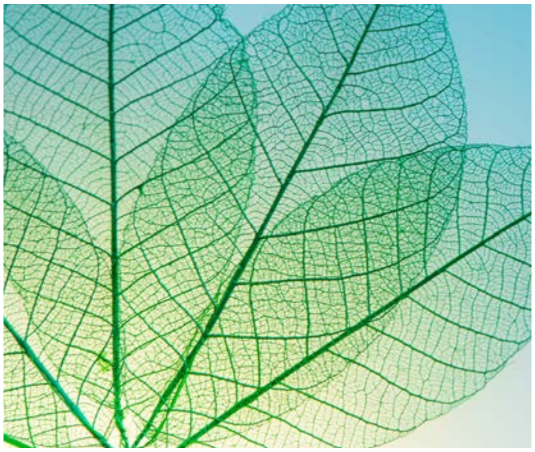
EDUCATION

Understanding Bladder Cancer



Allina Health

Understanding Bladder Cancer

First edition

Developed by Allina Health.

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rapidly changing state of scientific and medical knowledge, some of the facts and recommendations in the manual may be out-of-date by the time you read it.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

After you find out you have bladder 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 treatment plan. This plan will be unique to your needs, concerns and preferences.

This book was created to educate, help and guide you. It should not be used as a substitute for medical or professional advice. This is a general overview of bladder cancer and not everything may apply to your situation. 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

A 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:

- **Urologist**
  A urologist is a surgeon who treats a variety of conditions including cancer of the prostate, kidney, ureter, bladder, penis and testicles. They will talk with you about your treatment options and work with you to create a treatment plan that is right for you.
- **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.
- **Medical oncologist**
  A medical oncologist is a doctor who will meet with you if your treatment plan includes medicines. These medicines may include chemotherapy, targeted therapies (such as immunotherapy) or other medicines. These medicines are usually given through an intravenous (IV) line.

- **Radiation oncologist**
  A radiation oncologist is a doctor who will meet with you if your treatment plan includes radiation therapy.
- **Oncology clinic nurse**
  An oncology clinic nurse works with doctors in 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.
- **Pathologist**
  A pathologist is a doctor who works in the medical laboratory. This provider has special training in identifying diseases by studying cells and tissues under a microscope.
- **Social worker**
  A social worker will support you and your family by providing emotional support and information on resources you may need such as financial assistance, transportation or a health care directive.
- **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.
- **Advance practice provider**
  An advance practice provider can treat illnesses and diseases such as bladder cancer. An advance practice provider and doctor work together as a team. Advance practice providers include clinical nurse specialists, nurse practitioners and physician assistants.
- **Dietitian**
  A dietitian will work with you and your health care team to meet your nutritional needs and answer any nutrition-related questions.
- **Palliative care team**
  Palliative care 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. Palliative care is provided by a team of providers that may include a doctor, advance practice provider, nurse, social worker and spiritual care provider. The team helps you and your family understand your illness and treatment choices.

- **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 team can help you maintain or regain your independence and enjoy your life to the fullest. Your team may include: physical medicine and rehabilitation provider, physical therapist, occupational therapist, lymphedema therapist, or speech-language pathologist.
- **Home health care team**
  Home health care offers the support, knowledge and care to help you have a smooth transition back to your home. Examples of home health care include teaching you self-care such as how to care for a wound or how to take medicines.
- **Wound ostomy nurse**
  A wound ostomy nurse will teach you how to care for your stoma and the pouch, or a wound. The nurse will also talk about your recovery and life after surgery.
- **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.

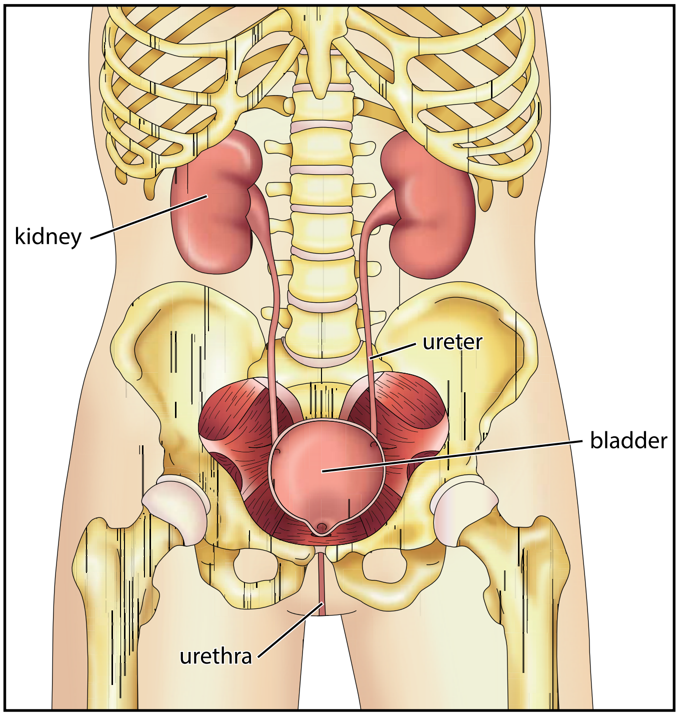
You may also come in contact with other health care providers, including integrative health, spiritual care and respiratory care.

Chapter 1: Understanding Bladder Cancer

Your Bladder

The bladder is a hollow organ in the lower part of the abdomen that stores urine made by the kidneys. The urine passes from each kidney through a long tube called a ureter into the bladder. The bladder holds the urine until it passes through the urethra and leaves the body.

- **Kidneys** filter waste and extra water out of your blood. The result of this filtering is urine, which drains from the kidneys through tubes (ureters) to the bladder.
- **Ureters** are tubes for draining urine from the kidneys to the bladder.
- **Bladder:** stores urine until the urine is released from your body.
- **Urethra** is the tube at the end of your bladder that urine passes through before being released from your body. It is controlled by a muscular valve called the sphincter .



