidelines above were created with those who have severely weakened immune systems in mind. Consult your physician or healthcare team for regular updates on your blood counts and the status of your immune system.
Must Have Grocery List

It’s always important to have good, healthy foods on hand, especially if you are fighting cancer or are a cancer survivor. Eating well during cancer treatment can help to improve your overall health, improve your response to treatment, and maintain good health during treatment and recovery. Having a well-stocked pantry can assure that you are getting the calories and nutrition your body needs. Below are some suggested items that are healthy kitchen staples. Take this list with you to the grocery store before beginning treatment to stock up.

Pantry

Grains
- Whole grain breads, English muffins, pita bread, flour or corn tortillas
- Crackers: saltines, club crackers, whole wheat crackers, graham crackers
- Whole grain brown rice or white rice
- Whole wheat and refined pastas such as, penne, bowtie, macaroni, egg noodles, etc.
- Quick cooking oats and steel cut oatmeal
- Couscous, bulgur, or quinoa
- Cream of wheat
- Grits
- Dry cereal
- Natural popcorn
- Flour, cornmeal, breadcrumbs

Fruit/ Vegetables
- Canned fruit
- Dried fruit
- Individual fruit cups
- Applesauce, no sugar added
- Potatoes and sweet potatoes
- Onions
- Garlic
- Canned tomatoes (diced, whole), tomato sauce, marinara sauce
- Canned no salt added vegetables
- Instant mashed potatoes

Dairy
- Nonfat dry milk powder or whey protein powder
☐ Evaporated Milk

Proteins
☐ Canned tuna, salmon, or chicken (Choose those packed in water, not oil.)
☐ Natural peanut and almond butter
☐ Unsalted nuts and seeds
☐ Canned or dried beans, vegetarian refried beans, lentils.
☐ Protein bars

Fats and Oils
☐ Oil, olive, canola, cooking spray

Other
☐ Canned low sodium soups
☐ Low sodium chicken, beef, or vegetable stock
☐ Dried herbs and spices
☐ Vinegars such as red wine and balsamic
☐ Decaffeinated teas
☐ Flavored drink mixes, lemonade
☐ Pudding or gelatin mixes
☐ Individual pudding or gelatin cups
☐ Honey, sugar, stevia

Refrigerator:

Fruits/Vegetables
☐ Fresh and jarred fruits and vegetables
☐ Packaged salad mixes such as spinach, romaine, and arugula

Dairy
☐ Low-fat milk,
☐ Low-fat plain or Greek yogurt
☐ Cheese slices, cheese sticks, shredded or crumbled cheese
☐ Reduced fat cottage or ricotta cheese
☐ Fortified soy, almond, or rice milk

Proteins
☐ Eggs
Skinless chicken breasts or ground chicken breast
Lean pork
Lean cuts or lean ground beef
Ground turkey or turkey breast
Nitrate and nitrite-free deli meats
Hummus

Fats and Oils
Mayonnaise
Salad Dressings
Reduced

Other
Beverages- 100% juices, tea, sports drinks, liquid nutrition supplements
Fat-free sour cream
Lemon juice, lime juice
Sauces and condiments like low sodium soy sauce

Freezer:
Grains
Frozen whole grain waffles
Whole grain breads, rolls, English muffins, bagels, etc.

Fruits/ Vegetables
Frozen vegetables and fruits
Frozen juice concentrate (100% juice)

Dairy
Frozen desserts: sherbet, frozen yogurt, ice cream

Proteins
Chicken breasts
Fish such as tilapia, salmon, flounder
Shrimp

Other
Popsicles
A cancer diagnosis brings with it practical concerns such as financial, emotional, and legal issues. If possible, it is best to address these concerns before you begin treatment because you may not want to deal with issues when you are feeling poorly. In the next few sections, you will find information on the following:

- Preparing financially for cancer
- Legal considerations
- Hospice and palliative care
- Finding emotional support

Financial Concerns and Cancer

A cancer diagnosis can cause financial concerns. Even if you have insurance, there are things you need to think about. Here are the questions you need to ask before you start treatment:

**Am I insured? Is my insurance going to cover the cost of treatment?**

- Before you begin treatment, take a look at your insurance plan to see what starting treatment will cost you.
- A portion of costs will be “out of pocket” with any insurance plan.
  - See if you can get this cost automatically taken out of your bank account or pay check or paid with a credit card.
- You have to meet your deductible before your insurance company will pay for care.
- As soon as possible, determine what your co-payment will be for each appointment and treatment.
  - Use this to make a budget for future treatments and doctor appointments
- Most insurance plans have the option for cancer patient to be assigned a case manager.
  - Be sure to ask for this service.
  - This person will be able to answer all your questions.
  - If your insurance company does not have a case manager service, ask to speak to the same representative each time you call.
  - If your insurance is through your employer, someone in HR will be able to answer questions about your coverage.
- You may need to find a supplemental program to cover fees that your primary insurance does not.

**What if I don’t have insurance?**

- State Medicaid: www.cms.gov
Can I afford treatment? What other expenses can I expect?

- Before you begin treatment, ask the billing department for the expected cost.
  - When you begin, your doctor will give you a treatment plan.
    - For example, you will do a certain number of rounds of chemotherapy or a certain number of weeks of radiation.
  - Take this plan to the billing department to get an estimate of the cost of your prescribed treatment plan.
  - The more information you get the better you can prepare.
- Ask the billing department if there are any ways you might be able to save money.
  - Many providers will give you a discount if you pay in full.
  - Ask if you can set up a payment plan where you pay a certain amount each month towards your bill.
- You will need to change your current budget to include costs related to your cancer diagnosis and care. Use the “Budgeting Worksheets” in the back of the Handbook.

Are there options for treatment that are less expensive? Are these options just as effective? Am I eligible for a clinical trial?

- Ask your doctor and healthcare team these questions.
- Be sure to discuss all your treatment options with your healthcare team.
- Clinical trials are not more or less expensive than other treatments. Many insurance plans cover clinical trial treatments. Ask your doctor and healthcare team for more information

Does my hospital or treatment center have options for financial assistance? Is there assistance I can apply for? Does my hospital have a reduced cost program? If so, what are the eligibility requirements?

- Many hospitals have options for financial assistance.
- Ask if there is someone you can talk to about your options.

What other costs should I expect?

- Additional expenses you need to consider include:
  - Transportation
  - Child care
  - Nutritional supplements
  - Additional prescriptions
  - Prostheses (artificial body parts) or wigs
  - Household chore services (cleaning, grocery shopping, etc.)
10 Financial Assistance Tips for Cancer Patients

Whatever your financial situation, a diagnosis of cancer can complicate your budget. Review these tips for greater financial peace of mind.

1. **Understand your current and upcoming financial situation.**
   - Use the “Budgeting Worksheets” in back of the Handbook to help you understand your regular income and expenses. Doing so can ensure that you are not blindsided by the impact of any extra expenses.
   - Learn about the costs of your treatment plan. Before you begin treatment, your doctor will prescribe a certain treatment plan; for example, a certain number of weeks of chemotherapy. The billing department of your doctor’s office or treatment facility may be able to give you an estimate.

2. **Ask your doctor if there are more affordable options for treatment.**
   - Start with these questions: Are there less expensive treatment options? Would these options be as effective?

3. **If you do not already have a system for handling your finances, now is the time to develop one.**
   - Decide how you will keep track of your finances moving forward. Will you keep handwritten records? Will you use a computer program? Set aside a day and a time every month to pay your bills (or weekly if needed).
   - Ask a financial planner for help; your bank may have a customer service agent who is helpful.

4. **Keep accurate records of all medical bills, insurance claims, payments, and receipts, as well as any mail regarding those items.**
   - Get a notebook or special folder to keep track of everything in one place.

5. **When looking for financial assistance, always start with your doctor’s office.**
   - Practices often have financial assistance and options for uninsured and underinsured patients. Your doctor’s office may also have a social worker or patient representative who can help you identify resources.
   - Be sure to request any applications or possible services offered.

6. **When contacting the billing department, ask to speak with the same representative each time.**

7. **When asking for assistance, see if the billing department is willing to set up a payment plan for you.** You may get a discount if you are able to pay your bill in full at the time of service.

8. **Working with your insurance company and understanding your coverage will help you know all your options.**
   - Many insurance companies offer case managers for diagnoses like cancer.

9. **Look to nonprofit organizations for help.**
• Many national organizations have local branches that may be able to help with specific costs. The assistance might not be much, but every little bit can help.
• Examples of organizations include: churches, American Cancer Society, CancerCare, Salvation Army, and the United Way.
  o American Cancer Society: (800) 227-2345
  o CancerCare: (800) 813-HOPE (4673)
  o United Way: Dial 211 or visit www.211.org or www.unitedway.org.

