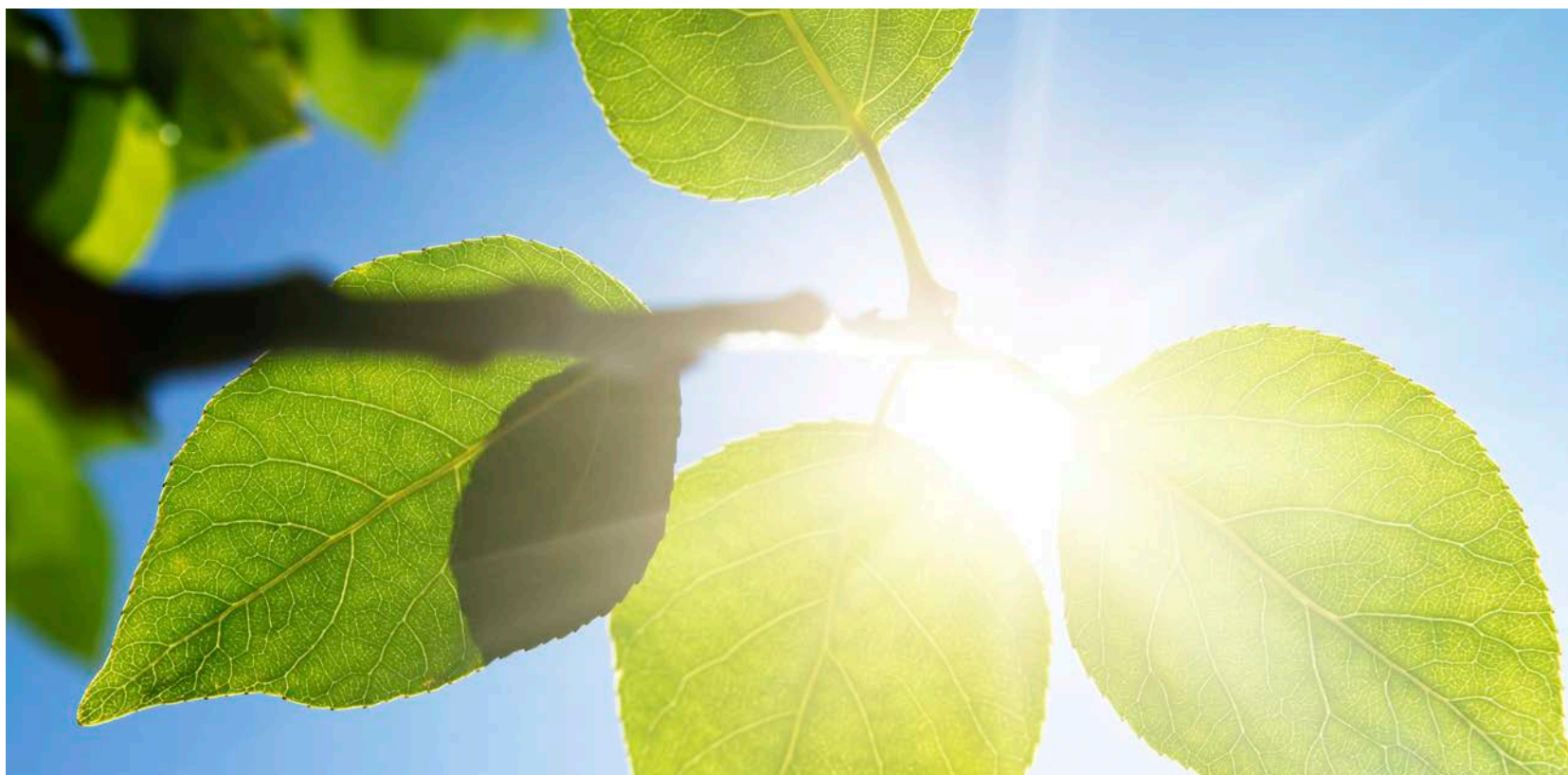


Understanding Breast Cancer

Information About Treatment and Recovery



Understanding Breast Cancer

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Fourth edition

Developed by Allina Health.

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The publisher believes that information in this manual was accurate at the time the manual was published. However, because of the rapidly changing state of scientific and medical knowledge, some of the facts and recommendations in the manual may be out-of-date by the time you read it. Your health care provider is the best source for current information and medical advice in your particular situation.

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Disclaimer

This publication is for general information only and is not intended to provide specific advice or recommendations for any individual. The information it contains cannot be used to diagnose medical conditions or prescribe treatment. The information provided is designed to support, not replace, the relationship that exists between a patient and his/her existing physician.

For specific information about your health condition, please contact your health care provider.





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Chapter 1: Introduction

After you find out you have breast cancer, it is easy to feel overwhelmed or confused. Your health care team will help you through this time.

You and your health care team will work together to develop a breast cancer treatment plan. This plan will be unique to your needs, concerns and preferences.

Many patients and their care circle (family, friends and others close to them) find it helpful to learn as much as they can about their breast cancer diagnosis and treatment plan.

This book was created to educate, help and guide you. It should not be used as a substitute for medical or professional advice. Read it at your own pace and write your questions in the margins.

Bring this book with you when you meet with your health care team. They will reinforce the information in this book and answer any questions you have.

Your Health Care Team

Your health care team will partner with you during your cancer treatment. Your team will include many health care providers who, along with you, will create your health care team. You are the center of your health care team.

Members of your health care team may include:

■ **Advance practice provider**

An advance practice provider can treat illnesses and diseases such as breast cancer. An advance practice provider and doctor work together as a team. Advance practice providers include:

- clinical nurse specialists
- nurse practitioners
- physician assistants.

You may work with an advance practice provider during your hospital stay or at a follow-up appointment.

■ **Breast surgeon**

A breast surgeon will talk with you about surgical treatment options and help identify the best treatment plan for you.

■ **Cancer rehabilitation care team**

Cancer rehabilitation may help you regain or improve the abilities you feel have changed as a result of your cancer or cancer treatment. Members of your cancer rehabilitation care team can help you maintain or regain your independence and enjoy your life to the fullest.

The team may include: physical medicine and rehabilitation provider, physical therapist, occupational therapist and lymphedema therapist.

■ **Genetic counselor**

A genetic counselor can help clarify concerns related to a personal or family history of cancer, or both. They will talk with you about risks, screening and prevention. A genetic counselor can also help determine which, if any, genetic tests may be helpful, coordinate the testing and then interpret the results.

■ **Medical oncologist**

A medical oncologist is a doctor who will meet with you if your treatment plan includes taking medicine. This medicine may include chemotherapy, targeted therapies or both.

■ **Nurse navigator**

A nurse navigator is a registered nurse who will support, educate and guide you through your course of treatment. Your nurse navigator will be part of your health care team from diagnosis through treatment and on to healing and survivorship.

■ **Oncology social worker**

An oncology social worker is available to support you and your family during your treatment and recovery. A social worker can:

- help find information and get referrals to community resources
- talk about any concerns that may come up during treatment such as financial, employment or transportation
- provide individual and family counseling to help you and your family cope with the emotional side of cancer
- help guide adults on how to talk with children about cancer and the changes it can often bring to a family.

■ **Pathologist**

A pathologist works in the medical laboratory and examines cells, body fluids and tissues samples for traces of cancer.

■ **Plastic surgeon**

A plastic surgeon will meet with you if you choose to have breast reconstruction to rebuild your breast.

- **Primary care provider**

Your primary care provider will have access to all of your treatment information. You will keep visiting your primary care provider for your usual health care needs.

- **Radiation oncologist**

A radiation oncologist is a doctor who will meet with you if your treatment plan includes radiation therapy.

- **Radiologist**

A radiologist is a doctor who specializes in medical imaging. This provider will use mammography, magnetic resonance imaging (MRI) or other radiology tests to look at images of the breast cancer.