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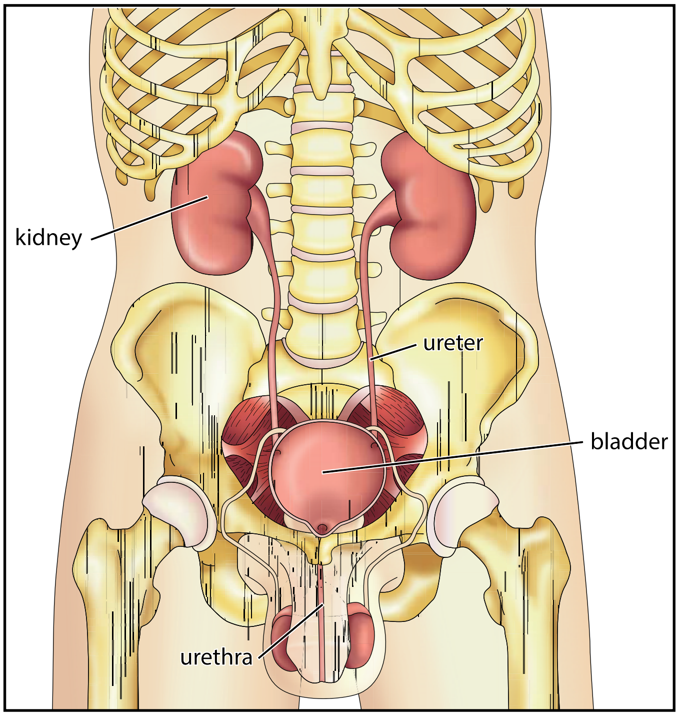
Female urinary system



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Male urinary system

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. Some risk factors, such as gender, age and family history, cannot be changed. Other risk factors can be modified to lower your risk.

The most common risk factors for bladder cancer include:

- smoking
- exposure to chemicals (such as high levels of arsenic in drinking water, or being exposed to paints or aniline dyes in the workplace)
- older age
- gender (more common in males)
- having a history of bladder infections
- chronic (long-lasting) irritation to the bladder such as using urinary catheters for a long time
- having certain changes in the genes that are linked to bladder cancer
- past treatment with chemotherapy or radiation therapy

Symptoms

Symptoms of bladder cancer may include:

- blood in the urine (slightly rusty to bright red in color)
- changes in urination such as frequent urination, difficulty urinating, and pain or burning during urination
- lower back pain or flank pain (pain in one side of the body between the upper belly area and the back)
- bladder pain
- loss of appetite
- weight loss.

Diagnosis

Important

Your health care provider may recommend other procedures, exams or scans to help diagnosis bladder cancer.

To diagnose bladder cancer, your urologist will talk with you about your health history, family history of cancer, current symptoms and any concerns. You may also have a urine test (if not done recently) and routine blood work.

Your urologist may also recommend that you have one or more of the following procedures, exams or scans.

CT exam

A 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. The result is an image that provides a clear and detailed picture of your body. Contrast will be used to help certain areas in your body be seen more clearly on the image.

A CT exam is used to determine:

- the cause of blood in the urine
- if your kidneys are working well, if there are any kidney stones, or if they are blocked by cancer
- if any cancer in the bladder has spread to other areas in the body.

Cystoscopy

A cystoscopy is a procedure that uses a cystoscope to look inside the urethra and bladder. A cystoscope is a thin, tube-like instrument with a tiny lens and light. Your urologist will fill the bladder with fluid and look at detailed images of the urethra and bladder linings on a computer monitor. A biopsy may be done if abnormal tissue is seen in the bladder.

Biopsy

A biopsy is removing a tissue sample with a needle or surgery. It is often done using a cystoscope (thin, tube-like instrument). 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.

Your health care provider may recommend some additional procedures or tests to help guide your cancer treatment.

Transurethral resection of bladder tumor (TURBT)

A transurethral resection of a bladder tumor (TURBT) inserts a resectoscope (tube-like instrument with a tiny lens and light) through your urethra to remove the tumor. Some normal tissue is also removed to determine how deep the tumor goes into the wall of the bladder. Anesthesia is used during this procedure and there are no incision made to remove the tumor. After the procedure, you will need to have a urinary (foley) catheter for a few days.

A TURBT is often done if abnormal tissue or growth is found inside of your bladder during a cystoscopy. It is possible that this procedure may need to be done twice. Your urologist may recommend removing more tissue to get the stage of the cancer.

Genetic testing

A variety of genetic tests can be done on the tissue samples taken from your bladder. These tests can help your urologist better understand your cancer and the best type of treatment for you. Tests that are commonly used include the Decipher® Test, FoundationOne® CDx or PD-L1 Expression Testing.

Imaging Tests

After a bladder cancer diagnosis is made, it is important to learn more about the cancer and to determine if it has spread outside the bladder. You may have one or more of the following imaging tests:

- A **bone scan** uses radioactive material to look at the inside of your bones. It collects in areas of the bone and is detected by a special camera. The scan shows changes in your bones.
- A **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, will be injected into your bloodstream. The PET scan creates colored pictures of chemical changes that take place in body tissues.
- **Magnetic resonance imaging (MRI)** is a painless way to look inside your body without using X-rays. MRI does not use radiation. MRI 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.

Pathology Report

A pathology report will show the results of the tissue samples taken during a biopsy or transurethral resection. It will provide information about your bladder cancer such as:

- **Diagnosis:** This is the type of bladder cancer or tumor.
  - Urothelial carcinoma (also called transitional carcinoma): This type of cancer forms in the urothelial cells that line the bladder, ureters and urethra. It is the most common type of bladder cancer.
  - Squamous cell carcinoma: When your bladder is constantly irritated by a urinary catheter or infection, a callus-like change occurs forming squamous (skin-like) cells. Squamous cell carcinoma is a type of cancer that forms from these cells and is less common.
  - Adenocarcinoma: This type of cancer forms in the glandular cells (produce mucus) in or near the bladder. Glandular cells may be found in some bladders that are constantly irritated by a urinary catheter or infection. This type of cancer is very rare.
- **Grade:** This is how abnormal the cells look under the microscope. High-grade cancer cells tend to grow and spread more quickly than low-grade cancer cells. High-grade cancers may need treatment right away or treatment that is more aggressive (intensive).