10. If you realize you are going to be late making a payment, be sure to call your creditors as soon as you can and let them know of your situation.
• Some companies like your credit card or mortgage company might temporarily change your payment requirements or interest rate.

Managing My Health Insurance

Even with insurance, the cost of cancer is high and often requires lots of visits with primary care doctors and specialists for labs, tests, and treatment. Your insurance may not cover the cost of everything. You will also have out-of-pocket costs such as co-pays and deductibles that may build up. To stay on top of these, make sure you know what to expect ahead of time. Here are some tips for navigating your health insurance and the cost of cancer care:

Be familiar with your health insurance policy.

Learning about your health insurance can be a very daunting task. The best place to find out about your policy is through your health insurance company.

• If possible, see if your provider will assign to you a case manager. If not, ask to speak with the same representative each time you call. This will make communication easier for both you and the representative.
• If your insurance is through your employer, you can also contact your Human Resources representative with any questions.

Know what you are expected to pay.

Before you start treatment, take a look at your insurance plan and see what is covered and what additional costs you will need to pay.

• A portion of the costs will be out-of-pocket regardless of your insurance plan.
• See if there is an option to get this cost automatically taken out of your bank account or pay by check or with a credit card.
Most health insurance companies have a deductible. A deductible is the certain amount that you will have to pay before the insurance plan will start paying. Even with the deductible met, you may have to make co-payments.

Always look in advance into what your co-payment will be for each appointment and treatment.

**Make a budget.**

Use coverage, co-pay, and deductible information to make a budget for future treatments and doctor’s appointments. This is also a good way to plan your new budget and not be surprised by the additional costs.

- Use the “Budgeting Worksheets” provided at the end of the Handbook.

**Submit everything to your insurance company.**

Submit all of your medical expenses, regardless if you think your insurance company will cover it or not. The only way to get an expense covered is to submit it. It is better to ask and be turned down than spend unnecessary money out-of-pocket.

**Look for financial assistance.**

If you are still having trouble managing costs, look to financial assistance programs. Forms of assistance include co-pay as well as premium assistance and prescription assistance programs. All financial assistance is usually dependent on income and cancer type.

The Patient Advocate Foundation offers a co-pay assistance program. Call (800) 532-5274 to learn more.

**The Basics of Medicare**

Medicare is an insurance program run by the United States government. Medicare is for people who

- Are 65 years and older and are eligible for Social Security benefits
- Are receiving Social Security Disability Insurance and have completed a 2-year waiting period for Medicare
- Have Railroad Retirement/Disability benefits
- Have end-stage renal disease or Amyotrophic Lateral Sclerosis

Medicare has 4 types of possible coverage.
**Part A (Hospital Insurance):** Part A covers inpatient care. It is free for most Medicare recipients. The services covered by Part A include hospital care, skilled nursing facility care, nursing home care, hospice, and home health services.

**Part B (Medical Insurance):** Part B covers medically necessary services, meaning services or supplies that are needed to diagnose or treat your medical condition and meet accepted standards of medical practice. Part B also covers preventive services such as healthcare to prevent illness or detect it at an early stage when treatment is most likely to work best. These services include clinical research, ambulance services, durable medical equipment, mental health, second opinion, and limited outpatient prescription drugs. Part B of Medicare does come at a cost. In most cases, participants pay a premium of about $105 a month.

*Note: Part A and B usually cover 80% of costs for individuals, leaving 20% left for the individual to pay. (For example, if your bill is $4,000, Medicare would pay $3,200 and you would pay $800.) With this type of Medicare, there are Medigap programs to cover the additional 20%. These programs have a limited enrollment period; if that period is missed, you may lose access.*

**Part C (Medicare Advantage Plans):** Part C plans are offered through private companies approved by Medicare. These plans cover all the services provided by Medicare Part A and Part B. These plans vary depending on location and have their own set premiums, deductibles, and co-pays.

**Part D (Prescription Drugs):** Part D may be covered by your premium if your income is below a certain amount. Otherwise, you will pay according to your income (no more than $69.30 a month).

If the cost of Medicare is too much, look to Medicare.gov for options to help pay your costs. Medicare.gov is also a great resource to look up what is specifically covered by Medicare.

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**I Am Uninsured. What Are My Options?**

If you are uninsured or underinsured and have been diagnosed with cancer, you should know your options for health insurance and reduced-cost medical care.

**Medicaid:**

Medicaid is an insurance program for those who are low-income and meet the eligibility requirements. Medicare is funded by state and federal government.

- Eligibility depends on what state you live in because each state individually runs its own program.
• Visit your local government website or Department of Human Services for more information.
• Medicaid programs have strict rules about who can qualify. If someone in your household is able to work, you may not be able to receive Medicaid.
• Medicaid programs often include:
  o Children
  o Pregnant women
  o Social Security insurance recipients
  o People diagnosed with some cancer types
• Even if you are in one of the above categories, you will still need to qualify based on your income.
• Under the Affordable Care Act, many states expanded their Medicaid programs to include almost all adults with an income below 138% of the federal poverty limit. For example, if two people live in your household and have a combined income of less than $21,707, you may qualify.
• For the most up-to-date information on these expansions, visit healthcare.gov and the Kaiser Family Foundation at kff.org.

COBRA:
The Consolidated Omnibus Budget Reconciliation Act (COBRA) was created to allow some people to temporarily keep insurance coverage if there are changes in their employment. The program allows you to keep your former job’s insurance by paying the full price of the insurance to your employer (not the reduced rate you paid as an employee).

• Examples of employment changes include the following:
  o Being fired or laid off from your job
  o Voluntarily leaving your job
  o Having your hours reduced, making you ineligible for insurance
  o Having health insurance through a spouse’s job, and he or she died, or you are now divorced or separated
• COBRA is a very expensive option and may seem unaffordable, but COBRA can buy you some time. If you have cancer, your medical bills from being uninsured could be more than COBRA.
• If you are eligible but have not signed up for COBRA yet, you may be able to pay past premiums once you obtain COBRA coverage.

Affordable Care Act:
The Affordable Care Act (ACA) was signed into law in 2010. The ACA changed a lot of the laws of the U.S. healthcare system. The goal of the ACA was to increase the quality and affordability of healthcare in the U.S. As part of the ACA, people can sign up for health
insurance through the government-run healthcare marketplace if they do not have insurance through their employers or another source.

- Now that the March 31, 2014, enrollment deadline has passed, the only way to apply for coverage through the ACA marketplace is to see if you qualify for a special enrollment period.
- The enrollment period for 2015 will begin on November 15, 2014. In the meantime, you can look to healthcare.gov to see if you might qualify for a subsidy and what your deductible and premiums might be.
- Now that insurance companies can no longer disqualify individuals based on pre-existing conditions, the marketplace has multiple options that are great for those with a cancer diagnosis.
- If you are under 26 years old, you can still be on your parent’s health insurance plan.
- Your options through the marketplace depend on where you live. It is best to check the marketplace directly to see your individual options. Visit healthcare.gov for more information.

**Local Health Department and Local Free Clinics:**

- Look to local free clinics to get your medical treatment.
- You can also do a search of free clinics in your area at The National Association of Free & Charitable Clinics at www.nafccclinics.org/clinics/search.
- In addition to free clinics, there are approximately 170 healthcare facilities that still provide free or reduced cost services under the Hill Burton free and reduced cost healthcare law.
- You must apply at the admissions office of the participating hospital to determine if you meet eligibility requirements.
- For more information, visit the US Department of Health and Human Services at www.hrsa.gov.

**Finding Transportation**

Transportation to and from treatment can be difficult to find and maintain. Some first steps to finding reliable transportation include the following:

- Always begin by asking your healthcare team if your treatment center provides transportation assistance.
- Try calling your insurance provider. Some insurance plans also provide help with transportation to and from treatment.
If neither of these options is helpful, try some of these resources:

**The American Cancer Society's Road to Recovery**

The American Cancer Society offers a volunteer-run service called Road to Recovery. This service provides transportation to and from treatment for people who have cancer and do not have a ride or are unable to drive themselves. Because this service is run by volunteers who donate their time and use their own cars, the drivers cannot usually drive long distances. Call (800) 227-2345 to learn how to schedule a ride in your area.

**Public Transportation**

Bus systems and local public transportation are good options. Most public transportation systems have door-to-door service options for medically needy and handicapped individuals. Note, however, that your healthcare team may advise you not to use public transportation if you have a weakened immune system.

**Financial Assistance to Cover Gas Costs**

If you are able to drive and have to travel a long distance, you may be able to find financial assistance to cover the gas costs of transporting yourself. There are multiple resources for this assistance including the American Cancer Society, CancerCare, and Grind for Life. These resources can provide a limited amount of financial assistance for the cost of gas or other costs of travelling, such as bus passes or the cost of medical transport. Also check with your treatment center. Sometimes local organizations provide gas cards directly to treatment centers to distribute.