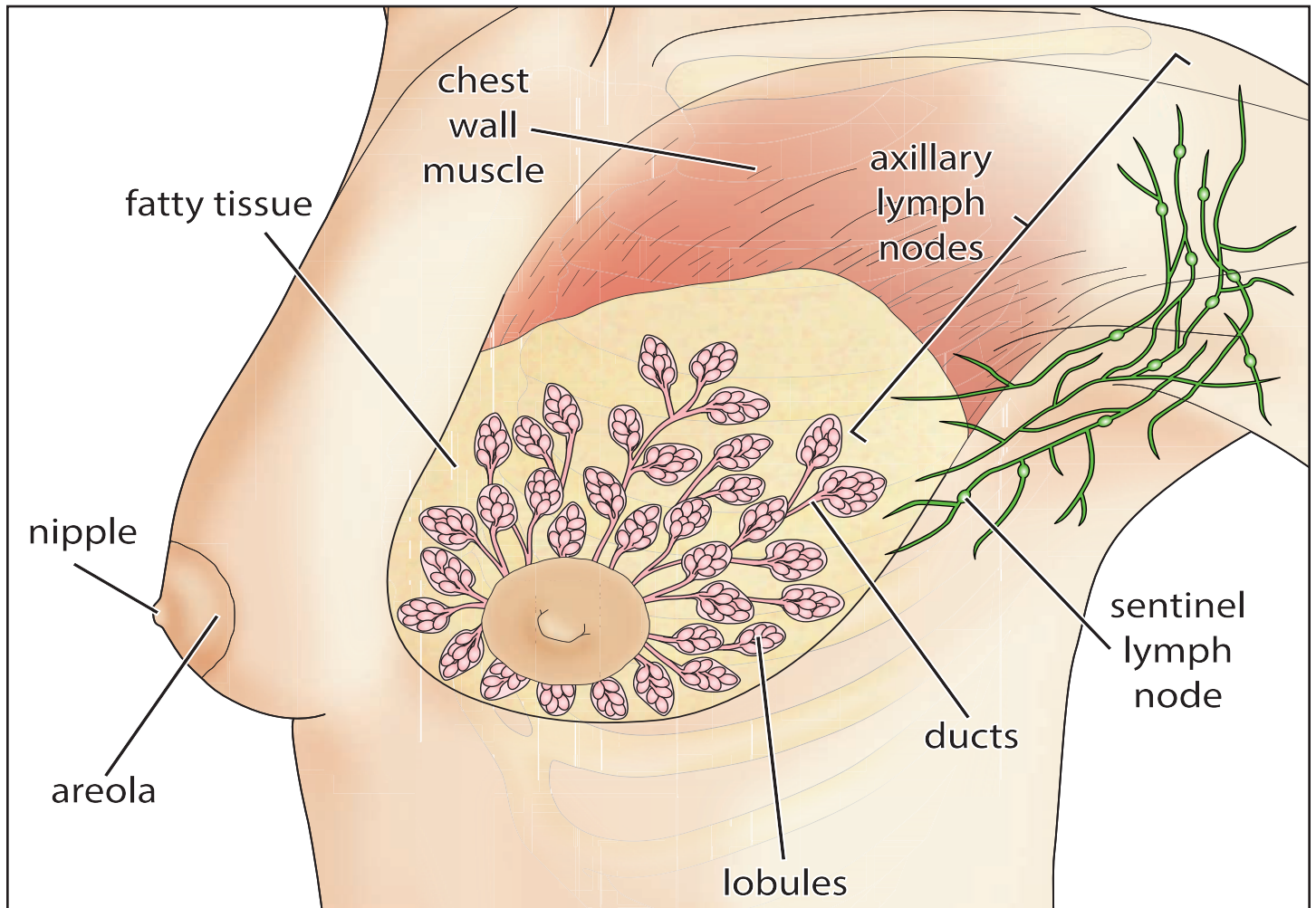
- **Registered nurse**

A registered nurse (RN) will provide and coordinate your personal care. An RN will educate you about your cancer and treatment, and provide support to you and your family.

You may also come in contact with other health care providers, including integrative health, dietary, spiritual care and respiratory care.

Understanding Breast Cancer

Parts of the breast

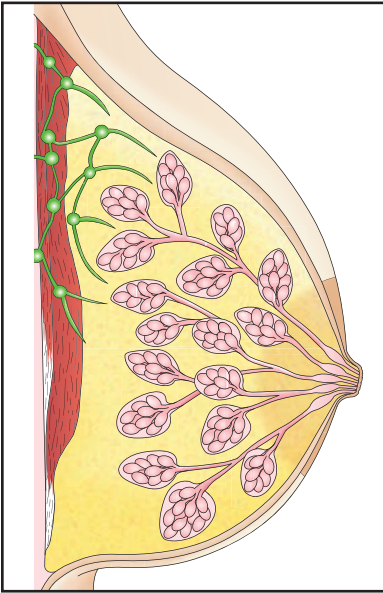


The parts of your breast and lymph nodes, including the sentinel lymph node.

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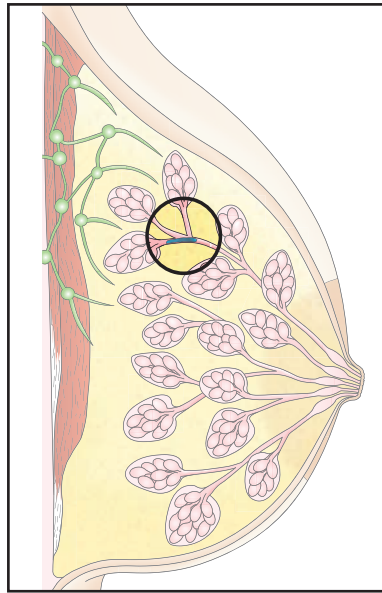
Breast cancer

Cancer is a disease in which cells in the body grow out of control. When cancer starts in the breast, it is called breast cancer. Breast cancer is the most common cancer among women.



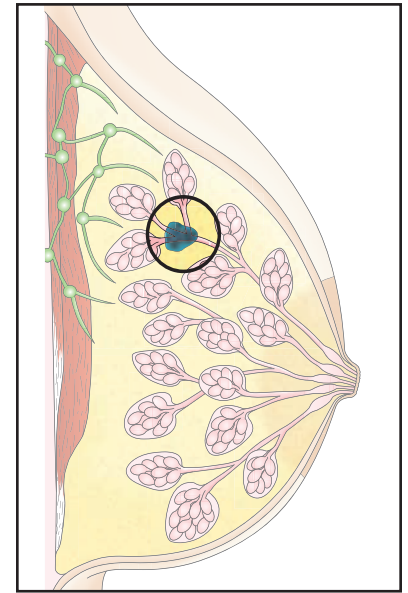
Normal breast tissue

- The cells are healthy.



Noninvasive breast cancer

- The cancer cells are only found in the ducts.
- This is known as ductal carcinoma in situ (DCIS).



All illustrations © Allina Health System

Invasive breast cancer

- The cancer cells have grown into surrounding tissue.

Important

The “grade” of your breast cancer is **not** the same as the “stage” of your breast cancer.

The stage of your breast cancer is determined by many different factors. Your health care provider will talk with you more about the stage of your breast cancer.

Pathology report

A pathology report will show the results of the tissue samples you had taken. It will provide information about your breast cancer such as:

- **diagnosis:** This is the type of breast cancer or tumor.
- **grade:** This is how abnormal the cells look under the microscope.
 - grade I: The cancer cells look more like normal cells. These cells may grow and multiply slowly.
 - grade II: The cancer cells look somewhat abnormal. These cells may grow and multiply a little faster than normal.
 - grade III: The cancer cells do not look like normal cells. These cells may grow and multiply more quickly.
- **hormone (estrogen and progesterone) receptor status:** This is a test to see if the tumor will respond to endocrine therapy.
- **HER2 (Human Epidermal Growth Factor Receptor 2) status:** This is a test to see if the tumor will respond to HER2 targeted therapy.

Genetic Counseling

Based on your type of breast cancer, your age, your family history or all three, your health care team may recommend that you have genetic counseling.

This can help you better understand genetic testing options and how this information may help you and your family. During the visit you can also learn about your risk for future cancers and what you can do to reduce that risk.

Genetic counseling may happen before, during or after your cancer treatment

- **Genetic counseling before or during your treatment** can be helpful in making a decision about the type of treatment that would be right for you. The results of genetic testing may help determine the best type of surgery or medicine for you.
- **Genetic counseling before or after your treatment** can help you plan future cancer care (screening and prevention) for you and your family.

During the visit, your genetic counselor will help you decide if genetic testing is right for you. If you have genetic testing, they will help you understand the results.

Chapter 2: Breast Cancer Treatments

Important

Cancer treatment could affect your fertility (being able to have a baby).

However, there are ways to preserve your fertility if you want to have the option to have children in the future.

Now is the time to talk with your doctor about your options.

You and your health care team will work together to decide the best treatment based on your pathology report, imaging tests and physical exam.

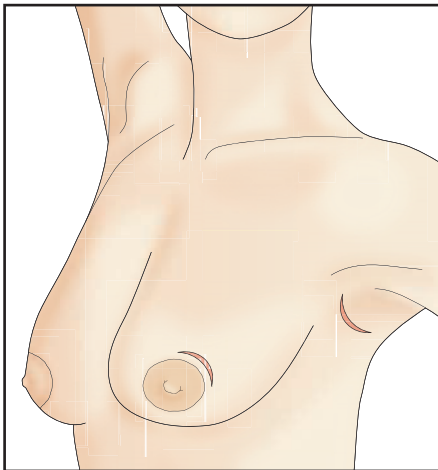
Treatment options may include one or more of the following:

- surgery
- radiation therapy
- chemotherapy
- targeted therapies
- clinical trials.

It is important that you take time to learn about your treatment options. Make sure you understand each type of treatment. If you do not understand something, ask a member of your health care team to explain it to you.

Surgery

There are two types of surgery to treat breast cancer: lumpectomy or mastectomy. You may also have lymph node removal during surgery.



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Lumpectomy

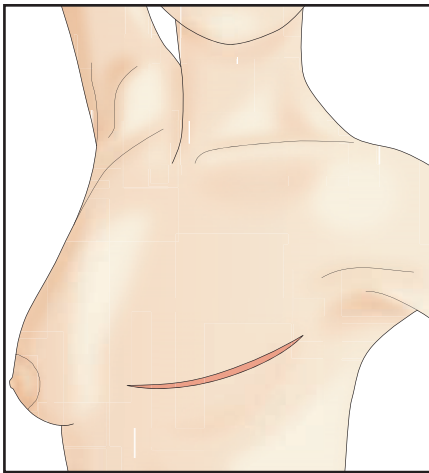
Lumpectomy (breast-conserving surgery)

Lumpectomy is a surgery to remove part of your breast. It removes the cancer and a rim of healthy breast tissue around the cancer. This healthy tissue is called the margin.