Important

The "grade" of your cancer is **<u>not</u>** the same as the "stage" of your cancer.

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 cancer.

Staging

The stage of your cancer is:

T: ______________________

N: ______________________

M: ______________________

Final stage: ______________

The results of your procedures, exams or scans will help your health care team determine the stage of your cancer and how to treat it. This is called the clinical or baseline stage.

The final stage will be determined after surgery. This is called the pathological stage.

The stage of your tumor is based on the TNM staging system:

- **T**: the size and spread of the tumor into the bladder wall or nearby organs (prostate, uterus, rectum)
- **N**: if the tumor affects nearby lymph nodes
- **M**: if the cancer has spread to other parts of the body or distant lymph nodes.

There are five stages of bladder cancer. Stage 0 is the earliest stage. Stage 4 is more advanced.

Genetic Counseling

Based on your type of bladder cancer, your age and your family history, 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.

Chapter 2:
Systemic Therapy and Bladder Instillation

Systemic Therapy

Systemic therapy is treatment prescribed by a medical oncologist. This treatment affects your entire body. Medicine is used to help slow the growth of cancer cells or destroy them. Types of systemic therapy include:

- chemotherapy
- targeted therapy (such as immunotherapy)

Chemotherapy

Chemotherapy is a medicine given through an IV (intravenous) line to destroy cancer cells through your whole body.

When chemotherapy is used

Chemotherapy can be used throughout treatment.

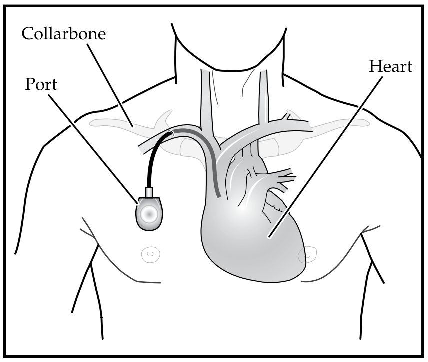
- **Neoadjuvant chemotherapy** is done before surgery and often at the same time as radiation therapy. The goal is to stop the cancer from spreading and make a tumor in the bladder or lymph node smaller.
- **Adjuvant chemotherapy** is done after surgery. The goal is to destroy any cancer cells that may be left.

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

Implanted port

An implanted port is a device used to access a vein to give medicines or draw blood to avoid needle sticks. Your health care provider places the port in your upper chest just below your collarbone. They will make an incision (cut) just under your skin to place the port.

A port will make it easier and more comfortable for you to receive chemotherapy. Your health care provider will help you decide if a port is right for you.



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A port is used to give you medicines through an IV line.

During chemotherapy

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 or your port will be accessed with a special needle. This is done 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.

Targeted Therapy

Targeted therapy is medicine designed to target specific features of cancer cells and stop them from growing and spreading. The most common side effects of targeted therapy are rash, joint pain, headache, fever, chills and diarrhea. You will need additional tests to see if this treatment is right for you.

Immunotherapy

Immunotherapy is a treatment that helps your immune system fight cancer. Several types of immunotherapies can be used to treat bladder cancer. Some side effects of immunotherapy are fever, chills, muscle or joint pain, headache, fatigue (tiredness) and inflammatory reactions.

Bladder Instillation

A bladder instillation uses a catheter to put medicine into your bladder to help destroy the cancer. After you receive the medicine, you will need to keep it in your bladder for a period of time. The medicine can be given one time or given in a series once a week.

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: Radiation Therapy

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.

Radiation therapy treatment

You will have a planning session with your radiation oncology team before your first radiation treatment. Treatment typically starts a few days after the planning session.

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 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.

