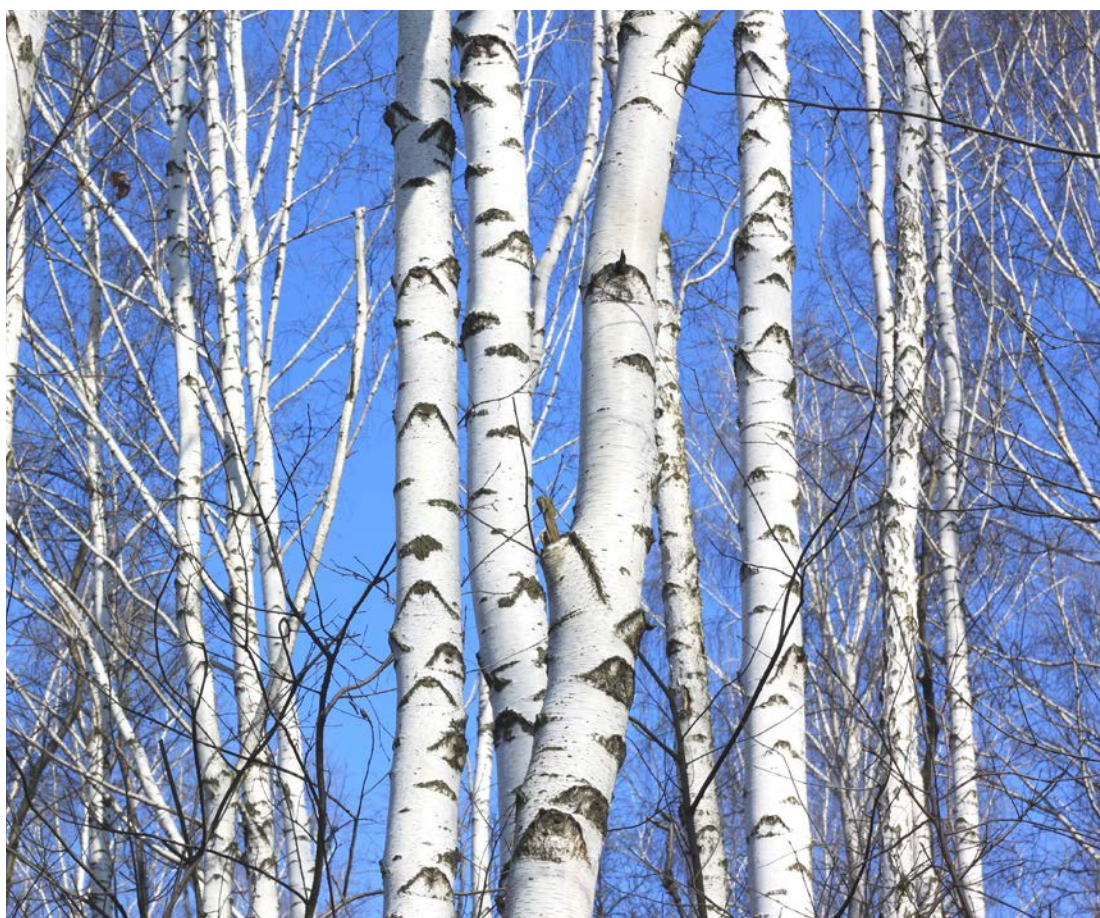


Understanding Gynecologic Cancer

Ovarian, fallopian tube or primary peritoneal cancer



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Ovarian, fallopian tube or primary peritoneal cancer

First 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rapidly changing state of scientific and medical knowledge, some of the facts and recommendations in the manual may be out-of-date by the time you read it.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 their 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 a gynecologic 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 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 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.

Please try to read the entire book before you begin your treatment. 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 esophageal cancer. An advance practice provider and doctor work together as a team. Advance practice providers include clinical nurse specialists, nurse practitioners and physician assistants.

- **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.