You can contact the organizations listed above using the following information:

- American Cancer Society: (800) 227-2345 or cancer.org.
- CancerCare: (800) 813-HOPE (4673) or www.cancercare.org.
- Grind for Life: (561) 252-3839 or www.grindforlife.org.

**Free or Reduced-Cost Flights**

Sometimes getting to treatment also includes having to fly for treatment. Angel Flight is an organization that provides free air transportation for medically necessary trips. They are a nonprofit of pilots and volunteers. You can contact Angel Flight by calling (918) 749-8992 or visiting www.angelflight.com.
Finding Lodging

A cancer diagnosis may require you to travel for doctor appointments and treatment. Some forms of treatment require you to visit a treatment center for multiple days in a row for weeks at a time. There are a couple of options to consider when having to make these kinds of extensive trips.

Checking with Your Treatment Center

If you need assistance finding or paying for lodging, tell your healthcare team as soon as possible. Some treatment centers have lodging coordinators especially if the center treats a lot of patients from out of town. Treatment centers may also have their own lodging such as a hospitality house. Ask your healthcare team if your treatment center has resources to help with lodging.

American Cancer Society’s Hope Lodge

The American Cancer Society (ACS) sponsors Hope Lodges in most major cities throughout the country. It is free to stay at all the Hope Lodge locations. If you have an ACS Hope Lodge in your area, your oncology nurse or social worker should be able to help with the application process. This resource is not for those who are homeless. ACS will check to make sure you have somewhere to stay once you have checked out. To contact the American Cancer Society, call (800) 227-2345 or visit www.cancer.org.

Hotels with Medical Rates

For discount lodging, hotels with medical rates are a great option. Most major hotel chains offer medical rates for those who are travelling for medical treatment. Make sure you book your rooms in advance. The hotel may require proof from your doctor that you are traveling for medical reasons.

Joe’s House

The nonprofit Joe’s House provides an online nationwide database of places that offer lodging for cancer patients. Check out their website to determine options in your area. You can search by state, city, and even treatment center. The search results include nonprofit lodging as well as hotels that provide medical discounts. Visit Joe’s House at www.joeshouse.org.

What Do I Need To Know About Social Security Disability Benefits and Cancer?

Do you have a cancer diagnosis? Are you no longer able to work? You may qualify for Social Security Disability benefits.
The Social Security Administration (SSA) offers financial assistance in the form of Social Security Disability benefits. A cancer diagnosis does not automatically make you eligible for SSA benefits. You have to apply. Here is what you need to know about Social Security Disability benefits and cancer:

- Social Security Administration (SSA) and Social Security Disability benefits
  - To qualify, you must meet the SSA’s definition of disability.
    - A cancer diagnosis does not automatically meet the SSA’s definition of disability.
    - The SSA processes cancer disability claims on a case by case basis.
    - You must prove you cannot work for at least one year because of your diagnosis.
    - You need proof from your doctor that you cannot work.
    - People who have stem cell or bone marrow transplants automatically meet the definition.
  - In cases of advanced stage cancer, you may qualify for “Compassionate Allowance.”
    - This allows applicants to qualify for benefits in as little as ten days.
  - Apply as soon as possible. The SAA denies most disability claims at first. You can appeal the decision.
  - You can fill out the forms online at http://www.ssa.gov/ or at your local Social Security Office.

The SSA offers two types of disability programs.

1. Social Security Disability Insurance (SSDI)
   - You must have worked jobs in which you paid Social Security taxes.
   - You must meet the SSA’s definition of disability.
   - People approved for SSDI are eligible for Medicare after a two year waiting period.
   - SSDI is not health insurance.

2. Supplemental Security Income (SSI)
   - SSI is a needs-based program. You must prove your income and assets are below the limit.
   - You do not need work credits to qualify.
   - You must meet the SSA’s definition of disability.
   - SSI is also available for individuals over 65 without a disability who meet the financial need requirement.
   - People approved for SSI automatically qualify for Medicaid.
   - In some cases, you may qualify for both SSDI and SSI.
   - SSI is not health insurance.

To check your eligibility for all SSA programs, use the Benefit Eligibility Screening Tool (BEST) at http://www.benefits.gov/ssa. Based on your answers, this tool lists benefits you may be eligible to receive. This tool does not guarantee approval.

For more information you can also call the Social Security Administration at (800) 772-1213.
Advanced Directives

Advanced directives or an advance care plan are legal papers. These papers tell your family and healthcare team your medical wishes. They are used in case you cannot make a medical decision. For example, if you are unconscious, your healthcare team and family will follow your advanced directives.

Advanced directives may differ by state. Your hospital or treatment center can give you the forms. Be sure to give your family members and healthcare team a copy of your advanced directives. If you change your mind about the kind of treatment you prefer, you can change your advanced directives.

Advanced directives may include living wills, medical power of attorney, or DNR orders. Here is a list of things to consider for your advance care plan:

- Life support or use of equipment such as dialysis machines, ventilators, and respirators
- DNR (Do Not Resuscitate)
  - DNR orders tell your healthcare team not to do CPR if your heart or breathing stops.
    - CPR (cardiopulmonary resuscitation)
      - First aid used when your heart or breathing stops. CPR can include chest compressions, electric shock, or medication.
- DNI (Do Not Intubate) orders
  - DNI orders tell your healthcare team not to put a tube through your nose or mouth to help you breathe.
- Artificial nutrition and hydration
  - If you are unable to eat or drink, your healthcare team will provide you with nutrition and fluids through an IV or feeding tube.
- Treatment of new conditions
- Organ and tissue donation
- Medical Power of Attorney
  - Medical power of attorney lets you name another person, such as a family member or close friend, who can make decisions about your medical care if you cannot.
  - This may also be called a healthcare proxy, appointment of healthcare agent, or durable power of attorney.
  - Most states will not allow anyone on your healthcare team to be your medical power of attorney.

A cancer diagnosis can be a stressful time. It may be scary to consider these issues before you are very sick. However, it is important to think about these issues early. You will not want to deal with them when you are feeling very ill.

My Advanced Directives

Check the following items that apply to you:

___ Advanced Directives, a Living Will, or a Five Wishes Document.
Medical Power of Attorney (Durable Power of Attorney for Healthcare)

DNR Statement (May be part of advanced directives or living will.)

My healthcare team has a copy of these records.

My caregiver has a copy of these records.

Paperwork has been notarized (if required).

The original copies are located: ________________________________

Although these legal documents are important, no legal documents replace the importance of talking with your family about your last wishes. Make sure your family members are aware of your requests and where to find the original paperwork.

Palliative and Hospice Care

At some point in your cancer journey, you may need to consider palliative care or hospice. Palliative care is a treatment that helps relieve pain and symptoms but does not provide a cure. Palliative care can be used along with your prescribed cancer treatment. Hospice is a type of palliative care. Specifically, hospice is end-of-life care. Both palliative care and hospice aim to improve quality of life. Talk with your healthcare team about what is best for you. Below you will find more information about hospice and palliative care. Use the questions at the end to guide talks with your healthcare team.

- **Palliative care**
  - Palliative care helps relieve pain and symptoms but does not provide a cure.
  - You may use palliative care at any point during your cancer journey. A patient does not have to be terminal to receive palliative care.
  - Palliative care can be combined with other forms of treatment.
  - You may use palliative care to manage side effects from treatment.
  - Some forms of palliative care may be covered by Medicare, Medicaid, or other insurance plans. Often, costs for palliative care fall on the individual.

- **Hospice**
  - Hospice is a type of palliative care.
  - Hospice is end-of-life care. Terminal patients with a life expectancy of six months or less often use hospice.
  - Hospice care is not usually given at the same time as other curative treatments. Hospice is given after treatment options have been exhausted.
  - Medicare pays for all hospice costs. In most states, Medicaid pays for hospice costs. Most other insurance plans have hospice benefits.

- **Questions to Ask Your Healthcare Team**
  - Should I consider palliative care now or in the near future?
  - Will my insurance cover my palliative care?
How long can I get palliative care?
Where will I get my palliative care?
Can I still do treatment for my illness while doing palliative care?
Should I consider hospice care now or in the near future?
Will insurance cover my hospice care?
If my life expectancy is longer than six months, can I still get hospice care?
Can I get hospice care in my home?
Who will be caring for me? Will they be doctors, nurses, social workers, or home health aides?
What legal issues such as advanced directives, living wills, or medical power of attorney should I think about?