Chapter 4: Surgery

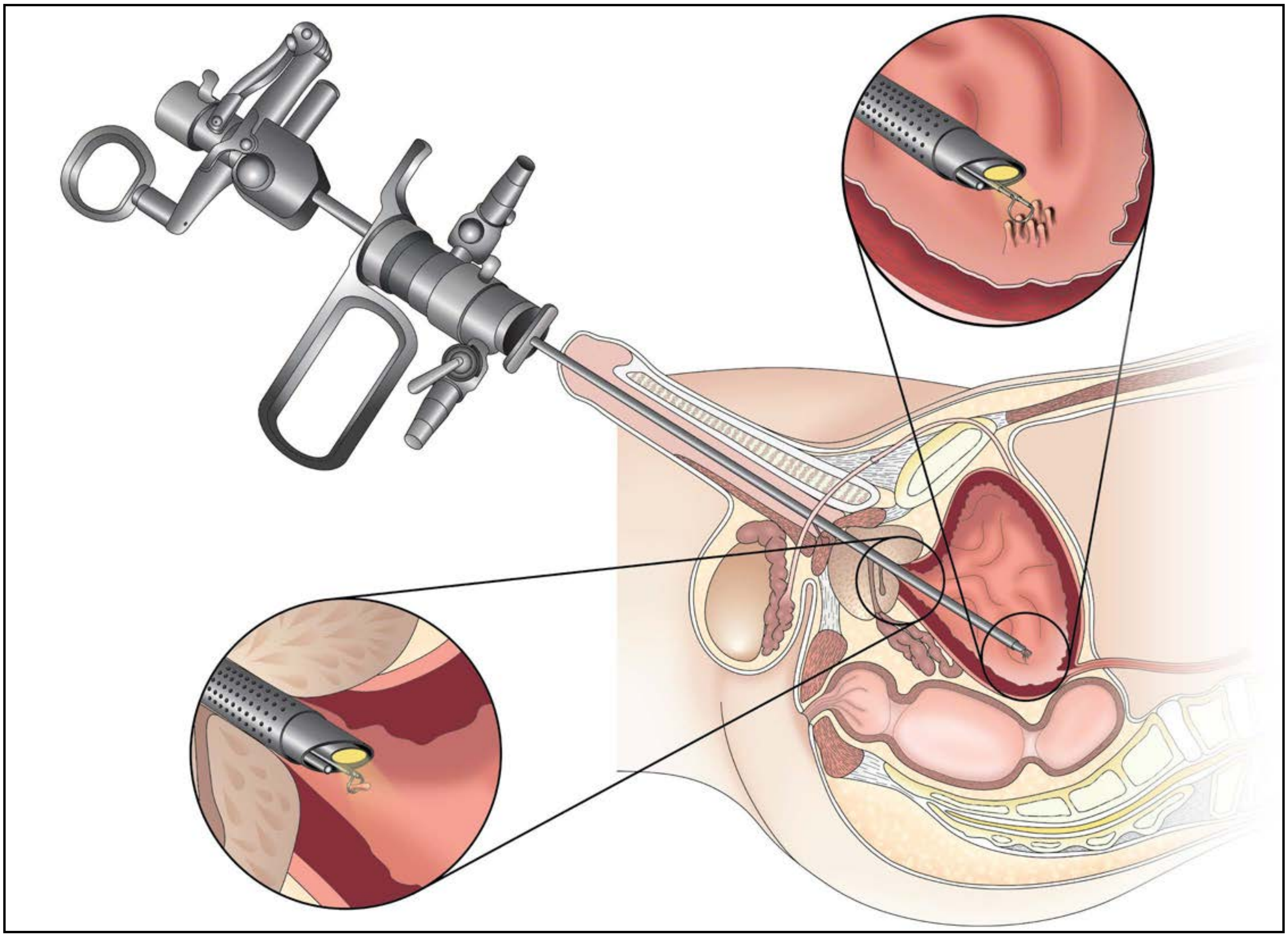
Types of Surgery

Surgery may be recommended as part of your treatment plan. There are different types of surgery to treat bladder cancer.

Transurethral resection of bladder tumor (TURBT)

A transurethral resection of a bladder tumor (TURBT) is the first surgery that is done. During this procedure, a resectoscope is inserted through your urethra to remove the tumor. Some normal tissue is also removed to determine how deep the tumor goes into the wall of the bladder.

You will have anesthesia during this procedure. No incisions need to be made since this procedure is done through the urethra. After this procedure, you will need to have a urinary (foley) catheter for a few days.



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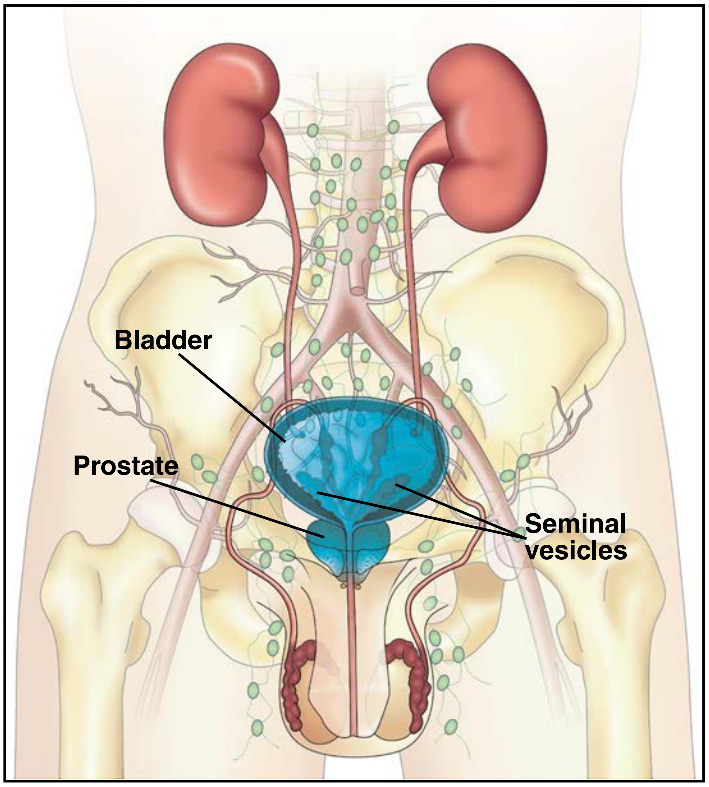
During this procedure, a resectoscope is inserted through your urethra to remove the tumor

Cystectomy

Cystectomy is surgery to remove part or all of the bladder. It can be either a partial or radical cystectomy.

- A partial cystectomy only removes the part of the bladder that has the tumor. You will be able to urinate normally after recovering from this surgery.
- A radical cystectomy removes all of the bladder and any nearby lymph nodes. Your surgeon will create another way for urine to leave your body (urinary diversion).
  - In males, the prostate and seminal vesicles are removed along with the bladder.
  - In females, the uterus, ovaries, and the top part of the vagina could be removed with the bladder.