- **Gynecologist**

A gynecologist is a doctor who specializes in diagnosing and treating diseases of the female reproductive organs.

- **Gynecologic oncology surgeon**

A gynecologic oncology surgeon is a doctor who specializes in diagnosing and treating cancers of the female reproductive organs. This provider has advanced training in cancer, cancer staging and treatments.

- **Infusion nurse**

An infusion nurse is a registered nurse who specializes in giving medicines and fluids through an intravenous (IV) line, a central line or a port.

- **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 clinic nurse**

An oncology clinic nurse works with doctors in surgical oncology, medical oncology or radiation oncology to review and coordinate your care. Your nurse will educate you about your cancer treatment and help you manage symptoms.

- **Oncology dietitian**

An oncology dietitian will help you meet your nutritional needs. This provider can help provide answers to your nutrition questions. If you are going through treatment, your dietitian can help you if eating is challenging.

■ **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.

■ **Palliative care team**

Palliative care is for anyone who is in any stage of an advanced illness. This is care that provides relief from the symptoms, pain and stress of a serious illness. The goal is to improve quality of life for both you and your family. A care plan is created to help you live each day to the fullest and be as independent and comfortable as possible.

■ **Pathologist**

A pathologist is a doctor who works in the medical laboratory. This provider diagnosis disease by examining cells, body fluids and tissue samples.

■ **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.