Emotional Support Programs

A cancer diagnosis can make you feel anxious and depressed. This is normal. It may help to talk to someone. It can be especially helpful to connect with other patients and survivors. You are not alone in your fight. You may find it helpful and inspirational to hear others’ stories. You may also be able to help someone else by sharing your story. Here is some information about available emotional support:

- **Support groups**
  - Connects you with a group of people in a similar situation
  - Support groups meet on a regular basis.
  - Support groups meet online, over the phone, or face-to-face.
  - Ask your healthcare team about local support groups.
  - Licensed social workers or other medical professionals facilitate most support groups.
  - Support groups can be for current cancer patients, survivors, or family members.
  - Some groups are defined by diagnosis, age, or sex.
  - A support group is meant to help you through your cancer journey. The first support group you go to may not be the right fit for you. If you do not enjoy the first group, try another.
  - Where can you find support groups?
    - Your hospital or treatment center
    - Your local American Cancer Society chapter
      - Visit cancer.org or call (800) 227-2345.
    - Cancer Support Community
      - This includes The Wellness Community and Gilda’s Club.
      - Visit cancersupportcommunity.org or call (888) 793-9355.
    - CancerCare
      - Visit cancercare.org or call (800) 813- HOPE (4673).

- **Connect with a Fellow Survivor**
  - One-on-one partnering programs will match you with a fellow cancer survivor. This person may have a similar diagnosis and may be finished with treatment.
These allow for a more personal connection.
Most programs are for family members as well as patients.
Usually these programs are run through phone or email.
How can you connect with a fellow survivor?
- Imerman Angels
  - Visit imermanangels.org or call (877) 274-5529.
- Cancer Hope Network
  - Visit cancerhopenetwork.org or call (800) 552-4366.
- American Cancer Society’s Reach To Recovery Program
  - Visit cancer.org or call (800) 227-2345.

- **Individual Counseling from a Medical Professional**
  - If you find it difficult to function in your daily life because of anxiety or depression, you may need individual counseling from a medical professional.
    - Ask your healthcare team for a recommendation.
    - Visit CancerCare’s website for more information, or call 800-813-HOPE.
Even after treatment ends, your cancer journey continues. Many cancer survivors refer to the time after treatment ends as the “new normal.” It may take you a while to readjust to life after treatment. You may wish to make changes in your nutrition and lifestyle to help prevent recurrence. Use these sections to help you navigate your “new normal” and to promote wellness during survivorship.

Screening Recommendations and Follow-Up Care

Follow-up care after completing breast cancer treatment is very important. Your healthcare team will help you manage long term side effects and watch for any changes such as the cancer occurring in the other breast, spreading, or coming back. Here are some things to remember about follow-up care:

- **Continue your monthly breast self-exams.**
  - If you had surgery (mastectomy, lumpectomy, or reconstruction), wait until the area has completely healed from surgery.
  - If you are having radiation, resume your self-exams after completion of treatments.
  - Look at your breasts for differences in your breast tissue or your nipples. Report any changes to your healthcare team.

- **Always go to your follow-up appointments.**
  - You will probably have follow up exams following treatment depending on the stage of your cancer. If you have any symptoms or changes, contact your healthcare team immediately. A typical schedule could be:
    - Every 3-6 months until you are 3 years past treatment
    - Every 6-12 months from 4-5 years past treatment
    - Once a year if you are 6 years or more past treatment
  - If you notice any changes in your health, always let your healthcare team know.

- **Follow your recommended breast screening schedule.**
  - Your screening schedule will depend on the stage of your cancer and other aspects of your medical history. Your healthcare team will decide what type of screening is best for you: mammogram, mammogram ultrasound, tomosynthesis, breast MRI, or PET scan.

- **Speak to registered dietitian about nutrition.**
  - Maintaining good nutrition after breast cancer treatment can be difficult.
  - Especially if your treatment affected your body’s hormone production, you may need to watch for weight gain.
• If you change your primary care physician, make sure your new doctor has all your medical records and history.
• Tell your doctor about any side effects.
  o Some side effects occur after treatment ends. Let you healthcare team know of any and all changes so they can help you manage them effectively.
• Keep your health insurance if at all possible.
  o Follow-up care, especially imaging, can be very expensive if you do not have health insurance.

Nutrition Guidelines for Breast Cancer Survivors

Eat at least 7 servings of fruits and vegetables (preferably fresh) per day.

Fruits and vegetables contain phytochemicals and antioxidants. It is important to introduce a wide variety of colors in to the body. Each color contains different phytochemicals that serve different purposes but they all have cancer fighting properties. Examples of antioxidants are vitamins A, C, and E. These fight against substances in the body called free radicals which may lead to cancer cell production. A serving of vegetables is a whole cup if raw or a ½ cup when cooked. A serving of fruit is about the size of a baseball if whole, ½ cup if canned or frozen.

Keep meat to a minimum.

Move toward a more plant-based diet including non-meat sources of protein such as beans. Limit red meat to no more than 18 ounces per week. For reference, 3 ounces of meat is about the size of a deck of cards. Red meat includes beef, pork, and lamb. Eat lean meats such as organic chicken and fresh fish (not farm raised). Limit processed meats such as hot dogs, bacon, sausage, and lunch meats. Select natural and uncured, nitrite-free versions of processed meats.

Eat beans.

Beans are a healthy, inexpensive alternative to meat. Beans are an excellent source of complex carbohydrates and fiber. They may reduce risk for breast cancer recurrence due to their fiber content. The fiber binds to circulating hormones and the excess hormones are ultimately excreted in the stool. Choose kidney, pinto, navy, cannellini, chick peas, etc. Introduce beans slowly into your diet to give the gastrointestinal tract time to adapt to the increased fiber.

Eat 3-6 servings of whole grains every day.
Select whole grains like oats, wheat, brown rice, and whole grain pasta. Whole grains are digested slowly due to their high fiber content, providing sustained energy. Choose grain products that have whole wheat or a whole grain flour listed as one of the first 3 ingredients. Avoid highly processed and refined grains (white enriched flour, baked goods, snack foods, sweets). A serving of whole grain is one slice of bread, ½ cup of cooked rice or pasta, and ½ cup of whole grain cold cereals and oatmeal.

**Eat 1-2 servings of low-fat dairy products every day.**

Low-fat dairy products include those made with reduced fat milk such as 1% or skim milk, low fat yogurt, 2% cheese or low fat kefir. Choose yogurt that is lower in sugar, not sweetened with artificial sweeteners, and that has active yogurt cultures listed on the label. Greek yogurt is naturally higher in protein and often contains less sugar than some other regular yogurts.

**Limit excess sugar.**

Sugar provides the body with excess calories without any nutrients. It also causes the body to produce more insulin. Higher levels of insulin circulating in the blood may increase risk for breast cancer recurrence. Excess sugar can also be problematic when attempting to achieve a healthy body weight. Try to choose a healthy sweet food such as fruit to satisfy cravings for sweets.

**Avoid artificial sweeteners.**

Artificial sweeteners are chemically based sweeteners including sucralose, acesulfame potassium, aspartame, and saccharin. Due the lack of research on these chemicals and their relationship to cancer, it is better to avoid them completely. A good alternative is a natural, plant-based sweetener called Stevia.

**Drink water and green tea.**

The human body is about 60% water. Every organ and organ system needs water to function optimally. Water is needed to transport nutrients to cells and to get rid of toxins from the organs. Water also helps to keep the environment of ears, nose, and throat moist. An easy starting point is to strive to drink eight 8 ounce glasses of fluid per day. Green tea and white tea are other good choices for beverages. Drink unsweetened green tea and limit calories from other beverages. Save calories for good whole foods especially when striving to reach a healthy body weight.

**Incorporate omega-3 fatty acids into your diet.**

Omega-3 fatty acids are found in fatty fish including salmon, albacore tuna, halibut, mackerel, lake trout, sardines, and herring. They are also found in walnuts, flaxseed, tofu, and soybeans. Omega-3 fatty acids have anti-inflammatory qualities. Reducing inflammation in the
body reduces risk for cancer recurrence as well as improves cardiovascular health. A fish oil supplement is recommended if food sources of omega-3 fatty acids are not regularly consumed. Consult a registered dietitian for the recommendation of a fish oil supplement.

**Have your vitamin D level checked.**

It is possible to be vitamin D deficient and not know. A simple blood test can determine the level of vitamin in your bloodstream. Although the research is inconclusive about the relationship between breast cancer and vitamin D level, it is still a good idea to make sure that your body has adequate vitamin D. Vitamin D helps to reduce inflammation, aids in the absorption of calcium, improves muscle strength, and boosts the immune system.

**Reduce or eliminate alcohol.**

Alcohol intake is a known risk factor for several types of cancer including breast cancer. If alcohol is consumed at all, it is best to limit it to no more than one drink per day for women and 2 drinks for men.