You may need to have a localization procedure before your surgery. A radiologist will place a thin wire or radioactive seed in the area of the cancer. The wire or seed will help your surgeon find the tumor during surgery.

After a lumpectomy, you will have one scar on your breast that is close to where the cancer was. You may have a second scar in your underarm area if your surgeon needs to remove some of your lymph nodes.

Most women need radiation therapy after a lumpectomy. Radiation therapy helps reduce the chance of breast cancer coming back in the same breast. You will have radiation therapy every weekday for 3 to 7 weeks.



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Mastectomy

Mastectomy

This is a surgery to remove your entire breast. This usually includes your nipple and areola.

After a mastectomy, you will have a scar across your chest and lose your breast's natural feeling and look.

You may choose to have breast reconstruction to rebuild your breast. Breast reconstruction involves a series of surgeries that may take up to 2 years to complete. The timing will depend on your other treatment needs (chemotherapy, radiation therapy) after the mastectomy.

A plastic surgeon will meet with you if you want to learn more about breast reconstruction. If you choose to have breast reconstruction, it is important to stop tobacco use before having this surgery. Some reconstruction surgeries may not be offered to you if you use tobacco or have used tobacco in the past.

Did You Know?

- Lymph nodes act like filters to remove dead cells and bacteria (germs) from the body and keep them out of the bloodstream.
- Some breast cancers can spread to the axillary (underarm) lymph nodes.

Important

If blue dye is found in a lymph node, it does not mean that there is cancer in that lymph node.

The blue dye helps your surgeon know which lymph node to remove to test for cancer cells.

Lymph node surgery

Most women have one or both of these surgeries. You and your surgeon will talk about which surgery is right for you.

- **Sentinel lymph node biopsy:** This is the removal of the sentinel lymph node(s) to see if the cancer has spread.
 - The sentinel lymph node is the first lymph node cancer would spread to if the cancer were to spread. Sometimes, there can be more than one sentinel lymph node.
 - You may need to have a sentinel lymph node injection before your surgery. A small amount of clear, radioactive liquid is injected just under the skin of the breast.
 - During your surgery, your surgeon may also inject a blue dye into the breast.
 - The liquid and dye are used to help identify the sentinel lymph node(s).
- **Axillary node dissection:** This is the removal of a group of lymph nodes under the arm to see if there are cancer cells in them.

Radiation Therapy

Tip

- Radiation therapy is usually recommended if you have a lumpectomy and sometimes recommended if you have a mastectomy.
- The goal of radiation therapy is to destroy any cancer cells that may be left and reduce the risk of cancer coming back at the treatment site.

Radiation therapy uses high-energy radiation (X-rays) to shrink or destroy cancer cells. During treatment, healthy cells are also affected by the radiation.

To decrease the risk to healthy cells, the radiation will be given in a way to reduce your exposure. Your radiation oncology team will help you get through the treatments feeling the best you can, with the least amount of side effects. You will be watched closely during your treatments.

Radiation therapy treatment

You will have a planning session with your radiation oncology team before your first radiation treatment. During each treatment you can expect the following:

- The therapists will position you on the treatment table.
- You will be alone during the treatment. The therapists will watch you closely on a TV monitor and listen to you on an intercom.
- You may hear a buzz from the treatment machine (called a linear accelerator) when you are receiving the radiation.
- The treatment machine may give you radiation from different angles.

Talk with your radiation therapist, radiation oncologist or nurse if you have any questions or concerns about the radiation treatments or side effects.

Chemotherapy

Tip

Chemotherapy can be done before or after surgery.

- **Neoadjuvant chemotherapy** is done before surgery or radiation therapy. The goal is to make a tumor in the breast or lymph node smaller.
- **Adjuvant chemotherapy** is done after surgery. The goal is to destroy any cancer cells that may be left.

Whether chemotherapy is given before or after surgery, the goal is to destroy any cancer cells found elsewhere in your body.

Chemotherapy is medicine given through an IV (intravenous) line to destroy cancer cells throughout your whole body. There are many different types of chemotherapy. You and your medical oncologist will decide if chemotherapy is right for you, along with which type of medicine.

During each treatment you can expect the following:

- You will go to your medical oncologist's office or a chemotherapy clinic.
- You will sit in a comfortable chair such as a recliner.
- You will have an intravenous (IV) line started. This will be used to give you fluids and medicines, including chemotherapy.
- During your treatment, you can watch TV, read, rest, or visit with a family member or friend.
- Each treatment will take a few hours.
- When the treatment is done, the IV will be stopped and removed. You will be able to go home. You may want to rest after your treatment.

Chemotherapy may have side effects. Everyone reacts differently to chemotherapy. Many people do not have any side effects or have only mild side effects. Your medical oncologist will talk with you about chemotherapy and possible side effects.

Targeted Therapies

Tip

Targeted therapies can be done before or after surgery.

Targeted therapies are medicines designed to target specific features of cancer cells and stop them from growing and spreading.

Endocrine therapy

Endocrine therapy may be used to treat estrogen receptor positive (ER-positive) breast cancer. Endocrine therapy medicines are pills you take by mouth. Most women are on endocrine therapy for 5 to 10 years. You and your medical oncologist will decide if endocrine therapy is right for you.

The two main types of endocrine therapy are:

- **SERMs (Selective Estrogen Receptor Modulators):** This type of medicine binds to estrogen receptor sites on cancer cells, blocking estrogen from entering the cancer cell. One example of a SERM is tamoxifen (Nolvadex®).
- **Aromatase inhibitors:** This type of medicine lowers estrogen levels in the body. One example of an aromatase inhibitor is anastrozole (Arimidex®).

Did You Know?

You may also hear endocrine therapy called anti-hormone therapy or anti-estrogen therapy.

Some possible side effects of endocrine therapy are hot flashes, bone and joint pain and changes in bone density. It may be possible to change the type of medicine you are taking, so talk about any side effects you may be having with your medical oncologist. Do not stop taking any medicine prescribed to you without first talking to your medical oncologist.

HER2 targeted therapy

HER2 targeted therapy medicines are used to treat HER2-positive breast cancer. These medicines are given through an IV line and are designed to bind to receptors that keep the cancer cells from growing. Some examples of medicines used are trastuzumab (Herceptin®) and pertuzumab (Perjeta®). This type of therapy is usually given with chemotherapy.

Bone-strengthening medicines

Some breast cancer treatments can cause changes in bone density. Bone-strengthening medicines may be given to help prevent osteoporosis and fractures.

Clinical Trials

Clinical trials (cancer treatment studies) are done to try to improve the prevention, detection, and treatment of breast cancer. If you are interested in being part of a clinical trial, talk with your medical oncologist to see if there is one that would be right for you.



Chapter 3: Preparing for Your Surgery

Your Health History and Physical Exam

Important

Your health history and physical exam needs to be done within 30 days before your surgery.

It is recommended to have the exam done 14 to 30 days before surgery.

Your primary care provider should do a health history and physical exam before your surgery. Call your primary care provider to schedule your appointment.

During the exam, your primary care provider will:

- evaluate your current health status
- review and perform any tests needed before surgery
- make sure you are ready for surgery.

If you take any medicines, make sure your primary care provider gives you instructions for the following:

- taking your medicines the morning of surgery
- stopping any prescription medicines before your surgery
- stopping any over-the-counter medicines before your surgery, including herbal medicines.

Diabetes

If you have diabetes, it is important to have good blood glucose levels before and after surgery. This will help you heal better after surgery and lower your risk of infection. Talk with your health care provider who manages your diabetes about having good blood glucose levels before your surgery.

Advance Care Planning

How to Get Started

Allina Health offers three ways to help you get started:

1. Sign up for a free advance care planning class at allinahealth.org/acpclass.
2. Fill out a free, secure health care directive online. Go to account.allinahealth.org to create an account.
3. Print out a health care directive at allinahealth.org/acp.

Planning for your future health care

Advance care planning is the process of giving information to others about your health care choices in case illness or injury prevents you from telling them yourself.

Talk with members of your care circle (family, friends or others close to you) about your health care choices. This is a time for you to share:

- what kind of care and treatment you do or do not want
- your wishes, goals and values and how they relate to your health care choices for the future.

You can put your health care choices in writing by creating a health care directive. Members of your care circle and your health care providers will use this document to interpret and understand your wishes, goals and values for your future health care needs.

Quit Tobacco for Your Surgery

Did You Know?

Tobacco products contain more than 7,000 chemicals. More than 70 are known to cause cancer.

Important

Secondhand smoke causes as much damage to healing as if you were smoking.

If you live with someone who smokes, ask them to smoke outside for at least the time of your recovery.

Tobacco and surgery risks

Tobacco products include cigarettes, electronic nicotine delivery systems (ENDS, includes e-cigarettes and JUUL®), smokeless tobacco (dip or chew), cigars, hookahs and pipes.