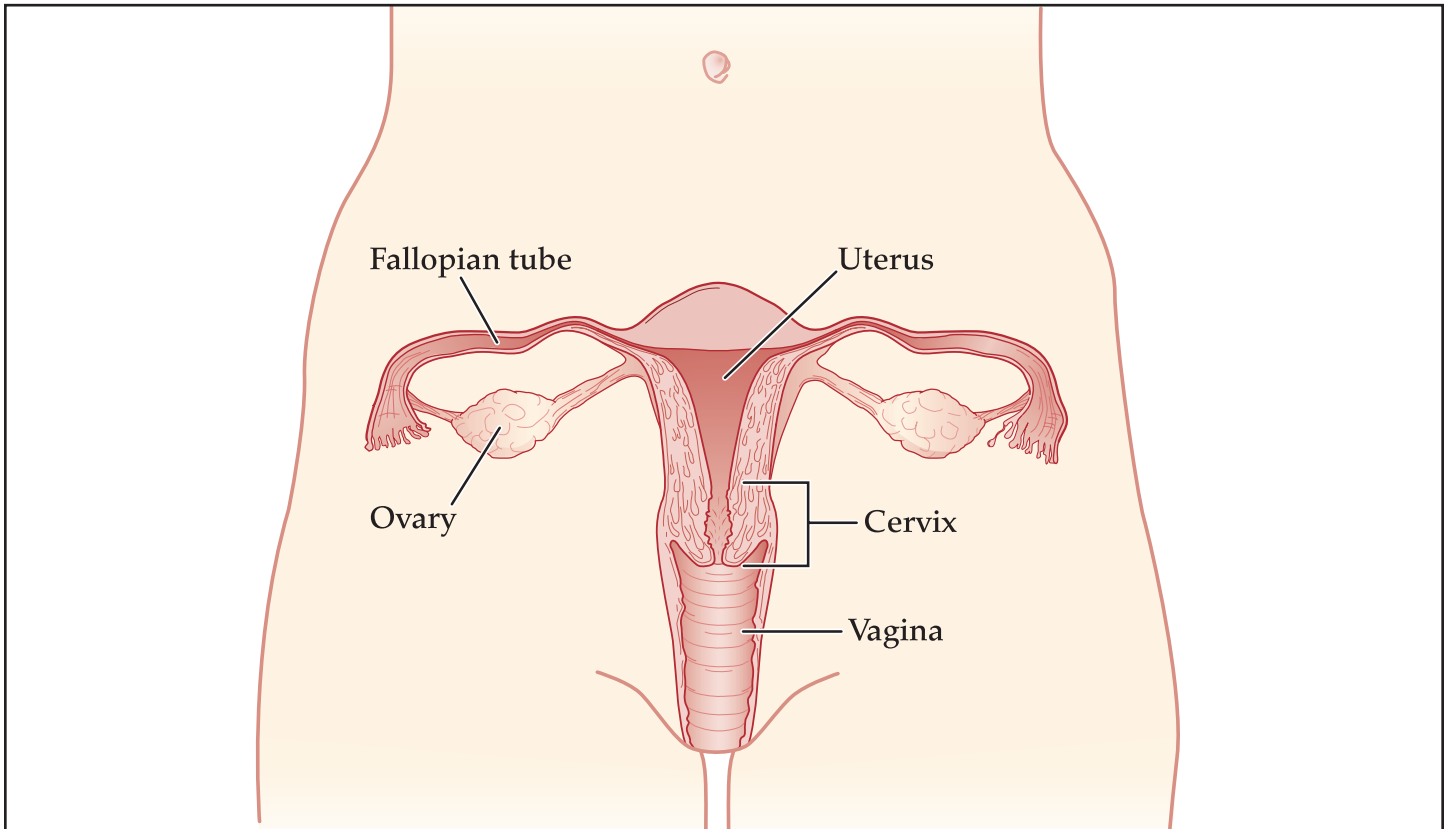
■ **Radiologist**

A radiologist specializes in X-ray. This provider will use radiology tests to look at images of the cancer.

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

Understanding Gynecologic Cancer

The Female reproductive system



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- **Uterus** (womb) is where a baby grows when a woman is pregnant.
- **Ovaries** produce eggs and hormones.
- **Fallopian tubes** carry eggs from the ovaries to the uterus.
- **Cervix** is the narrow neck-like part of the uterus that leads to the vagina. It is found at the top of the vagina.
- **Cysts** are fluid-filled sacs found in the ovary.
- **Fibroids** are non-cancerous tumors usually found in the wall of the uterus.
- **Polyps** are finger-like growths found in the uterus.
- **Lymph nodes** act like filters to remove dead cells and bacteria (germs) from the body and keep them out of the bloodstream.
- The **peritoneum** is the tissue that lines the abdominal wall and covers organs in the abdomen.
- The **appendix** is a finger-like pouch attached to the large intestine in the lower right area of the abdomen.
- **Omentum** is a large piece of fatty tissue that covers the abdomen (including the colon, liver and stomach).

Cancer

Cancer is a disease in which cells in the body grow out of control. It can start almost anywhere in the body.

Gynecologic cancer is any cancer that starts in the female reproductive organs.

Ovarian cancer

Ovarian cancer is cancer that starts in the ovaries. Your ovaries are female reproductive glands on either side of the uterus that produce eggs and hormones. One in 72 women will develop ovarian cancer in her lifetime.

Fallopian tube cancer

Fallopian tube cancer is cancer that can start at the end of the fallopian tube, near the ovary, and spread to the ovary. Your fallopian tubes carry eggs from the ovaries to your uterus.

Primary peritoneal cancer

Primary peritoneal cancer is cancer that forms in the peritoneum and has not spread there from another part of the body. This type of cancer sometimes spreads to the ovary. The peritoneum is the tissue that lines the abdominal wall and covers organs in the abdomen.

Risk Factors

In most cases, it is not possible to know exactly why one person gets cancer and another person does not get cancer.

Research has shown that there are risk factors that can increase a person's risk of getting cancer. The most common risk factors include:

- **family history** — having a mother, sister or daughter who has had the disease
- **personal history of cancer** — if you have had breast, uterine, colon or rectum cancer
- **age** — being older than age 55
- **obesity** — being overweight
- **never pregnant** — older women who have never been pregnant
- **BRCA carrier** — BRCA1 and BRCA2 are genes that make a protein to help control cell growth. Everyone has these types of genes. When either of these genes are altered it could increase your risk of getting cancer. When some altered genes are inherited (run in families), it can increase the risk of breast and ovarian cancers.