**Achieve and maintain a healthy body weight.**

Carrying extra weight is a risk factor for breast cancer recurrence. Excess body fat plays a role in hormone production which can lead to tumor growth. Lose weight by eating modest portions of healthy food combined with regular exercise. Begin keeping a food and exercise journal. Consult a registered dietitian for a specific calorie range.

A good reference can be found at www.aicr.org. It is called “The New American Plate” and is designed specifically for eating for cancer prevention.

**Move toward an active lifestyle.**

Exercise is vital to a healthy lifestyle. For breast cancer survivors it is the key to losing and maintaining weight. During treatment it is not uncommon to become more sedentary and as a result lose lean body mass (muscle). Hormonal changes also contribute to increased body fat and decreased muscle. Begin slowly and incorporate a combination of strength training, cardiovascular exercise, and flexibility/stretching. Sometimes there are support groups for survivors that make a point to exercise as a group. Having a friend, instructor, or trainer as an extra motivator is often helpful.

**Learn to relax.**

Stress increases inflammation in the body. Learning to manage stress effectively can greatly reduce this inflammation. For some people, exercise may be relaxing and for others a good deep tissue massage is relaxing. The key is finding what is relaxing to you. If you are finding it difficult to relax you may try progressive muscle relaxation, prayer, meditation, or imagery. Some support groups may focus on these as a group.
Fear of Recurrence

Many believe that once treatment ends, the cancer journey is over, but that’s not the case. Many cancer survivors struggle with the fear of recurrence. What if my cancer comes back? What if my cancer spreads? For some, these fears can become overwhelming even years into remission. These fears are completely normal, but there are things you can do to try to manage them.

Take charge of what you can.
You may feel afraid because of the lack of control you have over the situation. To take back some control in your life, try making positive changes.

- Talk to a registered dietitian about developing a survivorship nutrition plan. Good nutrition can reduce your chance of recurrence and make you healthier all around.
- Start an exercise program. Exercising is not only good for your body; it is also good for your mind. Exercising releases endorphins, natural chemicals that make you feel happier. Many people also say exercising helps clear their minds and lower stress. Always talk to your doctor before starting any exercise program.
- Stay on top of your screenings and checkups. At the end of your treatment, work out a screening and checkup plan with your oncologist. What kind of scans or tests do you need? How often do you need them?

Take a deep breath.
If you feel yourself starting to get worked up, close your eyes, take a deep breath, and count to ten. This may seem like silly or old advice, but taking a second to gather your thoughts can make you feel a lot better.

Try meditation or visualization. Find a quiet, comfortable spot in your home. Take a few moments to yourself to breathe deeply and reflect on the positive things in your life. Think about some of your goals, even simple ones, and imagine yourself reaching them. In the rush of everyday activities, we sometimes forget to just breathe.

Find a hobby.
Hobbies can be a great source of entertainment and can also take your mind off of negative things. Try one of the hobbies listed below or make up one of your own. Find something that you enjoy and are passionate about.

- Knitting
- Cooking
- Painting
- Hiking
- Photography
- Writing
- Yoga
Volunteer.
Volunteering can be a worthwhile way to pass your free time and make a difference in your community. Is there a cause you are passionate about? Education, the environment, animals. To find a variety of volunteer opportunities in your neighborhood, visit VolunteerMatch.org, Volunteer.gov, or the American Cancer Society at cancer.org.

A quick word of caution: For some, volunteering for a cancer support organization may hit too close to home. Consider how it may affect you to be in this environment with constant reminders of your experience. You need to do what is best for you. If you are unsure how it may affect you, volunteer once before committing more time.

Talk about it.
You may find it helpful to talk to someone. It can be especially comforting to connect with other survivors. Hearing other survivors’ stories can show you what you are feeling is normal, and you are not alone. You may also be able to help someone else by sharing your story. Here are some options for connecting with other survivors:

- **Support Groups**
  - Cancer Support Community hosts support groups around the country.
  - Visit cancersupportcommunity.org or call (888) 793-9355.
- **Ask your healthcare team about other groups in your area or at your hospital.**
- **One-on-One Partnering Organizations**
  - These organizations connect you with a fellow survivor. Usually the connections happen via phone.
- **Imerman Angels**
  - Visit imermanangels.org or call (877) 274-5529.
- **Cancer Hope Network**
  - Visit cancercopenhopenetwork.org or call (800) 552-4366.
- **Survivor Retreats**
  - Epic Experience offers outdoor adventure retreats to adults with a past cancer diagnosis. Activities are based on the season.
  - Visit epicexperience.org or call (855) 650-9907.
- **First Descents hosts retreats for young adults (18-39) to learn to rock climb, kayak, or surf.**
  - Visit firstdescents.org or call (303) 945-2490.

Educate yourself.
Knowledge is power. Talk to your oncologist about your fear of recurrence. Here are some questions to ask:

- What are my chances of recurrence?
- What can I do to lower my risk?
- What signs do I need to look for to know if my cancer has returned?
Armed with the answers to these questions you can better understand your situation and minimize fear of the unknown.

If you do face a recurrence, remember that every survivor’s situation is different. With clinical trials and new medications, there may be many treatment options available. Not all recurrences are equal.

Know what triggers your emotions, and avoid it.
Do movies or TV shows that address cancer upset you? Don’t watch them. Does the sight of the sweatshirt you wore on treatment days bother you? Throw it out or donate to a clothing bank. Do you get especially anxious around scan days? Ask a friend to go to lunch with you.

If you can identify the objects or activities that trigger negative feelings, you can make a special effort to avoid them.

Don’t dismiss your fear.
It is normal and understandable to fear recurrence. A cancer diagnosis is a scary thing. If you’ve already been through treatment, you know how difficult it can be. Don’t be too hard on yourself. It is okay to be scared. It is okay to be upset. Admitting your feelings can be an important first step to managing your emotions.

Remember what works for other people may not work for you. Try a few different things. Once you find an activity that makes you feel at ease, be sure to include it in your schedule. Take time for yourself.

If your fear of recurrence becomes overwhelming or interferes with your day-to-day activity, talk to your doctor. You may need individual counseling from a medical professional. Your doctor can make a recommendation for you.

Immunizations for Cancer Survivors

What are immunizations?
Immunizations help your body build a resistance to specific diseases. Most immunizations work by introducing a small, safe amount of the disease to your immune system. This way if you are ever exposed to the disease, your body’s immune system already knows how to fight it. Most immunizations are vaccines given as a shot or series of shots.

Many people receive one-time immunizations when they are children for diseases such as chickenpox. Some immunizations, such as tetanus shots, need boosters to keep them effective. Other immunizations, such as flu vaccines, need to be received annually.

What are the risks of vaccines?
As with any treatment or medication, vaccines can cause side effects. Each vaccine carries risk for different side effects. Most side effects are minor such as pain where you receive the shot and mild fever. There are risks for serious side effects, but vaccines are carefully tested for safety. In most cases, the great benefits of vaccines outweigh the minor risks. To learn more, visit the Centers for Disease Control and Prevention (CDC) at www.cdc.gov. Talk to
your healthcare team about the risks and benefits of vaccines to determine what is best for you.

I’m a cancer survivor; what immunizations do I need?
For cancer survivors, immunizations are especially important because cancer treatments weaken the body’s immune system. Below is the immunizations schedule recommended by the CDC for people with weakened immune systems, such as cancer survivors.

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>Influenza (flu)</td>
<td>Annually</td>
</tr>
<tr>
<td>Tetanus, diphtheria, pertussis (Td/Tdap)</td>
<td>One Tdap vaccine with Td booster every 10 years.</td>
</tr>
<tr>
<td>Varicella (chickenpox)*</td>
<td>Should NOT get vaccine**</td>
</tr>
<tr>
<td>HPV vaccine (women and men)*</td>
<td>3 doses through age 26</td>
</tr>
<tr>
<td>Zoster (shingles)</td>
<td>Should NOT get vaccine**</td>
</tr>
<tr>
<td>Measles, mumps, rubella (MMR)*</td>
<td>Should NOT get vaccine**</td>
</tr>
<tr>
<td>Pneumococcal (PCV13)</td>
<td>1 dose</td>
</tr>
<tr>
<td>Pneumococcal (PPSV23)</td>
<td>1 or 2 doses</td>
</tr>
<tr>
<td>Meningococcal</td>
<td>1 or more doses</td>
</tr>
<tr>
<td>Hepatitis A*</td>
<td>2 doses</td>
</tr>
<tr>
<td>Hepatitis B*</td>
<td>3 doses</td>
</tr>
</tbody>
</table>

Source: Center for Disease Control

* These vaccines are only for adults who did not get them as children.

** If you received these vaccines before your cancer diagnosis, there is no harm done. In fact, it is good that you are protected from these diseases. If you have not received these vaccines, it is not safe to receive them with a weakened immune system.