Using tobacco increases your risk of the following during and after surgery:

- heart problems
- lung problems (complications) such as pneumonia
- infections such as infections of your surgery site (incision)
- blood clots
- slower healing of your surgery site
- higher levels of pain and more problems with pain control.

Tobacco use keeps oxygen from reaching your surgery site and it can increase your recovery time.

Benefits of quitting

- Research shows that quitting 4 weeks before surgery can reduce any problems after surgery up to 30 percent.
- People who quit smoking report having better pain control.
- Your body responds quickly to quitting:
 - **8 hours:** the carbon monoxide level in your blood drops to normal. The oxygen level in your blood increases to normal.
 - **48 hours:** Nerve endings start to grow again.
 - **2 weeks:** Your circulation improves and your lung function increases. (Source: World Health Organization)

When you should quit

Ideally, you should quit as soon as possible. Research shows that:

- the harmful effects from cigarettes begin to go down about 12 hours after your last cigarette smoked
- at least 8 weeks without cigarettes is the best way to reduce problems almost as low as people who do not smoke.

The American College of Surgeons recommends at least 4 weeks without cigarettes.

Did You Know?

Using your surgery as a motivator to quit tobacco increases your success rate of quitting for good.

You should not use tobacco the day of surgery up to 1 week after your surgery. Your doctor may tell you when to quit before your surgery.

If you quit for surgery, you double the chance of staying off cigarettes for good. Many people report they have no cravings while in the hospital.

Not ready to quit? Consider taking a break!

If quitting tobacco makes you feel nervous and seems overwhelming, consider taking a break or a vacation from tobacco use.

- You will get the physical benefits for the period of time that you are not using tobacco.
- You will reduce your risk of problems during surgery and still increase your chances of a smooth recovery after surgery.

If you can, set a goal to stop using tobacco for 1 month after your surgery. This will allow your body to heal the best after your surgery.

Ways to quit or take a break

- abrupt stop (cold turkey)
- nicotine replacement therapy* (gum, lozenge, patch or inhaler)
- medicines (Chantix® and Zyban®)
- behavioral strategies (such as calling a friend or going for a walk)
- aromatherapy (black pepper oil)
- take a break (vacation) from tobacco.

Any step you take without tobacco is going to help you. Small steps are better than nothing!

Tip

For resources on how to quit tobacco, go to pages 74 to 75.

***Nicotine replacement therapy (NRT) can nearly double your chances of successfully staying off cigarettes. It works best if you use it with the help of a doctor or counselor. Ask your doctor about using NRT around the time of surgery. Go to quitforsurgery.com to learn more.**

Insurance Coverage

Health care benefits change and differ from plan to plan and provider to provider. It is important for you to understand your health care benefits before your surgery.

Now is a good time to call your insurance provider and find out exactly what is and is not covered under your plan, and how much you have to pay yourself.

Preparing Your Mind and Body for Surgery

Studies have shown that if your mind and body are ready for surgery you may sleep better and have less anxiety and pain. Your hospital stay may also be shorter.

There are some skills you can learn to help you to prepare your mind and body for your surgery. These skills include:

- meditation and relaxation techniques
- breathing techniques
- guided imagery and biofeedback
- self-care practices
- pain management techniques.

Talk with a member of your health care team if you would like to learn more about these skills.

Preparing for Surgery

You will receive information with the date and time of your surgery and the time you need to arrive at the hospital.

It is important to arrive on time. Your time of surgery could start earlier than expected. If you are late, your surgery may be delayed or it may need to be canceled and scheduled at a later date. Please call your surgeon's office if you have any questions.

What to Bring for Your Hospital Stay

Important

Please do not bring any of the following:

- valuables
- medicines (pills, inhalers)
- large amounts of money
- jewelry (wedding ring).

Please bring the following to the hospital.

- a current list of your medicines
- a copy of your health care directive (if you have one)
- driver's license or photo ID
- your insurance information (insurance card, Medicare card)
- glasses (if you wear them) and storage container (If you wear contacts, please wear your glasses and leave your contacts at home.)
- hearing aids (if you wear them), storage container and extra batteries
- clothing you will wear home, including a loose-fitting shirt (ideally one that opens in the front or buttons), comfortable pants, underwear and socks
- sports bra or other garment recommended by your plastic surgeon.

If you are staying overnight at the hospital, please also bring the following:

- personal care items such as a toothbrush, toothpaste, denture cleaner, comb, skin care products, deodorant, make-up and shaving kit
- CPAP machine (if you use one)
- reading materials (All rooms have a television and phone.)
- phone numbers of family and friends.

For your comfort, you may also choose to bring a robe and slippers.

The Day Before Surgery

Tell your surgeon if you have any changes in your health (sore throat, cold, fever, dental problem, urinating problem) or skin condition (rash, abrasions). You may need to schedule your surgery for a later date.

Food and Liquid Restrictions Before Surgery

Follow the instructions you were given by your surgeon or nurse on when to stop eating and drinking before your surgery.



Chapter 4: Your Surgery and Hospital Stay

What to Expect the Day of Surgery

Important

If you are having a localization procedure before your surgery, you may need to go to a different location to have the procedure before going to the hospital. If you have any questions, please ask your health care team.

You can read more about a localization procedure on page 15.

The day of your surgery

- If you were given instructions by your primary care provider to take medicines the morning of your surgery, take them as directed with a small sip of water.
- Put on clean, comfortable clothes to wear to the hospital.
- Arrive at the hospital at the time given to you by your health care team. Please arrive on time. If you are late, your surgery may be delayed or rescheduled.
- You will have visits from members of your health care team.
 - **Your nurse** will meet with you to complete your care plan, review what you can expect before and after your surgery and answer any questions.
 - **Your surgeon** will visit with you. They will answer any questions you may have. During this visit, you can tell your surgeon whom to talk with after your surgery.
 - **Your anesthesiologist** will also meet with you. They will review your medical history, talk about the anesthesia that will be used during your surgery and answer any questions. There are three types of anesthesia:
 - general. You are completely asleep and have no sensation of pain.
 - local. The surgeon injects a local anesthesia at the surgery site. You will be awake but comfortable during the surgery.
 - monitored anesthesia care (MAC). You will be sleepy and relaxed throughout your surgery. You may receive a sedative through an IV line before and during surgery.
 - **Your nurse anesthetist** will review your anesthesia plan, take you to the operating room and stay with you during your surgery.
- You will be asked to sign a consent form if you have not signed one already.

Information for your care circle

- While you are in surgery and recovery, your care circle can wait in the surgery waiting room.
- Your surgery time will vary depending on the type of surgery you are having. Your surgeon will talk with your care circle when your surgery is over.

Recovery room

- After surgery, you will be taken to the recovery room.
- Most people stay about 1 to 1 ½ hours in the recovery room. Your time in the recovery room will depend on your surgery and how fast you recover from the anesthesia.
- Your nurse will monitor your vital signs and help you if you have any side effects from the anesthesia.
- You may have some discomfort and pain when you wake up. Everyone reacts to pain differently. Your nurse will work with you to make you as comfortable as possible.
- If you have a lumpectomy, you will usually go home the same day. If you have a mastectomy (with or without reconstruction), you will usually stay at least one night in the hospital.

Hospital room

- When you are fully awake and your medical status is stable, you will be taken to your hospital room.
- When you are in your room, it is important to begin:
 - doing ankle pump exercises. This will help to prevent blood clots from forming in your legs.
 - using your incentive spirometer and doing the deep breathing exercises
- It is also important to get up and walk in the halls with help.

How to Manage Your Pain After Surgery

Important

Having no pain while in the hospital is not realistic, but pain can be controlled.

Your health care team will work closely with you to help manage your pain during your hospital stay and when you return home.

You and your health care team will establish a “pain goal” – the amount of acceptable pain you can tolerate during your hospital stay.

For most people, a pain goal of 3 or 4 out of 10 is an OK pain level that balances pain control with your ability to do physical therapy and daily activities.

Your right to pain management

You have the right to have your pain managed. Proper treatment of pain is necessary for you to achieve the best results during your recovery.

If you do not think your pain is being treated well, please tell a member of your health care team. They will talk with you about your pain and pain management needs.

Pain scale

Using a number scale (0 to 10) to rate your pain will help the health care team members know how severe your pain is and help them make decisions about how to treat it.

Allina Health Pain Assessment Scale

10	Worst Pain You Can Imagine
7-9	Severe Pain Pain keeps you from doing your regular activities. ⑨ Pain is so bad that you can't do any of your regular activities, including talking or sleeping. ⑧ Pain is so intense that you have trouble talking. ⑦ Pain distracts you and limits your ability to sleep.
4-6	Moderate Pain Pain may interfere with your regular activities. ⑥ Pain makes it hard to concentrate. ⑤ You can't ignore the pain but you can still work through some activities. ④ You can ignore the pain at times.
1-3	Mild Pain Pain doesn't interfere with your regular activities. ③ You may notice the pain but you can tolerate it. ② You may feel some twinges of pain. ① You may barely notice the pain.
0	No Pain

Adapted with permission by Dr. Armaan Singh, 2015.