Diagnostic Tests or Procedures

Biopsy

In most cases, a biopsy needs to be done to make a diagnosis of cancer. A tissue sample is removed using a needle or surgery. The sample is sent to a lab to test cells for possible cancer. The results will identify the type of cancer and help determine treatment options.

Lab tests

CA-125 is a test that measures the amount of protein CA-125 (cancer antigen 125) in your blood. A small amount of blood is collected and sent to a lab. The results can help monitor how well cancer treatments are working or if cancer has come back.

Because high CA-125 levels can be a sign of other conditions besides ovarian cancer, this test is not used to screen women at low risk for the disease. A CA-125 blood test is most often done on women already diagnosed with ovarian cancer.

Imaging tests

You may need to have one or more of the following imaging tests:

- **CT (computed tomography) exam** uses X-ray and a computer to get an in-depth look at your internal organs, tissues, blood vessels and bones.

Depending on the type of CT exam you will be having, you may need to have an intravenous (IV) contrast injection. The contrast will help certain areas in your body show up more clearly on an image. You may need a blood test to check your creatinine level (kidney function) before you have the injection. There is a small chance you could develop a contrast reaction. Reactions normally occur right after the injection. They are usually mild.

- **MRI (magnetic resonance imaging)** uses a magnetic field to make three-dimensional (3-D) images of almost any part of your body. These images show the difference between normal tissue and abnormal tissue. This test does not use radiation.
- **PET (Positron Emission Tomography) scan** is a three-dimensional (3-D) view of any part of your body. A small amount of radioactive material, known as a tracer, is injected into your bloodstream. The PET scan creates colored pictures of chemical changes that take place in body tissues.

Important

An elevated (raised) CA-125 level could be caused by cancer, infection or inflammation.

Important

You may need to have additional imaging tests depending on the stage of your cancer. You and your health care team will work together to decide what is right for you.

- **Ultrasound** uses sound waves to “see” the inside of your body. A computer monitor shows the images from the sound waves. These images can provide information to help diagnose and treat a variety of diseases and conditions
- **X-ray** uses low doses of radiation to create images of the inside of your body.



Chapter 2: Gynecologic Cancer Treatments

You and your health care team will work together to decide the best treatment for your cancer. Your treatment will depend on:

- the stage of the cancer
- the size and location of the tumor
- the risk of the cancer coming back in the future
- your overall health.

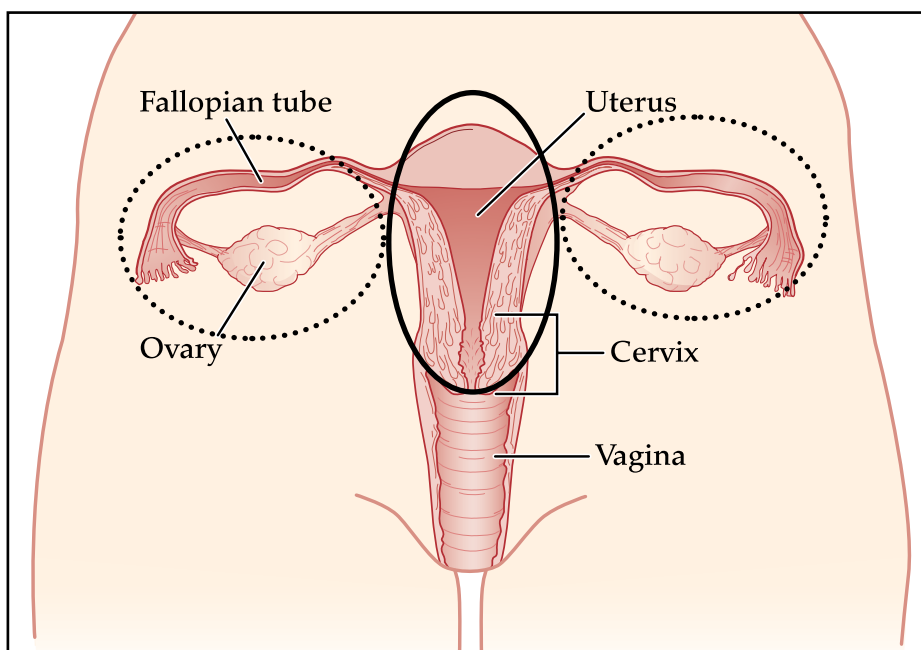
Treatment options may include one or more of the following:

- surgery
- chemotherapy
- radiation therapy
- 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 different types of surgery to treat gynecologic cancer.



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The parts removed during surgery.

———— Total Hysterectomy Salpingo-oophorectomy

Total hysterectomy

During a total hysterectomy, your uterus and cervix are removed.

Salpingo-oophorectomy

During a salpingo-oophorectomy, one or both of your ovaries and fallopian tubes are removed. (The term for this is unilateral or bilateral.)

- A salpingectomy is when only your fallopian tubes are removed.
- A oophorectomy is when only your ovaries are removed.

Important

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

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.

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.

Pathology Report

A pathology report will show the results of the tissue sample you had taken. It will provide information about your type of gynecologic cancer.

Staging

Stage is the extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.

There are four stages of gynecologic cancer. Stage 1 is the earliest stage. Stage 4 is more advanced.

Sentinel lymph node biopsy

Your surgeon may recommend having your lymph nodes examined 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.

A sentinel lymph node biopsy is the removal of the sentinel lymph node(s) to see if the cancer has spread.

Risks

The risks of a sentinel lymph node biopsy include:

- bleeding
- infection
- damage to nerves or surrounding tissue (this could cause numbness along the incision)
- seroma (a collection of fluid under the skin).

During your biopsy

- A small amount of clear, radioactive liquid is injected into the area around the cancer.
- During your surgery, your surgeon will also inject a blue dye into the area near the cancer.
- The liquid and dye are used to help identify the sentinel lymph node(s).
- Your surgeon will make a small incision and remove the sentinel lymph node(s).

Important

If you have sentinel lymph nodes removed, you have the potential to develop lymphedema.

See chapter 7 to learn more about lymphedema.

Follow-up Appointment

You will need to schedule a follow-up appointment with your surgeon 10 to 14 days after your surgery.

Please keep all follow-up appointments with your surgeon, even if you are feeling well.

After your biopsy

- You may have blue- or green-tinged urine or stools for a few days after the surgery. This is harmless and will go away.
- At the lab, a pathologist will look for the spread of cancer cells under a microscope. Your surgeon will give you the biopsy results in a few days.
- If cancer is found in a sentinel lymph node, your surgeon may talk with you about removing more lymph nodes in the same area. This procedure is called a lymph node dissection. Each lymph node that is removed will be sent to a lab for testing under a microscope.

Incision care

- You may put an ice pack on your incision. This may help relieve swelling, bruising and tenderness. Follow any instructions given to you by your surgeon.
- Keep the incision clean and dry for 48 hours. You may then remove the dressing and take a shower.
- Gently wash your incisions with soap and water. Pat dry. Do not rub or scrub your incision. Follow any additional instructions given to you by your surgeon.
- Do not take a tub bath, go into a pool or hot tub for 2 weeks after your surgery or until your surgeon says it's OK.

Activity

- Get regular activity. Try to walk for a total of 30 minutes each day. Increase the amount of time you walk as you can tolerate.
- Rest as needed.
- Slowly return to your regular level of activity.
- Save your energy by spreading out activities that make you tired.
- Follow your surgeon's instructions for how much you can safely lift.
- Do not drive while taking prescription pain medicines because it can impair your judgement and ability to operate the car safely. You can drive when your incision is comfortable enough to let you step on the brake quickly.