If you are planning to travel outside of the United States, check the recommended vaccines for where you are going. You may need additional immunizations.

Always consult with your oncologist before receiving any vaccine.

Use the “My Immunization Record” in the back of The Handbook to keep track of your vaccines and immunizations.

What else do cancer survivors need to know about immunizations?

Influenza (Flu)
If you are a cancer survivor, the CDC recommends getting the annual flu vaccine. However, only get the flu shot; do NOT get the nasal spray version. The nasal spray version contains live viruses so it is not safe for people with a compromised immune system.
Caregivers or anyone living with a cancer survivor should also receive the flu vaccine to lower the risk of infection.

**Pneumococcal**

There are two pneumococcal vaccines: PVV13 and PPSV23. For cancer survivors, doses of each may be needed. Ask your healthcare team about the best pneumococcal schedule for you.

**Meningococcal, Hepatitis A and B**

These vaccines are recommended for adults with certain jobs, lifestyles, or other health factors that increase their risk of these diseases. Your healthcare team can tell you if you are at a higher risk.

**Varicella, Zoster, and MMR**

As shown in the chart above, people with a compromised immune system, such as cancer survivors currently or recently out of treatment, should NOT receive these vaccines.

**Smoking Cessation**

**Why is smoking bad?**

Smoking increases your risk for heart disease, stroke, and emphysema. Smoking also increases your risk for a number of cancers, including:

- Lung
- Oral
- Nasal and Paranasal
- Throat
- Esophageal
- Bladder
- Kidney
- Pancreatic
- Ovarian
- Cervical
- Colorectal
- Stomach

If you already have a cancer diagnosis, smoking can increase your risk of recurrence.

**Why should I quit?**

Quitting smoking has almost immediate benefits. Here are some of the benefits of quitting smoking:
<table>
<thead>
<tr>
<th>Time Since Quitting</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 minutes</td>
<td>Blood pressure and heart rate drop</td>
</tr>
<tr>
<td>12 hours</td>
<td>CO2 levels in blood stream return to normal*</td>
</tr>
<tr>
<td>3 months – 9 months</td>
<td>Circulation and lung function improve</td>
</tr>
<tr>
<td>1 year</td>
<td>Risk of heart disease cut in half</td>
</tr>
<tr>
<td>5 years</td>
<td>Risk of mouth, throat, esophageal, and bladder cancer cut in half</td>
</tr>
<tr>
<td>10 years</td>
<td>One-half as likely to die from lung cancer, and risk of laryngeal and pancreatic cancer decreases</td>
</tr>
<tr>
<td>15 years</td>
<td>Risk of heart disease is the same as a non-smoker’s</td>
</tr>
</tbody>
</table>

Source: smokefree.gov

*If the CO2 (carbon dioxide) levels in your bloodstream are high, your lungs have to work harder to return these levels to normal. When you exhale, CO2 leaves your body.

**How can I quit?**

The first step is to talk to your healthcare team about the best quitting strategies for you.

With smoking, your body builds up a dependency on nicotine, a chemical found in tobacco. As you quit smoking, your body will go through withdrawals from nicotine. Some common symptoms and side effects of withdrawal include:

- Cravings
- Feelings of sadness
- Stress and anxiety
- Difficulty sleeping
- Restlessness
- Weight gain

Here are some tips to help you manage the side effects of withdrawal:

- With your doctor’s permission, you may wish to use nicotine replacement therapies (NRT).
  - NRTs give you a small, decreasing dose of nicotine without smoking to help you wean yourself off nicotine and minimize withdrawal symptoms.
  - NRTs come in many forms such as gum, lozenges, inhalers, and patches.
  - Some NRTs are available without a prescription, but always talk to your healthcare team first.
• Other prescription medications are also available to help you quit. Ask your doctor if these may be right for you.

• Tell your friends and family that you are trying to quit.
  o They can support you and hold you accountable.
  o Ask a friend or family member you trust to be your “sponsor.” If you feel the urge to smoke, you can call them to talk until the craving passes.
  o If your friends or family members smoke, ask them not to smoke around you and not to offer you cigarettes. This will only make achieving your goal harder.

• Join a support group or online support group to connect with other people trying to quit.

• Change your routine.
  o For example, if you always have a cigarette with your coffee, find a new morning routine. Try watching the news with your coffee, or replace your cigarette with a healthy snack.

• Know your triggers and have a plan.
  o What triggers your cravings—stress, food, other people smoking?
  o Avoid triggers if at all possible.
  o If you encounter a trigger, have a plan to keep yourself from smoking such as chewing gum, counting to 10, or calling a friend.

• If you have a setback, don’t be too hard on yourself. Get back on track as soon as possible. However, do not use a slip as an excuse to start smoking regularly again.

• Do not use other tobacco products or e-cigarettes as a replacement for smoking.
  o Other tobacco products can also increase your risk for cancer and diseases.
  o E-cigarettes have not been studied enough to know their safety. The chemicals inhaled with e-cigarette use may have their own risks.

Resources for Quitting

Smokefree.gov

Call (800) Quit-Now to connect with your state’s helpline.
The following worksheets can help you organize your life and keep track of all your information during your cancer journey. If you visit, My PearlPoint at my.pearlpoint.org and sign up for a personalized dashboard, you can print as many worksheets as you need.

- My Diagnosis
- Questions for Your Healthcare Team
- My Medical History
- Immunizations Record
- Appointment Notes
- My Healthcare Team Contact List
- Treatments and Side Effects Logs
- Laboratory Flow Sheet
- Drain Bulb Record
- Budgeting Worksheets
- Calendars
My Diagnosis

Your healthcare team will give you details about your diagnosis. Ask your nurse navigator to fill out this worksheet to help you better understand your diagnosis.

*Note: Some questions do not apply to some cancers.*

Tumor location: Draw the location of the tumor.
Tumor size: Tumor size is the largest dimension of the tumor. Use these images to understand the size of your tumor. What is the size of your tumor?

What type of breast cancer do I have?

What is the grade of the cancer?

- 1
- 2
- 3

What is my hormone receptor status?

- ER- positive
- ER negative
- PR-positive
- PR-negative

What is my HER2/ neu status?

- Positive
- Negative

Are any of my lymph nodes involved? If so, how many?
What is the stage of the cancer?

Are there any metastasis?

Other information:
Questions for Your Healthcare Team

When you are diagnosed with cancer, you may feel overwhelmed with information. Ask your oncologist the following questions to make sure you have the answers you need.

What is my diagnosis?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

What stage is my cancer? What is my prognosis?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

What are my treatment options? What would you recommend?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Am I eligible for a clinical trial?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

What are the long-term and short-term side effects of treatment? How will these affect my normal activities?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

How can I manage these side effects?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

How can I keep myself as healthy as possible during treatment?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Will I be able to have children? What are my options to preserve fertility?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

Where can I find help with financial concerns?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

Where can I find help with lodging or transportation?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

What will my follow-up care plan include?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
My Medical History

Your healthcare team will need to know your medical history so they can determine the care that is best for you. They may have specific forms for you, but this form will help you collect basic information you will need before your appointments.

Basic Information

Name:
Birthdate:
Phone Number(s):
Address:

Social Security Number:
Employer:
Spouse's Name:
Spouse's Phone Number:
Emergency Contact:
Emergency Contact’s Phone Number(s):

Primary Care Physician

Primary Care Physician:
Practice:
Phone Number:
Address:
My Medical History (continued)

Past Medical History

In the past, have you been diagnosed with any of the following?
Circle all that apply.

Anemia  Arthritis  Asthma  Blood Clots  Cancer  Colitis  Concussions  Depression  Diabetes  Heart Disease  Hepatitis  High Blood Pressure  High Cholesterol  HIV/AIDS  Impaired Mobility  Irritable Bowel Syndrome  Kidney Disease  Liver Disease  Lung Disease  Migraines  Other STDs  Urinary Tract Infections  Other______________

List any past surgeries, imaging, hospitalizations, or other major procedures you’ve had in the past.

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Description</th>
<th>Date</th>
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</tbody>
</table>
My Medical History (continued)

Family Medical History

Has anyone in your family experienced any of the following? If so, who?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Relation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td></td>
</tr>
<tr>
<td>Blood Clots</td>
<td></td>
</tr>
<tr>
<td>Cancer (List Cancer Type)</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
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<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Heart Disease</td>
<td></td>
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<tr>
<td>High Blood Pressure</td>
<td></td>
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<tr>
<td>High Cholesterol</td>
<td></td>
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<tr>
<td>Blood Clots</td>
<td></td>
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<tr>
<td>Low Blood Pressure</td>
<td></td>
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<tr>
<td>Kidney Disease</td>
<td></td>
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<tr>
<td>Lung Disease</td>
<td></td>
</tr>
<tr>
<td>Irritable Bowel Syndrome</td>
<td></td>
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<tr>
<td>Liver Disease</td>
<td></td>
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<tr>
<td>Colitis</td>
<td></td>
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<tr>
<td>AIDS/HIV</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
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<tr>
<td>Other</td>
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</tr>
</tbody>
</table>

Do you know any other pertinent family medical history?