Important

When medicines are used correctly to manage pain, addiction rarely occurs. Talk to a member of your health care team if you have concerns about this issue.



Important

If you had a mastectomy, **do not** put a heating pad on your breast or chest area. You will have a decrease in sensation or feeling in that area and could get burned.

Your role in managing pain

After surgery, it is common to have some pain. Your nurse will monitor your pain level often and help you manage the pain.

Since you are the only one who knows where and how severe your pain is, you have an important part in managing your pain.

If you have pain, tell a member of your health care team.

All of the following information will help your health care provider prescribe the right medicine and therapy for your pain, and prevent serious side effects (complications). Tell a member of your health care team:

- where you feel pain and how much pain you have (use words to describe how the pain feels)
- what makes your pain better or worse
- what methods of pain control have worked or have not worked well in the past
- if you take pain medicines on a regular basis
- if you have allergies or reactions to pain medicine(s)
- your goals for managing your pain
- what vitamins, herbal and natural products you are taking
- if you smoke
- if you drink more than two alcoholic drinks each day
- if you take illegal (street) drugs
- if you are in a methadone maintenance program.

Treatments for pain

There are many different types of treatments for pain including:

- medicines
- cold (ice packs) (Ask your health care provider if this type of treatment is OK to use.)
- integrative therapies: such as acupuncture, music, relaxation techniques, massage, aromatherapy
- psychological therapies
- nerve blocks.

Tip

Take pain medicine when pain first begins. If you know your pain may get worse with activity, take your pain medicine before the activity.

Do not wait for pain to get worse before taking medicine. Tablets or pills may take up to 30 minutes to begin working. Timing of when to take medicines is important.

Talk to a member of your health care team about how to time your pain medicines before therapy or activity.

Pain medicine side effects

All medicines have some side effects, but not everyone gets them. When side effects occur, it is usually within a few hours after taking the medicine. Most side effects can be managed and go away in time.

Tell a member of your health care team right away if you have:

- constipation
- sleepiness
- dizziness
- itching, a rash or both
- upset stomach (nausea) and throwing up (vomiting)
- slowed breathing
- trouble concentrating
- forgetfulness
- increased anxiety.

Pain control can help you

The right pain control can help:

- you be more comfortable
- you get back to your normal routine
- you participate more completely in your exercises and therapy
- promote healing.

Before you go home

A member of your health care team will give you instructions for managing your pain at home. Be sure to have written instructions with a health care provider's name and phone number who will manage your pain after you go home.

It is important you follow any instructions you receive for taking pain medicine. Ask a member of your health care team if you need help.

Call the health care provider who prescribed the medicine or your primary care provider if you have concerns or side effects from pain medicine.

Preventing Problems (Complications)

Tip

Ask a member of your health care team if you have any questions about the activities to help prevent complications.

Your health care team will do many things to reduce your chance of developing a complication after surgery.

- Your blood pressure, temperature and pulse will be taken often.
- You will do ankle pumps to improve circulation and strength. You may also use a sequential compression device (SCD). These stockings are used to increase circulation and help prevent blood clots.
- You will do deep breathing, coughing exercises and use an incentive spirometer to help protect your respiratory system.
- Your dressing and incision will be checked regularly. Your health care team will tell you how to care for your incision.
- You may have a Jackson-Pratt drain. It will draw out excess blood and fluid from the area around your incision. It will be removed 1 to 2 weeks after surgery. You can read more about a Jackson-Pratt drain on pages 51 to 52.
- You will have an IV line during your hospital stay.
- Your decreased activity and pain medicine combined can cause constipation. To help prevent this:
 - Drink six to eight 8-ounce glasses of liquid each day.
 - Be as active as you can each day.
 - Talk to a member of your health care team about a bowel program if you are uncomfortable and the actions above are not working. You may receive a stool softener medicine to help prevent constipation.

Ask a member of your health care team if you have questions about these care activities.

Chapter 5: Care After Surgery

After your surgery, there is a variety of things you need to know for your safety, recovery and comfort. Before you go home, you will receive instructions on your diet, medicines, activity level, follow-up appointment, and signs and symptoms to watch for.

This chapter includes what to expect during your recovery, a list of commonly asked questions, and information about pain medicines.

If you have any questions, ask your surgeon or nurse. They want your recovery to be as smooth as possible.

Care After a Lumpectomy or Mastectomy



Important

If you had a mastectomy, **do not** put a heating pad on your breast or chest area. You will have a decrease in sensation or feeling in that area and could get burned.

Activity

- Increase your activity as you feel strong enough to do more.
- You may need to rest often so you do not get too tired.
- Avoid repetitive activity such as vacuuming and lifting heavy objects.
- Your surgeon will tell you when it is OK for you to shower and drive.
- Use normal arm movement on your surgery side to prevent stiffness. If you have a drain in place, do not lift your arm over your head until the drain is removed.
- If your surgeon wants you to do certain shoulder exercises, your nurse or surgeon will show you how to do them. Start the exercises only when your surgeon says it is OK.
- Avoid smoking.

Clothing

- You may go home wearing a special bra or camisole. Follow any instructions given to you by your surgeon.
- When your surgeon says it is OK, you will want to wear a comfortable, supportive bra. (It may be more comfortable to wear a bra without an underwire.)
- If you had breast reconstruction, follow the instructions given to you by your surgeon.
- Wear comfortable, loose-fitting tops. Try to wear tops that are easy to get in and out of such as a button-up shirt.
- You may want to wait to buy many new bras until your treatment is done. Your size, shape and incision discomfort will get better during this time.

Commonly Asked Questions

Did You Know?

- It is common to have numbness around your incision(s).
- If a lymph node has been removed, it is common to have an abnormal sensation on the underside and back of your upper arm (on the surgery side). This can feel numb, extra sensitive or sore. This will go away over time.

When should you call your surgeon?

Call your surgeon if:

- you have a temperature of 101 F or higher
- you have nausea (upset stomach) or vomiting (throwing up) that will not stop
- you have increased pain that cannot be relieved with rest or pain medicine
- you have bleeding at the incision site
- you have an increase in bloody fluid in your drain
- your incision becomes red, more tender, has increased drainage, or signs of infection:
 - pain
 - swelling
 - redness
 - odor
 - warmth
 - green or yellow discharge
- you have hives (itchy raised rash)
- you feel dizzy or lightheaded
- you have any changes in sensation (new numbness or tingling)
- you have new confusion
- you have signs and symptoms of a blood clot including calf pain, leg pain, leg swelling or shortness of breath.
- you have any questions or concerns.

Call 911 or have someone take you to the nearest hospital Emergency Department if you have:

- a severe headache
- problems with your vision
- problems breathing
- any change in movement (such as new weakness or if you are not able to move as usual).

Important

Please see your After Visit Summary for how to take care of your incision after surgery.

How do you take care of your incision and change the dressing?

Follow your surgeon's instructions on how to take care of your incision and change the dressing.

How soon can you take a bath or shower?

Follow your surgeon's instructions on when you can take a bath or shower.

When can you return to your normal diet?

As soon as you are able, eat well-balanced meals to help you recover more quickly and to help you feel your best. What you eat after your surgery affects your well-being. You need to eat healthful foods and drink a lot of liquids.

Follow these guidelines to have a balanced diet:

- Resume your normal diet as soon as you are able.
- Do not skip meals. Eating three balanced meals will help you maintain your health.
- Balance your diet between the basic food groups: dairy, meat, fruits, vegetables and grains.

How do you manage constipation after surgery?

It is common for bowel movements to slow after surgery. This can be caused by pain medicines, decreased daily activity and changes in eating habits. Constipation after surgery is common.

Signs of constipation are:

- fewer number of bowel movements
- small, hard stools that are difficult to pass
- feeling bloated and uncomfortable
- gas
- abdominal cramping.

How to prevent constipation

- Drink six to eight 8-ounce glasses of liquids each day.
- Add more fiber to your diet with whole grain bread, bran cereals, fresh fruit and vegetables.
- Be as active as you can each day. Walking around your house or apartment will help.
- Take less pain medicine, if possible. Follow your doctor's instructions for taking pain medicine.

Use of constipation medicines

As long as you are taking prescription pain medicine, you may be told to take a stool softener. Call your nurse navigator or surgeon's office if you have any questions or concerns about constipation.

When can you drive a car?

- You can drive when your incision is comfortable enough to let you step on the brake quickly.
- Do not drive while taking prescription pain medicines because it can impair your judgement and ability to operate the car safely.
- If you have a drain in place, do not drive until your surgeon says it is OK.

When can you return to work or your hobbies?

You may need to wait anywhere from 1 to 8 weeks to return to work or your hobbies, depending on what type of surgery you had. Talk with your health care team about how long you need to wait before returning to your normal routine.

When can you resume sexual activity?

You can continue with sexual activity as long as it is comfortable for you.

Important

After your follow-up appointment, you will be given a prescription for a breast prosthesis (if needed).

When do you need to see your surgeon?

Call your surgeon's office to schedule a follow-up appointment. This appointment is usually 1 to 2 ½ weeks after your surgery.

If you have a drain in place, talk with your surgeon about when to schedule your follow-up appointment.