Food and beverages

- You may return to your normal diet. Eat well-balanced meals.
- Drink enough liquids.
- Avoid alcohol while you are taking prescription pain medicine.

Chemotherapy

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

During each IV treatment you can expect the following:

- You will have lab draws done before each treatment.
- You will go to your gynecologic oncologist's office, medical oncologist's office or a chemotherapy clinic.
- You will sit in a comfortable chair such as a recliner.
- You will have an 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.
- You will be watched closely during treatment for any reactions or intolerance to the chemotherapy.
- 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 gynecologic oncologist or medical oncologist will talk with you about chemotherapy and possible side effects.

Radiation Therapy

Tip

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. This is called a simulation. 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.

Targeted Therapies

Targeted therapies are medicines designed to target specific features of cancer cells and stop them from growing and spreading. Some possible side effects of targeted 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.

Clinical Trials

Allina Health Research

- **email:**
AHCIresearch@allina.com
- **phone:** 612-863-8716.

Allina Health is dedicated to staying on the cutting edge of cancer research. As part of this research, you have the opportunity to participate in promising new treatments for cancer at one of Allina Health's clinical research locations:

- Abbott Northwestern Hospital
- Mercy Hospital
- Mercy Hospital – Unity Campus
- United Hospital.

Allina Health Research partners with the Allina Health Cancer Institute to conduct high quality clinical trials (cancer treatment studies) for people with or at risk for cancer. Clinical trials are done to try to improve the prevention, detection and treatment of cancer.

In addition to clinical trials, cancer research studies are done to develop and test methods to enhance patient care, manage side effects of cancer treatments, and improve the effectiveness of cancer diagnostics and treatments.

National Cancer Institute-sponsored research studies are also offered at our Allina Health locations through the nonprofit Metro-Minnesota Community Oncology Research Consortium (MMCORC).

If you are interested in being part of a clinical trial, talk with your medical oncologist or reach out to the research team to see if there is a clinical trial that would be right for you.

Resources

- **Allina Health Research**
allinahealth.org/research
- **Cancer.Net®**
cancer.net/research-and-advocacy/clinical-trials
- **National Cancer Institute**
cancer.gov/about-cancer/treatment/clinical-trials

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 (pre-surgery physical) 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.

Health Care Directive

How to Get Started

Go to allinahealth.org/hcd.

- Print the form of your choice. Or, ask your health care provider for a copy.
- Read the [guide](#) if you need help filling out your health care directive.

You can also fill out a secure health care directive online. Go to account.allinahealth.org to create an account.

Planning for your future health care

A health care directive is a written document of your health care choices in case illness or injury prevents you from telling them yourself.

Members of your care circle (family, friends or others close to you) and your health care team use this to interpret and understand your wishes, goals and values for future health care.

You can write:

- who you want to make your health care choices (known as a health care agent)
- what kind of care and treatment you do or do not want
- your wishes about the quality of your life.

Quit Tobacco For Your Surgery

Learn More

Maybe you tried to quit tobacco already. Maybe this is your first time.



The good news is there are many ways to quit. It's important to choose methods that appeal to you.

It may take practice to find the best way for you to quit but keep working on it. You can do this!



Visit allinahealth.org/quit to learn more.

Tobacco and surgery risks

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

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.)

Did You Know?

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

Nicotine Replacement Therapy (NRT)

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.

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.

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 (varenicline 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!