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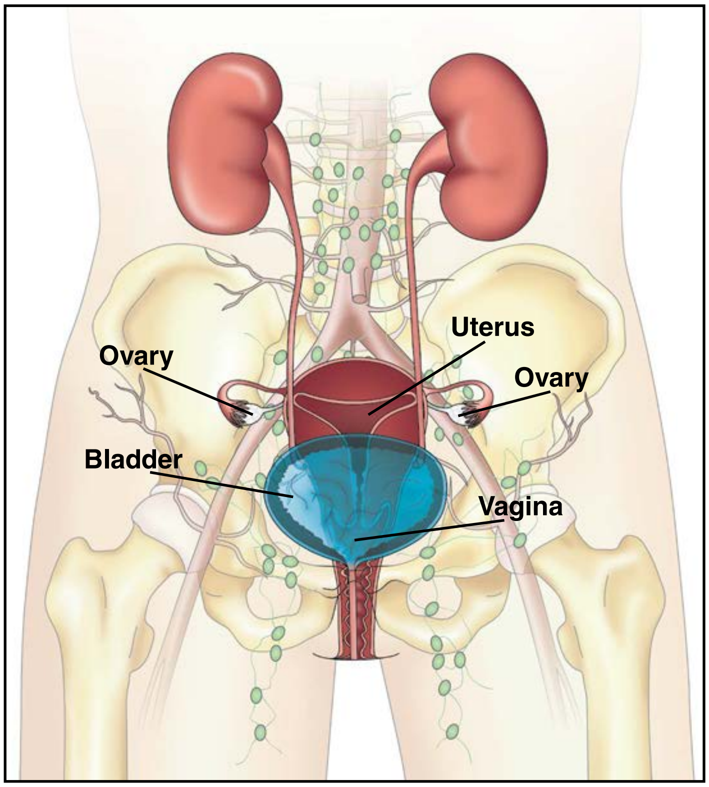
In males, the prostate and seminal vesicles are removed along with the bladder.



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In females, the uterus, ovaries, and the top part of the vagina could be removed with the bladder.

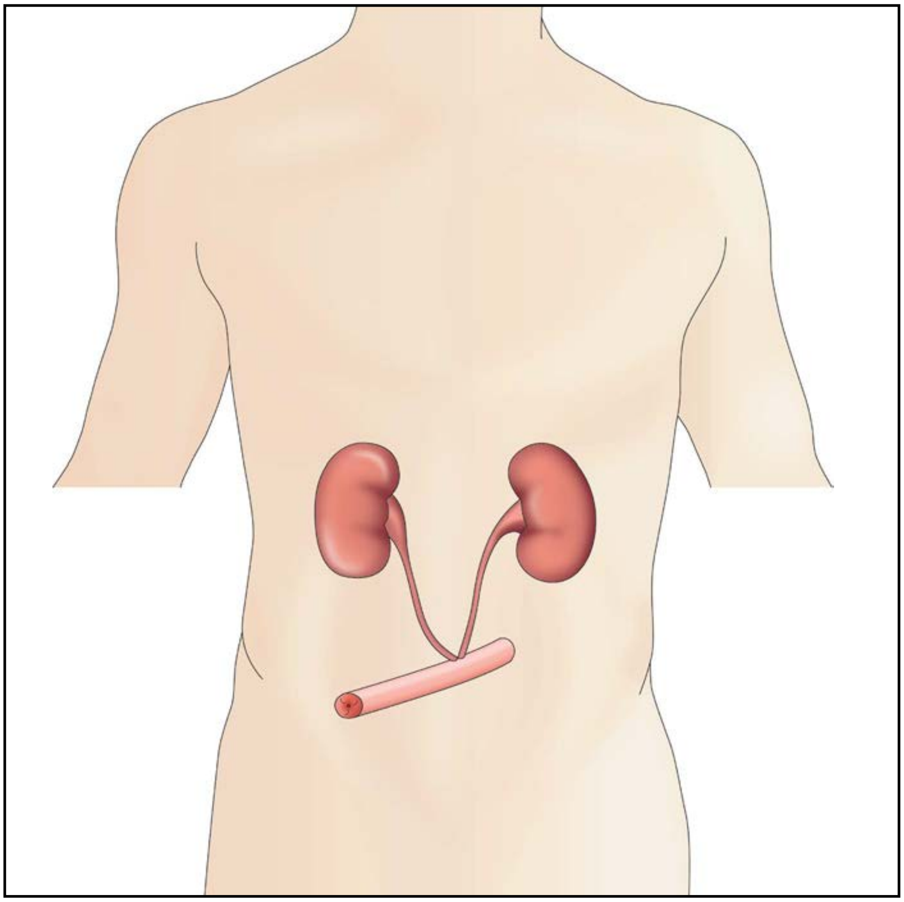
Urinary diversion

Urinary diversion is surgery to make a new way for your body to store and pass urine. This can be done three different ways. You and your surgeon will work together to decide the best option for you.

Ileal conduit

Your surgeon will make a conduit (passage) from a section of the ileum (part of your small intestine). This passage creates a new way for urine to leave your body. This is the most common type of urinary diversion.

- One end of the passage is sewn closed. The other end of the passage is brought through the abdominal wall to form a stoma. The ureters are disconnected from the bladder and connected to the conduit to allow urine to flow through and leave the body through the stoma.
- Urine and mucus move out of your body through the stoma and is stored in a plastic pouch you wear. There is no muscle in the stoma. You cannot decide when to pass urine and you do not feel when the urine passes into the pouch.



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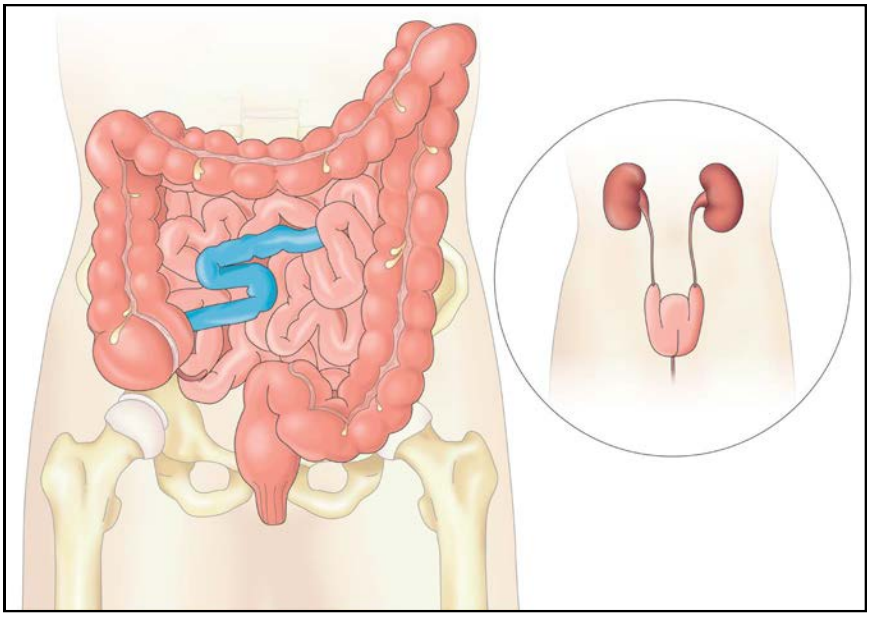
Your surgeon will make a conduit (passage) from a section of the ileum (part of your small intestine).