Pain Medicines

Important

Call your primary care provider or surgeon right away if you have unusual feelings after taking a pain medicine (such as feeling dizzy or itchy, have nausea or a rash). Stop taking the medicine right away.

What to remember when taking pain medicines

- Some pain medicines (like Tylenol®) have acetaminophen. Taking more than 4,000 milligrams (4 grams) of acetaminophen in 24 hours may damage your liver. Acetaminophen is also found in some cough and cold medicines, too.
- Do not drink alcohol while taking pain medicine.
- Do not drive any motor vehicles while taking opioids or pain medicines that make you sleepy.
- Eat a well-balanced diet and drink six to eight 8-ounce glasses of water each day. If you are constipated, talk with your surgeon or pharmacist on what you can do.
- Taking your pain medicine with a small amount of food may be helpful to control stomach upset.
- If you are running low on a prescription pain medicine and you still feel you need it to help manage your pain, please call the doctor who prescribed this medicine. Together, you and your doctor will talk about the best way to manage your pain.

Your pain should lessen every week. Take the pain medicine as directed by your surgeon to help ease your pain.

You may also continue to use integrative therapies to help manage your pain. These include relaxation techniques, listening to music or relaxation CDs, visualization or guided imagery, massage, acupuncture or aromatherapy.

Arm Exercises After Breast Surgery or Axillary Surgery (When the Drain is in Place)

After breast surgery or axillary surgery, you may need to have a drain. The drain will help reduce fluid from collecting under your skin.

Your shoulder on the side of the surgery may get stiff and sore. To help prevent this, it is important to do arm exercises.

However, too much movement of the shoulder can cause an increase in fluid in the arm. It can also increase the time the drain has to stay in place.

While the drain is in place, you should do the exercises on the following pages every day. This is a safe way to help keep your shoulder from getting stiff and sore.

Important

- Do not do repetitive arm movements on the side of the drain (such as vacuuming, raking, painting walls, digging or sanding).
- Avoid arm movements higher than 90 degrees (shoulder level) until the drain is removed. You may do basic, daily activities, such as combing or washing your hair, but limit these movements.
- Do not lift more than 5 pounds (such as full laundry baskets, bags of groceries or children).
- Do not do more arm exercises than those on pages 45 to 46.

Arm Exercises When the Drain is in Place

Do the following exercises with your arm on the side of the surgery.

- Hold a small ball or a rolled-up washcloth in your hand.
- Squeeze your hand tightly 5 times.
- Repeat one more time.

Do this exercise at least 2 times each day.



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- Hold your arm against your side at a right angle.
- With your arm against your side, roll your shoulder all the way in and then all the way out.
- Go only until you feel pulling, no pain, and stop.
- Do 5 times.
- Try to gently go a little farther each time.
- Repeat 2 times each day.

- Stand sideways to a wall.
- Place your arm, from elbow to hand, flat against the wall.
- Walk your arm up the wall as far as you can, until elbow is at shoulder height, but no higher.
- Hold for 5 seconds.
- Walk your arm back down to your side.
- Repeat 2 times each day.



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- Stand facing a wall.
- Place your arm, from elbow to hand, flat against the wall.
- Walk your arm up the wall as far as you can until your elbow is at shoulder height, but no higher.
- Hold for 5 seconds.
- Walk your arm back down to your side.
- Repeat 2 times each day.

Arm Exercises After Breast Surgery or Axillary Surgery (When You Have No Drain or the Drain is Out)

These exercises will help you regain your shoulder range of motion.

Do them slowly until you feel pulling, not pain.

Do each exercise 5 to 8 times each, 2 to 4 times each day.

Shoulder Flex, Lying Down



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- Lie on your back.
- Holding a cane or broom handle, slowly raise your arms over your head.
- Return to the starting position. Relax.

Scissors



A

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B

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- Sit in a chair with a back.
- Put your arms in front of you. (A)
- Gently move your elbows back as you squeeze your shoulder blades together. (B)
- Return to the starting position.

Wall Walks, Forward

- Face the wall.
- Raise your arm forward, in front of your body. Slide your hand up the wall.
- Take a deep breath and relax into the stretched position.
- Return to the starting position.



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Wall Walks to the Side

- Stand sideways to the wall.
- Raise your arm out to the side. Slide your hand up the wall.
- Take a deep breath and relax into the stretched position.
- Return to the starting position.



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Ball Squeezes

- Hold a small ball or towel roll.
- Gently squeeze it.
- Hold for 5 seconds.
- Relax.

Chapter 6: Jackson-Pratt Drain

The Jackson-Pratt drain is tubing with an attached bulb that promotes draining from a surgical incision. Draining extra fluid helps your tissue heal.

The color of the fluid will usually change from a bright red (right after surgery) to a straw-colored yellow. The fluid may have small blood clots or tissue debris. This is normal.

How to Care for the Jackson-Pratt

- Do not ever disconnect the bulb or take it apart.
- Keep the bulb compressed all the time, except when you empty it. The compression creates the suction to drain the fluid.
- There is usually more fluid in the bulb the first few days after surgery. Empty the bulb when it is half full. (The bulb does not make enough suction when it is too full.)
- Each time the bulb is emptied write down the amount of drainage on the chart on page 53.
- As the amount of drainage decreases, empty the bulb at the same time every day (usually at bedtime). Keep track of the totals on page 53.
- Follow any instructions your surgeon gives you about:
 - how to take care of your dressing
 - when you can take a shower or tub bath.
- Drain tubes are stitched in place and should not slip out. Your nurse will show you how to secure your drain tube before you leave the hospital.

How to Empty the Jackson-Pratt

- Wash your hands with soap and water.
- Open the stopper to release suction.
- Empty the bulb into the measuring cup that is sent home with you from the hospital. To do this:
 - Open the stopper cap.
 - Turn the bulb upside-down over the measuring cup. You may need to squeeze the bulb to completely empty it.
 - Set the measuring cup aside.
- Compress the bulb by folding it in half. Squeeze it tightly, making a fist. Replace the stopper while the bulb is compressed.

- Check to make sure the tube is secured after emptying the bulb.
- Measure the drainage and write down the amount on the chart on page 53. If you have more than one drain, figure the totals separately.
- Flush the drainage down the toilet.
- Wash your hands with soap and water.

When to Strip the Jackson-Pratt

- Strip the Jackson-Pratt only if your surgeon has given you instructions to do so.

How to Strip the Jackson-Pratt

If your surgeon has told you to strip the Jackson-Pratt, follow these steps.

- Pinch the top of the tubing close to your body with your thumb and index finger
- Moisten your other thumb and index finger with hand lotion, Vaseline® or rubbing alcohol.
- Squeeze and slide your fingers along the tubing toward the bulb, pinching it all the way down.

When To Call Your Surgeon

Call your surgeon if:

- the drain comes out
- the bulb or tube is damaged
- the bulb does not stay compressed after closing
- there is an increase in bloody fluid in your drain
- you have signs or symptoms of infection:
 - chills or a temperature higher than 101 F
 - foul odor or drainage from the tube insertion site (where the tube enters your body)
 - increased redness, swelling or drainage from the insertion site.
- you have any questions or concerns.

Jackson-Pratt Drainage Chart

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Date	Time	Time	Time	Daily Total (mL)
Tube 1				
Tube 2				
Tube 3				

Chapter 7: Lymphedema

How to Reduce the Risk of Lymphedema After Lymph Node Biopsy or Surgery

The lymphatic system removes extra fluid from body tissue into the bloodstream.

Lymphedema is the swelling of body tissue that can be caused by tissue damage or lymph node removal. Some people without cancer get lymphedema but the main cause in the U.S. is cancer or cancer treatment, such as surgery, radiation or lymph node removal.

This swelling most often occurs in your arm or leg. Only the side of your body that had damage or nodes removed would be affected.

Lymphedema can develop right away after surgery or many years later. All people who have had lymph node surgery have the potential to develop lymphedema.

How to Lower Your Risk

There is no way to prevent lymphedema but there are guidelines for reducing your risk of developing it.

You will see and hear a lot of information about lymphedema “prevention.” It focuses on limiting things that can cause swelling in the affected area.

These sources usually tell people who could develop lymphedema to do the same things as people who already have it. This can be confusing.

There is no proof that limiting all things that could cause swelling will keep you from getting lymphedema. Some people are careful to follow all of the limitations and still develop lymphedema. Some people do nothing after surgery and cancer treatment and never have problems with swelling.

Risk-reduction guidelines

The guidelines below have the most evidence-based proof:

- Early detection is extremely important to prevent severe swelling and problems using the affected area over time.
- You are more likely to get lymphedema if you are obese. Talk with your primary care provider about a healthy weight for you.
- You will be less likely to have swelling if you have more muscle mass in your arm or leg. Exercise to improve muscle mass is beneficial.

The biggest risk factor for developing lymphedema is lymph node removal. Because of this, your health care providers recommend that you see a certified lymphedema therapist after lymph node biopsy or removal.

It is important that you know what symptoms to watch for during and after treatment. The sooner you recognize symptoms, the easier they will be to treat.

What You Need to Do

- If you do not have an appointment to see a certified lymphedema therapist after lymph node removal, ask your primary care provider or surgeon for a referral.
- Talk with your primary care provider if you have concerns about your weight.