Product-specific Resources

- financial aid Nicotrol® inhaler
 - 1-844-989-PATH (7284)
 - pfizerrxpathways.com
- Plant Extracts aromatherapy
 - 1-877-999-4236
 - plantextractsinc.com

Resources to help you quit

Allina Health (for your hospital stay)

- 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
- Tobacco Intervention Services at Allina Health United Hospital – Hastings Regina Campus
 - 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

Other

- Quit Partner
 - 1-800-QUIT-NOW (1-800-784-8669) or quitpartnermn.com
 - American Indian: 1-833-9AI-QUIT or aiquit.com
 - Spanish: 1-855-DEJELO-YA (1-855-335-3569) or quitpartnermn.com/es
 - asiansmokersquitline.org
- online tobacco cessation support
 - smokefree.gov
- American Lung Association/Tobacco Quit Line
 - 651-227-8014 or 1-800-586-4872
- *Mayo Clinic Nicotine Dependence Center's Residential Treatment Program
 - 1-800-344-5984 or 1-507-266-1930

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

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 (Include all prescription, over-the-counter, vitamins, herbal or natural products.)
- 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, comfortable pants, underwear and socks.

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

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.

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.

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 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.

Commonly Asked Questions

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 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.
- It is important not to skip meals. Eating 3 well-balanced meals is essential to maintain your health. It may be helpful to eat 5 or 6 small meals each day instead of 3 large ones. Include foods from 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. Drinking warm liquids (such as coffee or tea) may help with bowel movements.
- 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.

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?

If your uterus was removed, do not douche, have intercourse or place anything inside your vagina (including tampons) for 6 weeks.

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.

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 pain medicines that make you sleepy.
- Eat a well-balanced diet and drink six to eight 8-ounce glasses of liquids 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.

Chapter 6: Cancer Survivorship

Cancer Survivorship Visit

After Your 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:

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

An important part of your cancer care is what happens after your treatment. Allina Health Cancer Institute offers a program to optimize healing after treatment and help you get better as soon as possible.

During this visit, you will:

- review a summary of your cancer treatment, as well as your follow-up plan
- talk about your overall health including:
 - energy level
 - activity level
 - side effects from treatment
 - pain
 - sexual health
 - emotional health
 - nutrition concerns
 - financial concerns
- learn about the side effects of treatment, including long-term or “late effects,” and what to watch for and what you can do
- receive a personalized plan to promote your best physical and emotional recovery.

Ask your cancer care team if a survivorship visit is right for you.

Insurance coverage

This is a one-time appointment with an advanced practice provider. This visit is billed as a provider office visit. Please call your insurance provider to find out if this visit is or isn't covered under your plan, and how much you may have to pay yourself.



Chapter 7: Cancer Rehabilitation and Lymphedema

Cancer Rehabilitation Program

Tip

The Cancer Rehabilitation Program can help you with core strength and pelvic floor therapy.

Your health care team may refer you to the Cancer Rehabilitation Program. This program offers consultations by health care providers who specialize in physical medicine and rehabilitation, and therapists who have advanced training in cancer rehabilitation.

These health care providers provide care options to address the unique needs of people who have cancer such as:

- lymphedema
- balance and coordination
- core strength
- pelvic floor strength
- pain and fatigue
- muscular strength and range of motion
- thinking and processing information.

If you are at risk for developing lymphedema, you will be scheduled to see a certified lymphedema therapist. They will teach you about lymphedema including symptoms to watch for and what to do if you have symptoms. You will also learn how to do range of motion exercises.

For more information, please talk with a member of your health care team.

Lymphedema

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’s 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

- 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.

Tip

For a list of resources to learn more about lymphedema, go to page 62.



Chapter 8: Support Services and Resources

Going through 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. These services are also a way to connect with other people who have similar concerns.

Ask your oncology social worker or nurse navigator for more information on the support services listed and how to make an appointment.

Support services are available on an individual basis and in many group settings.

Fertility

Cancer treatment could affect your fertility (being able to have a baby). Talk with your health care team about how your treatment may or may not affect your fertility and what options are available to you.

Genetic Counseling

Did You Know?

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.

Your health care team will 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.

Hospice Care

Hospice care is a special way of caring for you, your family and your caregivers if you have advanced cancer. Hospice focuses on your comfort and quality of life while treating your physical, emotional and spiritual needs. The focus is on comfort and providing the highest quality of life possible.