Neobladder

Your surgeon will use a section of your small intestine to create a new bladder and reconnect it to the urethra. You will not need to wear a pouch. However, this is a more complicated surgery with a longer recovery time. It also has higher risks of complications (problems).



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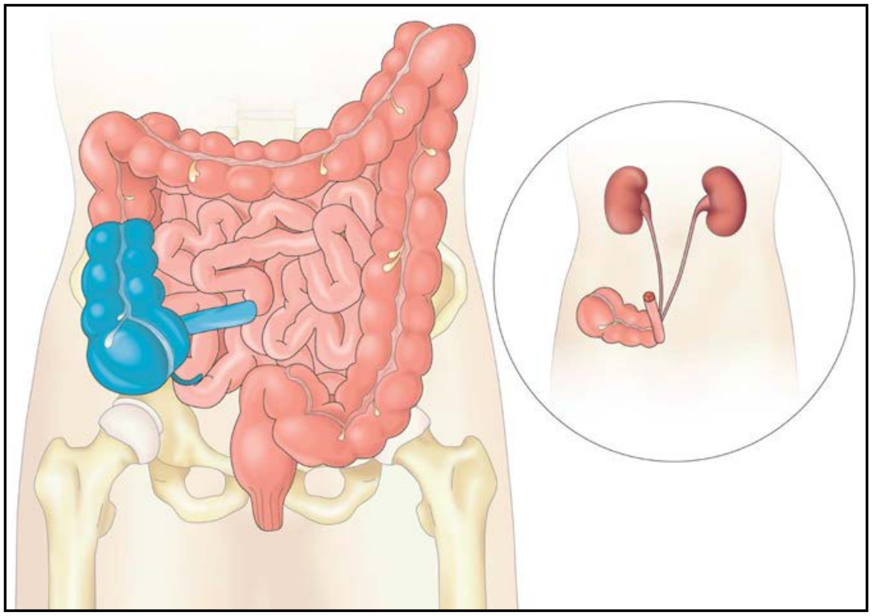
Your surgeon will use a section of your small intestine to create a new bladder and reconnect it to the urethra

Continent cutaneous diversion

Your surgeon will use a section of your small intestine to create a new bladder. One end of your new bladder will be attached to the ureters. The other end will be attached to a stoma in your abdominal wall.

To empty your new bladder, you will need to put a catheter (thin, flexible tube) through the stoma several times each day. You will not have to wear a pouch. This is the least common type of urinary diversion.



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Your surgeon will use a section of your small intestine to create a new bladder.

Risks or Complications of Surgery

All surgeries have some risk. Possible risks or complications of surgery may include:

- general anesthesia risks
- bleeding that requires a blood transfusion or another surgery
- infection at an incision site
- pneumonia
- other respiratory problems that require breathing support
- heart attack, abnormal heart rhythm, stroke or blood clots
- weakness, loss of muscle strength that requires rehabilitation
- blood clots in the legs or lungs
- urinary tract infections
- small bowel obstructions that may require surgery
- a delay in the return of bowel function (ileus)
- an internal urine leak
- scar tissue ureters or conduit (the new passage)
- hernias
- the possibility that the cancer cannot be removed.

You may have other complications that are not on this list. Please talk with your surgeon about any concerns or questions you have.

Chapter 5: Preparing for Your 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.

Your Health History and Physical Exam

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.

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.

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.

Wound Ostomy Appointment

If you will be having all of your bladder removed, you will meet with a wound ostomy nurse within 2 weeks of your surgery. During this visit, you will learn how to take care of your stoma and the pouch. The nurse will also talk about your recovery and life after surgery. They will also draw on your body the best place for your stoma.

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.

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.

Health Care Directive

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.

Scan the QR code for the health care directive and guide.

How to get started

Go to allinahealth.org/hcd or scan the QR code.

- Print the form of your choice. You can also ask your health care provider for a copy.
- Read the guide if you need help filling out your health care dirctive.

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

Quit Tobacco Before Your Surgery

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.)**

Learn More

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


Tobacco Intervention Program

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.

Did You Know?

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

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.

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.

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.**

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.

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 comfortable shirt and pants, underwear, socks and shoes

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 or 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 Your 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 Directions Before Surgery

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

Chapter 6: Your Surgery and Hospital Stay

What to Expect the Day of Surgery

Learn More

Learn more about these ways to help control pain after surgery:

- epidural catheter (pages 49 to 50)
- PCA pump (pages 51 to 52)
- peripheral nerve block catheter (pages 52 to 54).

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.
  - **A pre-surgery nurse** will meet with you to review your care plan and what you can expect before and after your surgery.
  - **Your surgeon** will meet with you and 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 to 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.
- The nurses 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. Your nurse will work with you to make you as comfortable as possible.