What to Watch For

- Check for early symptoms of lymphedema:
 - changes to your skin
 - skin feels sore or tight
 - your arm or leg feels heavy
 - you have a cut or burn that does not heal
 - your clothing feels tighter
 - your rings, shirts, pants or socks do not fit as well.

- You will often hear that you should not get blood pressure or blood draws in the arm that had lymph node removal. Research does not show that this will cause lymphedema.
 - Talk about this with your health care provider or surgeon. Together, you can decide if you want to limit blood pressures and blood draws on the side you had surgery.
 - You should tell all members of your health care team that you have had a lymph node biopsy or removal and are at risk for lymphedema.

Check Your Skin

Get in the habit of checking your skin for signs of increased swelling, or tight or thickened tissue. Look at your skin creases to see if they are thicker.

Do this often. Symptoms do not usually show up and go away. Usually, when lymphedema is starting, symptoms will slowly get worse over time.

Whom to Call

Tip

For a list of resources to learn more about lymphedema, go to page 74.

- Call your health care provider **right away** if you have:
 - **rapid, severe swelling**
 - redness, warmth or tenderness in the affected area
 - blisters or rash
 - chills
 - fever
 - questions or concerns for infection.
- For specific information on your own medical history and risk of developing lymphedema, make an appointment to see a cancer rehabilitation specialist. (These doctors are experts in managing and treating lymphedema.)
 - You do not need a referral to schedule this appointment.
 - Call 612-863-2123 to make an appointment.



Chapter 8: Cancer Survivorship

Cancer Survivorship Care Plan

“Breast Cancer: A Survivor’s Guide to Hope and Endurance”

In the back pocket of this book, you will find a copy of “Breast Cancer: A Survivor’s Guide to Hope and Endurance.” This guide was written for breast cancer survivors, by cancer survivors. It is not a medical resource, but a way to share what breast cancer survivors have learned about their own survivorship experiences.

Life changes the moment you are diagnosed with cancer. In that moment, you become a cancer survivor. The goal of the Cancer Survivorship Care Plan is to help you and your family start to manage the impact of your cancer experience. It will focus on maintaining and improving your quality of life, as you define it, during and after your treatment.

You will have a survivorship visit with an advanced practice provider at your surgeon or medical oncologist’s office. When you have this visit will depend on the type of treatment you have for your cancer.

Together, you will create a plan for your ongoing health care. During this visit, your provider will:

- review your recent medical history
- talk about physical health changes
- talk about and help you manage side effects of cancer treatment.

After treatment, it will take some time for you to heal and start to feel better. Some of the changes you may experience may include:

- breast changes
- skin numbness or tightness
- weight gain
- hot flashes
- skin and nail changes
- fatigue (tiredness)
- thinking (cognitive changes)
- intimacy and sexuality
- infertility
- insomnia
- nutrition
- emotional recovery.

If you have any questions or concerns about cancer survivorship, please talk with a member of your health care team.



Chapter 9: Support Services

Going through breast cancer treatment can be overwhelming. There is a lot of information to take in and understand. You may be experiencing many different emotions and physical changes. It is important to take time to care for yourself before, during and after your treatment.

There are a variety of programs and services available to you during your treatment and survivorship. Support services are designed to help you cope with the feelings of grief, anger, sadness, fear, and the overall adjustment to life with cancer. They provide an opportunity to talk about your overall well-being and how best to navigate through breast cancer. These services are also a way to connect with other people who have similar concerns.

Support services are available on an individual basis and in many group settings. Ask your oncology social worker or nurse navigator for more information on the support services listed and how to make an appointment.

Support services included in this chapter are:

- support groups
- counseling
- social services
- spiritual care
- integrative therapies.

Support Groups

Support groups are designed for people and families affected by cancer. These groups provide a place to connect with others and share thoughts, feelings and ask questions. Groups are usually led by a trained oncology professional and open to anyone.

- General support groups: These groups are for people with any type of cancer diagnosis. They often include talk about general topics such as adjustment and coping.
- Breast cancer support groups: These groups are for women who have breast cancer and who are at any phase of treatment or experience.
- Metastatic breast cancer groups: These groups are for women who have metastatic breast cancer. It provides a place to share thoughts, feelings and information with each other.

Counseling

Sometimes people need to talk with a licensed, skilled professional about the emotional impact of being diagnosed with cancer and receive support and guidance in addressing individual concerns. Counselors are available to meet with you alone as well as with your spouse, partner or family members.

Social Services

An oncology social worker is available to support you and your family during your treatment and recovery. A social worker can:

- help find information and get referrals to community resources
- talk about any concerns that may come up during treatment such as financial, employment or transportation
- provide individual and family counseling to help you and your family cope with the emotional side of cancer
- help guide adults on how to talk with children about cancer and the changes it can often bring to the family.

Spiritual Care

Through spiritual care services, support is offered for individuals and families to address concerns and feelings raised by the diagnosis, and to encourage each person's own journey of faith and hope. The sacraments and rituals of numerous faith traditions are available.

Integrative Therapies

Tip

For more information on services offered by the Penny George Institute, or to schedule an appointment, call 612-863- 3333.

The Penny George Institute for Health and Healing offers education to promote wellness, the prevention of illness and healing.

Integrative therapies treat the whole person — body, mind and spirit — at the same time. It puts the person at the center to restore or maintain their health.

Types of integrative therapies include:

- integrative nutrition
- acupuncture
- healing touch
- therapeutic massage
- guided imagery
- reflexology
- therapeutic yoga.



Chapter 10: Resources and Notes

Breast Cancer

Tip

Some Allina Health cancer resource centers have a resource library where you can look up information or check out books on different topics such as breast cancer.

It is common to go to the Internet for information and answers to questions when diagnosed with cancer. Keep in mind that there is a lot of information and advice on the Internet that is not always accurate or specific to your cancer and situation.

Please do not hesitate to ask a member of your health care team if you have any questions or concerns. Listed below are websites that can provide helpful resources and information:

- **Allina Health**
 - allinahealth.org/breastcare
- **American Cancer Society**
 - cancer.org
 - 1-800-227-2345
- **ASCO's Cancer.net**
 - cancer.net
- **Breast Cancer Awareness Association (local)**
 - breastcancereducation.org
 - 763-548-1306
- **Cancer Support Community**
 - cancersupportcommunity.org
- **CancerCare**
 - cancercare.org
 - 1-800-813-4673
- **Living Beyond Breast Cancer**
 - lbbc.org
- **National Breast Cancer Foundation**
 - nationalbreastcancer.org
- **National Cancer Institute**
 - cancer.gov
 - 1-800-422-6273
- **National Comprehensive Cancer Network Breast Cancer Guidelines**
 - nccn.org

- **Susan G. Komen for the Cure**
 - komen.org
 - 1-877-GO-KOMEN
- **The Oncology Institute of Hope and Innovation**
 - theoncologyinstitute.com
- **Triple Negative Breast Cancer Foundation**
 - tnbcfoundation.org
- **Young Survival Coalition**
 - youngsurvival.org

Lymphedema

- **Lymphatic Education & Research Network**
 - lymphaticnetwork.org
- **Lymphology Association of North America**
 - clt-lana.org
- **National Cancer Institute**
 - cancer.gov
- **American Cancer Society**
 - cancer.org
- **National Lymphedema Network**
 - lymphnet.org

Quitting Tobacco

Allina Health

- Tobacco Intervention Program at Abbott Northwestern Hospital
 - 612-863-1648
- Tobacco Intervention Program at Mercy Hospital
 - 763-236-8008
- Tobacco Intervention Program at River Falls Area Hospital
 - 715-307-6075
- *United Hospital Lung and Sleep Clinic Tobacco Cessation Program
 - 651-726-6200
- *Penny George™ Institute for Health and Healing (LiveWell Center) tobacco intervention coaching
 - 612-863-5178

***There may be a cost to you.
Check with your insurance provider.**

Other

- Quit Partner
 - 1-800-QUIT-NOW (1-800-784-8669) or quitpartnermn.com
- Minnesota Department of Health
 - health.state.mn.us/quit
- online tobacco cessation support
 - smokefree.gov
- American Lung Association/Tobacco Quit Line
 - 651-227-8014 or 1-800-586-4872
- Chantix® GetQuit Support plan
 - 1-877-CHANTIX (1-877-242-6849) or get-quit.com
- financial aid for Chantix® or Nicotrol® inhaler
 - 1-866-706-2400 or pfizerrxpathways.com
- *Mayo Clinic Nicotine Dependence Center’s Residential Treatment Program
 - 1-800-344-5984 or 1-507-266-1930
- Plant Extracts aromatherapy
 - 1-877-999-4236

*There may be a cost to you.
Check with your insurance provider.

Transportation

Tip

Some insurance companies cover transportation costs. Be sure to check with your insurance provider to see if you are eligible.

- **Abbott Northwestern Hospital’s transportation program**
 - 1-800-258-1210
 - Provides van service to the hospital and affiliated metropolitan area physicians’ offices for patients coming from Greater Minnesota and western Wisconsin. Riders will be billed for the ride and must be ambulatory.
- **American Cancer Society Road to Recovery**
 - 1-800-227-2345
 - acs.org
 - Provides transportation to and from treatment for people with cancer who do not have a ride or are unable to drive themselves. Must call ahead to register and based on availability.
- **Metro Mobility**
 - 651-602-111
 - metromobility.org
 - Transportation service for those that are unable to use public transportation. Application required and must meet eligibility guidelines.