___________________________________________________________________________
___________________________________________________________________________
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___________________________________________________________________________
My Medical History (continued)

Current Medications and Allergies

Please list all current medications, including any vitamins, supplements, or over-the-counter medications.

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Dosage and Time</th>
<th>Reason Taken</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

List all allergies.

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
My Medical History (continued)

Current Issues

Are you experiencing any of the following? Circle all that apply.

- Bloating
- Constipation
- Diarrhea
- Dry Mouth
- Fatigue
- Gas
- High Blood Sugar
- Nausea
- Pain
- Unable to Sleep
- Vomiting
- Weight Gain
- Weight Loss
- Other__________________

Please describe any problems you are having.
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

Are you able to go about daily activities normally?  Yes or No

Do you feel like your normal self?  Yes or No

What questions do you have for the doctor?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
My Medical History (continued)

Insurance Information

Be sure to take all insurance and prescription cards with you to your appointment.

Insurance Provider:
Policy/ Group #:
Policy Holder’s Name:
Patient’s Relation to Insured:

Secondary Insurance Provider:
Account Number:
Policy Holder’s Name:
Patient’s Relation to Insured:
My Immunization Record

For cancer patients, immunizations are especially important because cancer treatments weaken the body’s immune system. Immunizations help your body build a resistance to specific diseases. Most immunizations work by introducing a small, safe amount of the disease to your immune system. This way if you are ever exposed to the disease, your body’s immune system already knows how to fight it. Ask your healthcare team which immunizations you need. Use this chart to keep track of your immunization record.

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Date Given</th>
<th>Next Date Due</th>
<th>Comments/Reactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetanus</td>
<td></td>
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<tr>
<td>Diphtheria</td>
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<tr>
<td>Pneumococcal Influenza</td>
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<td></td>
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<tr>
<td>MMR</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Hepatitis B</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Hepatitis A</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Influenza (Flu)</td>
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<td></td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Other</td>
<td></td>
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</tbody>
</table>
Appointment Notes

Take notes on all the new information your healthcare team provides at appointments. Write down any new instructions, medications, treatment plans, etc., so you can reference them later.

Date: _______________   Doctor: __________________

Questions:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Notes:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Plan:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

List lab work, imaging, or other tests.

<table>
<thead>
<tr>
<th>Test &amp; Date</th>
<th>Purpose</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
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<tr>
<td>Test:</td>
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<td>Date:</td>
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<td></td>
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<tr>
<td>Test:</td>
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<td></td>
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<tr>
<td>Date:</td>
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</tbody>
</table>

Next Appointment: ______________________________________________________________
# My Healthcare Team Contact List

Your healthcare team may include many different doctors, nurses, and specialists. Keep all your important contact information in one easy-to-find place.

<table>
<thead>
<tr>
<th>Name</th>
<th>Contact Info</th>
</tr>
</thead>
</table>
| Caregiver          | Phone:  
                        Phone:  
                        Fax:    
                        Email:  
                        Address: |
| Primary Care Doctor| Phone:  
                        Phone:  
                        Fax:    
                        Email:  
                        Address: |
| Medical Oncologist | Phone:  
                        Phone:  
                        Fax:    
                        Email:  
                        Address: |
| Radiation Oncologist| Phone:  
                        Phone:  
                        Fax:    
                        Email:  
                        Address: |
<table>
<thead>
<tr>
<th>Name</th>
<th>Contact Info</th>
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<tbody>
<tr>
<td>Surgeon</td>
<td>Phone:</td>
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<td></td>
<td>Phone:</td>
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<td></td>
<td>Fax:</td>
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<td>Email:</td>
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<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Nurse Navigator</td>
<td>Phone:</td>
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<td></td>
<td>Phone:</td>
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<td>Fax:</td>
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<td>Email:</td>
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<tr>
<td></td>
<td>Address:</td>
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<tr>
<td>Hospital</td>
<td>Phone:</td>
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<td>Phone:</td>
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<td>Fax:</td>
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<td>Email:</td>
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<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Phone:</td>
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<td>Phone:</td>
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<td>Fax:</td>
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<td>Address:</td>
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<tr>
<td>Name</td>
<td>Contact Info</td>
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</tr>
<tr>
<td><strong>Home Health</strong></td>
<td>Phone:</td>
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<td>Phone:</td>
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<td>Email:</td>
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<td></td>
<td>Address:</td>
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<tr>
<td><strong>Physical Therapist</strong></td>
<td>Phone:</td>
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<td>Address:</td>
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</tbody>
</table>
Treatments and Side Effects Log

Keeping track of your treatments, medications, side effects, and overall well-being is very important during your cancer journey. How your nutrition, activities, and medications affect the way you feel can provide insight for you and your healthcare team.

Date(s)/Week: __________

**Treatments or procedures:**
Include specific dates, descriptions, and medications given.

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

**Foods Eaten:**

<table>
<thead>
<tr>
<th>Breakfast</th>
<th>Lunch</th>
<th>Dinner</th>
<th>Snacks</th>
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</thead>
<tbody>
<tr>
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</table>

**Activity or Exercise:**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Duration</th>
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</tbody>
</table>
## Treatments and Side Effects Log (continued)

### Medications/ Vitamins/ Supplements:

<table>
<thead>
<tr>
<th>Name</th>
<th>Dosage &amp; Time</th>
<th>Reason Taken</th>
<th>Prescribed By</th>
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</table>

Current Weight: ______  Physical Well-Being*: ______  Emotional Well-Being*: ______

*On a scale of 1-10. 10 = feeling your best. 1 = feeling your worst.
Treatments and Side Effects Log (continued)

**Side Effects:**
Record all side effects experienced by checking mild, moderate, or severe. If none, leave blank.

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in taste and smell</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Diarrhea</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Difficulty swallowing</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Dry mouth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling full quickly</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gas and bloating</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hair loss</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Lactose intolerance</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Loss of appetite</td>
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<td></td>
<td></td>
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<tr>
<td>Lymphedema</td>
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<td></td>
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<tr>
<td>Nausea</td>
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<td></td>
<td></td>
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<tr>
<td>Neuropathy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Skin changes (blisters, rashes, itchy, etc.)</td>
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<tr>
<td>Sore mouth, throat, or tongue</td>
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<tr>
<td>Weight loss</td>
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<tr>
<td>Weight gain</td>
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For help managing side effects, download PearlPoint’s new Cancer Side Effects Helper app to your smart phone.

**Notes:**
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
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___________________________________________________________________________

To keep track of this information online, visit *My PearlPoint* (my.pearlpoint.org) to create a personalized dashboard. On your dashboard, you can virtually track your well-being and save notes on your progress.
Laboratory Flow Sheet

Your healthcare team monitors the effects and toxicity of chemotherapy treatments by watching your Complete Blood Count and Differential (CBC) results. These ranges are listed on the report your doctor receives after routine blood work. Use this report or ask your healthcare team to help you fill out the sheet below so you can monitor your CBC.

If you notice a change in levels, ask your healthcare team for an explanation. Lab work will be ordered for your needs. Lab work may vary slightly between males and females and between different labs.

<table>
<thead>
<tr>
<th>Lab Values</th>
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<tbody>
<tr>
<td>Date</td>
</tr>
<tr>
<td>Weight</td>
</tr>
<tr>
<td>CBC</td>
</tr>
<tr>
<td>WBC</td>
</tr>
<tr>
<td>ANC</td>
</tr>
<tr>
<td>HGB</td>
</tr>
<tr>
<td>HCT</td>
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<td>PLT</td>
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<tr>
<td>RBC</td>
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<td>MPV</td>
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<td>MCV</td>
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<tr>
<td>MCH</td>
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<tr>
<td>MCHC</td>
</tr>
<tr>
<td>RDW</td>
</tr>
<tr>
<td>Differential</td>
</tr>
<tr>
<td>Other</td>
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</tbody>
</table>
Lab Reports and Terminology

Complete Blood Count and Differential

Your WBC, RBC, HGB, HCT, PLT, and MVP will be monitored throughout the course of your treatment. These lab results give important information about how your body is affected by the chemotherapy.

**WBC:** white blood cells or leukocytes. White blood cells help the body to fight infections. There are several different types of white cells that have different functions. The WBC is the total of all the white cells counted.

**RBC:** red blood cells. These are also called erythrocytes or corpuscles. Immature red blood cells are called reticulocytes. RBCs carry oxygen from the lungs to the tissues of the body.