Palliative Care

Palliative care is for anyone who is in any stage of an advanced illness. This is care that provides relief from the symptoms, pain and stress of a serious illness. The goal is to improve quality of life for both you and your family. A care plan is created to help you live each day to the fullest and be as independent and comfortable as possible.

Integrative Medicines

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

Did You Know?

Integrative medicines can be helpful if you have health problems such as:

- nausea
- pain
- anxiety
- fatigue (tiredness)
- headaches.

Integrative medicine visit

An integrative medicine visit allows you to work with a health care provider specializing in whole-person care (integrative medicine provider).

Your health care provider will review your medical history and ask you questions about your lifestyle (stress level, nutrition, sleeping patterns) that could affect your health. Together, you will create a care plan that is right for you.

Your care plan may include:

- integrative therapies such as acupuncture, massage or meditation
- integrative nutrition consultations
- natural medicines such as herbal supplements
- other medicines as needed.

Acupuncture

Acupuncture is part of an ancient medical system called traditional Chinese medicine.

An acupuncturist, a person who has special training, gently inserts fine, sterile acupuncture needles through your skin to help promote health and treat illness or pain.

Did You Know?

Acupuncture can help with chemotherapy-related pain such as nausea and vomiting.

Acupuncture moves Qi (pronounced “chee”). Qi is energy that moves through your body along channels. When you are healthy, the Qi moves freely. When you are in pain, sick or emotionally upset, the Qi can become stuck. The needles correct the imbalances of Qi leading to relief of pain and other symptoms.

Acupuncture is known to improve more than 200 health conditions and symptoms and helps to prevent disease, such as:

- musculoskeletal pain (low, mid and upper back, neck, shoulder, hip and knee)
- pain related to nerve injury
- depression and anxiety
- headache pain
- stomach and intestinal pain.

Social Work

A 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.

Sexuality and Intimacy

Cancer treatment can cause physical and emotional changes that may affect your sexuality and intimacy with others.

If you have any concerns or questions about your sexual health, please talk with a member of your health care team. They can talk with you about what treatment options are available for you.

Sexual health

- Talk with your partner and health care team about your feelings or concerns with sex or intimacy.
- Experiment with new ways of being together. You may find pleasure in giving foot or back massages, caressing, cuddling, holding hands or going on dates.
- Always use a reliable birth control to prevent getting pregnant.
- Use a water-soluble lubricant such as K-Y Jelly®. Do not use petroleum-based lubricants.
- Do not have sex if either person has an infection or open sore.

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.

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. They often include talk about general topics such as adjustment and coping.

Online Resources

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.

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 a gynecologic cancer.

- **American Cancer Society**
 - cancer.org
 - 1-800-227-2345
- **ASCO's Cancer.net**
 - cancer.net
- **Cancer Support Community**
 - cancersupportcommunity.org
- **CancerCare**
 - cancercare.org
 - 1-800-813-4673
- **National Cancer Institute**
 - cancer.gov
 - 1-800-422-6273
- **National Comprehensive Cancer Network**
 - nccn.org
- **The Oncology Institute of Hope and Innovation**
 - theoncologyinstitute.com
- **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

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
 - mngel.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
- cancer.org
- The American Cancer Society has lodging agreements with several area hotels to provide reduced rate lodging for patients and families traveling for treatment.

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**
 - 612-882-9061
 - pathwaysminneapolis.org
- **Penny George**
 - 612-863-3333
 - wellness.allinahealth.org/servicelines/802
- **CaringBridge**
 - 651-789-2300
 - 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

- **Jack's Caregiver Coalition**
 - 612-547-6929
 - 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.

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**
— mangel.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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- get lab results
- email your care team
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*Availability varies by location. Ask your clinic or hospital if this service is available.

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- create a health care directive





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Fax: 612-262-4370
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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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