Financial

Call your oncology social worker to find out if you are eligible for any financial grant programs. Listed below are some programs that are used often.

- **Allina Health Financial Services and Allina Partners Care**
 - 612-262-9000 or 1-800-859-5077
 - allinahealth.org/Customer-Service/Financial-assistance
- **Angel Foundation**
 - 612-627-9000
 - mnangel.org
 - The Emergency Financial Assistance program provides assistance to adults in active treatment for their cancer for their basic, non-medical living expenses such as food, gas, utilities and rent or mortgage payments. Must meet eligibility guidelines.
- **Cancer Care**
 - 1-800-813-HOPE (4673)
 - cancercare.org
 - Financial Assistance Program Helps with treatment-related costs, such as transportation, home care and child care. Must meet eligibility guidelines.
- **Social Security Administration**
 - 1-800-772-1213
 - ssa.gov
 - Information regarding applying for Social Security and disability benefits, etc.
- **Med Eligible Services**
 - (MES) 763-585-8400
 - Application assistance with Social Security
 - Disability and Supplemental Security Income

Insurance/Legal

- **Cancer Legal Care**
 - 651-917-9000
 - cancerlegalcare.org
 - Provides free legal care to Minnesotans affected by cancer who otherwise have no access to an attorney's help for the legal issues that directly impact their health and quality of life.
- **Senior Linkage Line**
 - 1-800-333-2433
 - seniorlinkageline.com
 - Information on Medicare, Long term care and health insurance, including help comparing plans and policies.
- **Disability Hub**
 - 1-866-333-2466
 - disabilityhubmn.org
 - Disability Hub MN offers tools and services so people with disabilities can get up-to-date information about community resources, including work, housing and benefits.

Lodging

- **The Hope Lodge American Cancer Society**
 - 612-379-6352
 - 2500 University Ave SE, Minneapolis, Minn.
 - A free place to stay for patients and a caregiver for those who live 40 miles or greater from where they are receiving treatment.
- **American Cancer Society Hotel Partners Program**
 - 1-800-227-2345
 - The American Cancer Society has lodging agreements with several area hotels to provide reduced rate lodging for patients and families traveling for treatment.
- **Sheraton Minneapolis Midtown Hotel**
 - Connected to Abbott Northwestern by skyway and offers a free shuttle service to and from the hospital. For reservations or more information, visit the Sheraton web site or call toll-free 800-325-3535 or 612-821-7600.

General Support

- **Allina Support Groups**
 - allinahealth.org/cancercare
- **Gilda's Club Twin Cities**
 - 612-227-2147
 - Gildasclubtwincities.org
 - Clubhouse with supportive activities for patients and families
- **Angel Foundation**
 - 612-627-9000
 - mnangel.org
 - Facing Cancer Together is offered to Minnesota families with children (ages 0-26) who are facing a parental or caregiver cancer diagnosis. Program activities are provided free-of-charge to any local family.
- **Pathways**
 - pathwaysminneapolis.org
- **Penny George**
 - wellness.allinahealth.org/servicelines/802
- **CaringBridge**
 - caringbridge.org
- **Open Arms**
 - 612-872-1152
 - openarmsmn.org
 - Free meal delivery for those who are in active treatment and meet criteria.

Patient and Caregiver Mentoring Programs

- **Firefly sisterhood**
 - fireflysisterhood.org
 - Local and specific to breast cancer
- **Jack's Caregiver Coalition**
 - jackscaregiverco.org
 - Local caregiver support for men

Wigs, Prosthesis and Post-surgery Garments

Please ask a member of your health care team for a list of local resources that provide these items.

High-risk and Hereditary Breast Cancer Resources

- **Bright Pink**
— brightpink.org
- **FORCE**
— facingourrisk.org

Cancer Survivorship Resources

- **American Association for Cancer Research**
— aacr.org
- **Cancer.Net**
— cancer.net/patient/survivorship
- **Cancer Survivors Network (ACS)**
— acscsn.org
- **Life After Cancer Treatment (NCI)**
— cancer.gov/cancertopics/life-after-treatment
- **National Cancer Institute**
— survivorship.cancer.gov
- **National Coalition for Cancer Survivorship**
— canceradvocacy.org
- **Patient Advocate Foundation**
— patientadvocate.org

Resources to Help Children Cope

Simple Talk for Tough Times: Talking with Children about Cancer

This is a how-to-guide for moms and dads and aunts and uncles and grandmas and grandpas and all adults.

- Free book provided by Allina Health. Ask your health care team how to get a copy.)
- Visit allinahealth.org/simpletalk to learn more.

Simple Talk program

When a family is touched by illness, everyone feels its effects in their own way. This program is dedicated to meeting the needs of parents diagnosed with cancer, who have children under age 18.

Based on the book *Simple Talk for Tough Times* this program can guide adults in the conversations they have with the children in their lives about a cancer diagnosis and help them cope with the ongoing changes cancer often brings.

Simple Talk offers:

- in-person sessions with you and your family members
- resources including books, journals, and other written material, that you will be able to take home and use
- referrals to community programs and other online resources
- Angel Backpacks — provided by the Angel Foundation and filled with activities and items for each individual child
- special events.

Oncology social workers are available to meet with you and your family members during this difficult time.

- Abbott Northwestern Hospital: 612-863-0200
- United Hospital: 651-241-5111
- Mercy Hospital: 763-236-0808
- Mercy Hospital - Unity Campus: 763-236-5600

Websites

- **Kids Konnected**
— kidskonnected.org
- **Angel Foundation**
— mngel.org
- **Children's Treehouse Foundation**
— childrenstreehousefdn.org

Books

There are many books available that offer education, support, and guidance for children and parents when effected by a cancer diagnosis. Some books are geared toward a specific age group or topic. Ask your oncology social worker for a complete list or visit your cancer resource center. Listed below are some books that have been helpful to others.

Because Someone I Love Has Cancer: Kid's Activity Book

American Cancer Society

A spiral bound book offering creative activities for children ages 6 to 12 to encourage the expression of feelings and coping skills as they deal with uncertainty and change. To order call 1-800-227-2345 or visit cancer.org.

Butterfly Kisses and Wishes On Wings: When someone you love has cancer...a hopeful, helpful book for kids

Ellen McVicker

A gentle story with illustrations about a child whose mother has cancer. The story line lends itself to a simple and clear understanding of cancer.

Chemo Cat

Cathy Nilon

Luca and Mama cat, aka Cat-Cat, personified as a family of cats, take you through the emotions and realities of that most difficult time. It is meant to open a dialog with children without adding to their fears. It explains the changes they can expect when their mother loses her hair and is sick from chemotherapy and can't be with them all the time.

Kemo Shark

H. Elizabeth King

A 16-page illustrated pamphlet that uses a shark character to help explain a parent's chemotherapy to children ages 4 to 10. Available in English and Spanish. Kidscope, Inc., Atlanta, GA. 1996. To request a free copy call 404-892-1437 or visit kidscope.org. Electronic version can be downloaded at website.

My Parent Has Cancer And It Really Sucks: Real-life advice from real-life teens

Maya Silver and Marc Silver

Currently one million American teenagers live with a parent who is fighting cancer. It's a hard blow for those already navigating high school, preparing for college, and becoming increasingly independent. This is the first book written especially for teens to help during this tough time.

When Your Parent Has Cancer: A Guide for Teens

National Cancer Institute

A booklet that offers information on cancer treatment, the ways teens can talk to family and friends, changes in the family, taking care of yourself and finding support. National Cancer Institute, Baltimore, MD Individual copies at no charge at 1-800-422-6237 or cancer.gov.

When a Parent Has Cancer: A Guide to Caring for Your Children

Wendy S. Harpham

A 2-book package, written by a physician who is also a parent and cancer survivor. Outlines approaches for preventing and responding to common problems, and offers advice on how to help children deal with anxiety. Important points for parents in bold for easy reading. Includes a chapter on teens.

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Health is a journey that happens beyond the walls of your clinic or hospital and we will be there to help you – whether it's a question that pops into your head at midnight or recalling the date of your last tetanus shot. When you sign up for an Allina Health account online, you get better communication with your clinic, hospital and provider; faster answers and your (and your loved one's) health information organized and at your fingertips anytime.



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Affordable Care Act – Section 1557

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 - ◊ qualified sign language interpreters, and
 - ◊ written information in other formats (large print, audio, accessible electronic formats, other formats)
- provides free language services to people whose primary language is not English, such as:
 - ◊ qualified interpreters, and
 - ◊ information written in other languages.

If you need these services, ask a member of your care team.

If you believe that Allina Health has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, gender identity or sex, you can file a grievance with:

Allina Health Grievance Coordinator
P.O. Box 43
Minneapolis, MN 55440-0043
Phone: 612-262-0900
Fax: 612-262-4370
GrievanceCoordinator@allina.com

You can file a grievance in person or by mail, fax or email. If you need help filing a grievance, the Allina Health Grievance Coordinator can help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.





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