**HGB:** hemoglobin. Hemoglobin is the pigment of the red blood cells that actually carries the oxygen.

**HCT:** hematocrit. This is the percentage of RBCs in the volume of the whole blood in your body. This is also called packed cell volume or PCV.

**PLT:** platelets or thrombocytes. These cells help the blood to form a clot when your body has had a trauma or is bleeding.

MCH, MCHC, MCV, RBC, HCT, HGB all give us information in the diagnosis of anemia. Anemia is defined as a lack of the proper amount of red blood cells.

**MVP:** mean platelet volume. This is the average volume of platelets. A high MPC means there is the presence of larger platelets. A low MPV indicates the platelets are smaller than normal.

**MCV:** mean corpuscular volume. This is the calculation of the average volume of the RBC and is determined by the hematocrit count divided by the RBC count.

**MCH:** mean corpuscular hemoglobin. This is the calculation of the average weight of Hgb of each RBC. This is determined by the hemoglobin divided by the RBC.

**MCHC:** mean corpuscular hemoglobin concentration. This number tells us the concentration of hemoglobin in an average RBC. It is calculated by dividing hemoglobin by hematocrit.

**RDW:** red cell distribution width. This is the numerical expression of the degree of variation in the volume of the population of red blood cells. Normally, as new normal sized cells are produced, the RDW increases.
**Differential:** a differential count calculates the total white blood cells and categorizes their different types. The differential is reported as a percentage and an absolute number by type of cell.

**Other Terminology**

**Granulocyte:** white blood cells with a grainy appearance under a microscope. Neutrophils, eosinophils, and basophils are all granulocytes. Neutrophils are further classified as either bands or segs. This defines the level of maturity of these cells. These cells fight infection.

**Polymorphonuclear leukocytes:** also called PMNs or Polys. These refer to granulocytes which are neutrophils, eosinophils, and basophils. The name means “possessing a nucleus (or center) consisting of many parts or lobes.” This is another descriptive name for white blood cells.

**Blast, myelocyte, metamyelocyte, progranulocyte:** these are immature WBCs that are not normally in the peripheral blood circulation.

**ANC:** absolute neutrophil count. Neutrophils are white blood cells that help the body fight infection. This number is used to monitor neutropenia and the effects of chemotherapy and colony stimulating factors.
**Drain Bulb Record**

After breast surgery, you may have drain(s) in your armpit or breast area to keep fluid from collecting in the surgical site. You will need to empty the fluid from the detachable drain bulb several times a day. You will also need to record the amount of fluid collected in the bulb. Your surgical team will teach you how to care for your drain before you leave the hospital. The drain will be removed in a follow up visit. Your drain bulb record will help your surgeon determine when to remove the drains.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Drain 1</th>
<th>Drain 2</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
### Budgeting Worksheets

#### Sources of Income:

<table>
<thead>
<tr>
<th>Sources of Income</th>
<th>Expected:</th>
<th>Actual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSI/SSDI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment Benefits: Short-Term Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investments</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Have you had to stop working due to your diagnosis? Have you considered applying for Social Security Disability Insurance?

#### Monthly Expenses:

<table>
<thead>
<tr>
<th>Monthly Expenses</th>
<th>Expected:</th>
<th>Actual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortgage/Rent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Energy Bill/ Gas Bill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water Bill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Groceries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Credit Cards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Car Payment</td>
<td></td>
<td></td>
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<tr>
<td>Gasoline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loans</td>
<td></td>
<td></td>
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<tr>
<td>Home/Cell Phone</td>
<td></td>
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<tr>
<td>Cable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housecleaning/Landscaping</td>
<td></td>
<td></td>
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<tr>
<td>Child Care</td>
<td></td>
<td></td>
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<tr>
<td>Insurance Premiums (health, life, home, etc.)</td>
<td></td>
<td></td>
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<tr>
<td>Clothing</td>
<td></td>
<td></td>
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<tr>
<td>School</td>
<td></td>
<td></td>
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<tr>
<td>Other Fees</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

To reduce these costs, have you considered:

- Are you eligible for Food Stamps?
- Are you able to get assistance with your electric bill from Low Income Heating Energy Assistance Program (LIHEAP)?
- Is there a local free cleaning service in your area?
- Do you qualify for government assistance for housing, child care, or cell phone?
### Budgeting Worksheets (continued)

<table>
<thead>
<tr>
<th>Medical Expenses:</th>
<th>Expected:</th>
<th>Actual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance Deductible</td>
<td></td>
<td></td>
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<tr>
<td>Co-Payments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescriptions</td>
<td></td>
<td></td>
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<tr>
<td>Transportation (parking fees, flights, etc.)</td>
<td></td>
<td></td>
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<tr>
<td>Medical Supplies</td>
<td></td>
<td></td>
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<tr>
<td>Caregiving/Home Care</td>
<td></td>
<td></td>
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<tr>
<td>Supplements</td>
<td></td>
<td></td>
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<tr>
<td>Mental Health Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel</td>
<td></td>
<td></td>
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<tr>
<td>Assistance Received:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Possible sources of assistance:

- Have you considered a prescription assistance resource like NeedyMeds to reduce costs of prescriptions? Call (800) 530-6987 or visit www.needymeds.org.
- Are you eligible for co-pay assistance based on cancer type?
- Can you reduce transportation and gas costs through resources like Road to Recovery or CancerCare?
  - For Read to Recovery call the American Cancer society at (800) 227-2345 or visit www.cancer.org.
  - Call CancerCare at (800) 813-HOPE (4673) or visit www.cancercare.org.
- Is there a sliding scale resource in your area for mental health services?

<table>
<thead>
<tr>
<th>Total Income:</th>
<th>Expected:</th>
<th>Actual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Expenses (Monthly/Medical):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>After Expenses: (Total Income – Total Expenses = After Expenses)</td>
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</tbody>
</table>

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**Budgeting Worksheets (continued)**

**Financial Assistance**

When applying for financial assistance, keep track of your applications (as outlined in the chart below) to make sure you submit everything and hear back from the programs in a timely manner. You may have to follow up with some programs. If a program provides reoccurring support, you will want to make note of that in the frequency column.

<table>
<thead>
<tr>
<th>Assistance Organization:</th>
<th>Date Applied:</th>
<th>Status:</th>
<th>Frequency:</th>
<th>Amount:</th>
<th>Need:</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Ex: CancerCare</em></td>
<td>2/11/14</td>
<td>Applied</td>
<td>One-Time</td>
<td>$125</td>
<td>Gas</td>
</tr>
</tbody>
</table>

|                       |              |         |            |         |       |
|                       |              |         |            |         |       |
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|                       |              |         |            |         |       |
## Calendars

**Month:**

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
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<th>Saturday</th>
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**Notes:**

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Calendars (continued)

Week: ____________________________________________

<table>
<thead>
<tr>
<th>Monday</th>
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<tbody>
<tr>
<td>Tuesday</td>
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<td>Wednesday</td>
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<td>Thursday</td>
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<td>Friday</td>
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<tr>
<td>Saturday/Sunday</td>
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</tbody>
</table>

Notes:
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

_______________________________ __________________________ __________________

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Appointment Details

Use this sheet to plan the details of your appointments in advance.

Date:
Time:
Location:

Provider:
Reason:

☐ Office visit
☐ Imaging
☐ Lab work
☐ Surgery
☐ Treatment
☐ Other ______________

Transportation:
_________________________________________________________________________
_________________________________________________________________________

Lodging:
_________________________________________________________________________
_________________________________________________________________________

Notes:
_________________________________________________________________________
_________________________________________________________________________
**Additional Resources**

**My PearlPoint**
At *My PearlPoint*, a website for adults impacted by cancer, you can find more educational, nutritional, and practical information to help you through your cancer journey. You can also find recipes, videos, survivor stories, and more. Create a personalized dashboard to save all the resources you find in one convenient location.
mypearlpoint.org
(877) 467-1936 X 101
guidance@pearlpoint.org

**American Cancer Society**
For more than 100 years, the American Cancer Society (ACS) has worked relentlessly to save lives and create a world with less cancer and more birthdays. Together with millions of our supporters worldwide, we help people stay well, help people get well, find cures, and fight back against cancer.
www.cancer.org
(800) 227-2345

**National Cancer Institute**
A collection of information run by the National Institutes of Health.
www.cancer.org
(800) 4-CANCER

**Breastcancer.org**
Breastcancer.org is a nonprofit organization dedicated to providing the most reliable, complete, and up-to-date information about breast cancer.
www.breastcancer.org

**Susan G. Komen**
Komen has invested more than $2.5 billion to fulfill a promise, working to end breast cancer in the U.S. through research, community outreach, advocacy, and programs.
www.koman.org