Hospital room

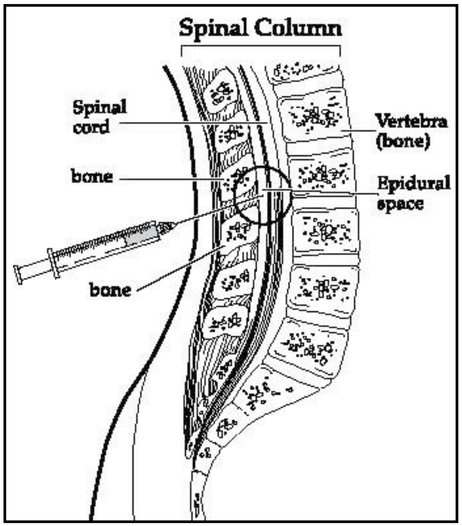
- When you are fully awake and your medical status is stable, you will be taken to your hospital room.
- When you are in your room, it is important to begin:
  - — doing ankle pump exercises. This will help to prevent blood clots from forming in your legs.
  - — using your incentive spirometer and doing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

Epidural

An epidural is a catheter that delivers medicines to the nerves near your spine. It is used to control your pain after surgery. The epidural (small plastic tube) is placed in your back. The tip of the catheter rests in the area just outside the spinal cord. This area is called the epidural space. Medicines are injected through the catheter into the epidural space to control pain. The epidural will be placed before your surgery.

Your anesthesiologist will insert the catheter and give you the pain medicine.

Using an epidural means you will need less narcotic pain medicine. This will help reduce side effects such as nausea, vomiting, constipation and itching. You will also be less sedated so you can take an active role in your recovery.



© Allina Health System

The place in your spinal column where the epidural is placed.

During the procedure

- You will sit and bend over or lie on your side.
- Your back will be carefully cleaned.
- The anesthesiologist will numb your skin. You may feel a slight burning (like sunburn) for a few seconds.
- Once your skin is numb, the anesthesiologist places a special epidural needle into your back and into the epidural space. This space is just outside the spinal cord. (See the drawing on the left.)
- They thread the catheter through the epidural needle into the epidural space.
- The anesthesiologist removes the epidural needle and tapes the catheter to your back.
- The catheter will come up over your shoulder so the nurses or doctors have easy access to it.
- You will be able to lie on the catheter.

After the procedure

- Pain medicine enters your body through this catheter. The medicine can be given continuously (without stopping) as well as from time to time.
- You may also receive other pain medicines in addition to the epidural. Your anesthesiologist will prescribe what is right for you.
- The catheter will be left in place for 24 to 48 hours. You may need it for a longer period of time.

Benefits

Using an epidural will allow you to:

- have better pain control
- be up walking sooner after your surgery
- be able to eat a regular diet sooner after surgery
- be able to go home sooner after surgery.

Side effects of an epidural

- You may get a headache.
- Your lower back may become tender at the catheter entry site.
- Your blood pressure may drop at times.

Very rare complications (problems) include:

- bleeding around your spinal cord
- infection near your spinal cord
- injury to your spinal cord.

Other information

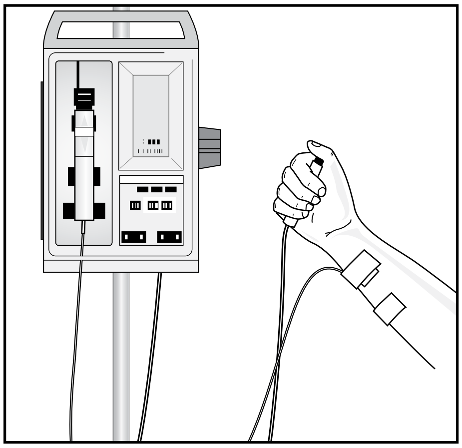
- The nurses will watch you closely during and after the medicine is given.
- Your nurse will place a pulse oximeter sensor on your finger when the epidural is in place. The sensor will record the amount of oxygen in your blood.

When to call your nurse

Call for a nurse if you have:

- nausea
- vomiting
- itching
- problems urinating
- changes in your pain/comfort level
- extreme back pain
- inability to move your legs.

PCA Pump



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PCA pump

PCA stands for patient-controlled analgesia. Analgesia means relief of pain. The PCA pump is a small machine that lets you give yourself a dose of pain medicine when you need it.

A small tube connects the pump to an intravenous (IV) catheter in your vein. The tube will carry the pain medicine right to your bloodstream.

You will have a hand-held button to push when you need pain relief. This will release the amount of medicine your surgeon has prescribed for you.

Nurses will program the pump to make sure you get the right dose of medicine each time. Timers prevent the pump from releasing medicine too often. When you start to feel discomfort, push and release the button for a dose of medicine.

The push button control prevents you from getting a dose by mistake. Rolling onto the button or bumping it will not give you a dose. You must push and release the button before you get any medicine.

Take pain medicine when the pain first begins. If you know your pain may get worse with activity, take your pain medicine before the activity. Don't wait for pain to get worse before taking medicine.

If your pain is well-managed but you feel the pain medicine is making you feel too sleepy, you may want to wait to give yourself a dose. Whenever you have a question about the best thing to do for your pain, ask your nurse.

Benefits

Your surgeon has prescribed a PCA pump because the pain medicine goes directly into your bloodstream. This means that:

- it starts working quickly to decrease the pain, usually within minutes
- you may need less medicine, which means you may have fewer side effects such as drowsiness, upset stomach or itching
- you can manage your own pain and take only as much medicine as you need to keep yourself comfortable and free from pain.
- The pump should not interfere with activities you will be doing, such as bathing, walking or coughing.

Other information

- For your safety, family members and other health care providers are not allowed to push the PCA button for you.
- For your safety, you may not leave the nursing unit while you are connected to the PCA pump except for tests and procedures.
- The pump can sound an alarm for many reasons. If the alarm sounds, call your nurse. The alarm gives the nurse information about the pump.
- You, your surgeon and nurse will discuss how long you can use the pump. Once your pain is improving and you can eat and drink, you will switch from the PCA pump to pain medicine by mouth.

When to call your nurse

Call for a nurse if you have:

- pain that does not improve or gets worse
- upset stomach
- vomiting
- itching
- sleep problems or problems staying awake during the day
- other unusual symptoms.

Peripheral Nerve Block Catheter

A peripheral nerve block catheter delivers numbing medicine near some of the nerves that give feeling to your surgery site.

The block reduces your feelings of pain but may not take away all of the pain. Even with a nerve block, most people still need to take a prescription pain medicine.

Peripheral nerve blocks affect the nerves that control pain, feeling and movement. The nerve block may cause numbness, tingling, heaviness, warmth, weakness, or an inability to move your affected arm or leg. Effects of the nerve block will stop when the medicine wears off.

Peripheral nerve blocks can be used for many surgery sites including:

- upper body: shoulder, collar bone, elbow, forearm, wrist and hand
- lower body: hip, knee, ankle and foot.

Types of nerve blocks

Your anesthesiologist will decide which nerve block is right for you. There are two types of nerve blocks:

- a single shot that lasts 12 to 24 hours after surgery. You will need to take pain medicine by mouth to manage your pain.
- a continuous (nonstop) block through a catheter that provides ongoing pain relief for 72 hours after surgery.
  - The catheter (tube) is connected to a small portable pump. The pump will provide the numbing medicine nonstop.
  - If you go home with the nerve block catheter, your nurse will give you instructions. You may want to have a family member or friend hear the instructions to help support your care and recovery at home.
  - **Note:** You may feel an increase of pain when the catheter is removed and the effects of the block wear off.

Benefits of a nerve block

A nerve block can:

- reduce your pain during and after surgery
- decrease your need for prescription pain medicine
- reduce the side effects from prescription pain medicine
- allow you to rest better after surgery
- help you increase your activity level after surgery, such as physical therapy
- shorten your hospital stay.

How the nerve block catheter is inserted

Before the nerve block is inserted, you will receive another medicine through an intravenous (IV) line to help you relax before surgery. The IV will be inserted into your hand or arm. (The nerve block can also be done during surgery.)

- The anesthesiologist (specially trained doctor) will locate the nerve to be blocked.
- After finding the right location, numbing medicine will be put into your skin before the needle is inserted.
- The numbing medicine is injected. You will feel pressure. This is normal.
- After your skin is numb, the anesthesiologist will insert the needle near the nerves that need to be blocked.
- The anesthesiologist inserts a small, flexible catheter and removes the needle.

- A clear dressing will cover the site.
- You may feel warmth, heaviness or tingling from the nerve block.
- The procedure takes 15 to 20 minutes.
- The nerve block will begin working 20 to 30 minutes after the procedure.

When to call your anesthesiologist

Tell or call the anesthesiologist if you have any of the following symptoms from the nerve block:

- drowsiness
- lightheadedness, dizziness or feeling disoriented
- signs of infection: tenderness, redness, swelling, drainage at the catheter site
- pain not controlled by the pump or prescription pain medicine
- anxiety
- numbness around your mouth
- metallic taste in your mouth
- blurred vision
- ringing in your ears
- any questions or concerns.

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)

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.

Tip

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

Chapter 7: Care After Surgery

After your surgery, there is a variety of things you need to know for your safety, recovery and comfort.

Before you leave the hospital, a social worker and discharge planner will meet with you to decide if you are able to go home or if you will need transitional care (short-term rehab). If you are able to go home, you will need home care services. Nurses will come to your home 1 or 2 times each week. The home health agency will contact you when you leave the hospital.

You will also receive instructions on your diet, medicines, activity level, follow-up appointment, and signs and symptoms to watch for before you leave the hospital.

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.

Urinary (Foley) Catheter

Your surgeon may send you home from the hospital with a urinary (Foley) catheter. This is most common if you had a neobladder urinary diversion. A urinary catheter is a thin tube that has a water filled balloon on the end. The end of the tube is gently inserted through your urethra and into your new bladder. You will need to have the catheter for 3 to 4 weeks to allow your bladder to heal and help prevent any leakage of urine.

A cystogram will be done before removing the catheter to make sure you bladder has healed. This exam uses X-rays to get images of your bladder. During the exam, contrast will be dripped into your bladder through a catheter. This will help your bladder show up on the X-ray screen.

Jackson-Pratt Drain

You may have a Jackson-Pratt drain (tubing with an attached bulb). It will draw out excess blood and fluid from the area around your incision. The drain is usually removed a few days after your surgery.

You may go home with the drain if there is still a large amount of drainage. Your nurse will teach you how to care for the drain, as well as how to empty the bulb. 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.

The drain will be removed when your surgeon determines the amount of drainage is low enough.

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
- 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.

Urinary Stent

During surgery, stents may have been placed in your ureters going all the way up to your kidneys. The stents will allow urine to drain from your kidneys while your new bladder is healing. The stents are made of rubber. Usually, the upper end of it curls into your kidney while the lower end rests in your bladder.

The stents are usually removed a few days after surgery. It is possible you will go home with the stents in place. They will be removed by your surgeon at the clinic.

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 of 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 surgeon'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 8: Nutrition

Good nutrition is important to help maintain energy, maintain weight and stay hydrated, fight infection and tolerate your treatment with less side effects. If you will be having surgery, good nutrition can also help you heal well after surgery.

Within this chapter is nutrition information for during and after treatment. You will also find ways to cope with common side effects related to having cancer and treatment.

Nutrition During Treatment

Eating Hints: Before, During, and After Cancer Treatment

Eating Hints is a booklet that covers common types of eating problems and ways you can manage them.

You can download a copy at: cancer.gov/publications/patient-education/eating-hints.

You can also ask a member of your health care team for a copy of the booklet.

Tip

Please ask your health care provider for a referral if you would like to meet with a dietitian.

The goals of nutrition during treatment are to help you:

- maintain energy
- maintain weight and stay hydrated
- fight infection
- tolerate your treatment with less side effects
- heal well after surgery.

Common side effects

Some common side effects of chemotherapy and targeted therapy include:

- constipation or diarrhea
- decreased appetite
- dry mouth
- fatigue (tiredness)
- increased risk of infection
- mouth sores
- nausea (upset stomach) or vomiting (throwing up)
- taste changes

Some common side effects of radiation therapy include:

- diarrhea
- nausea or vomiting.

Vitamins, minerals and herbal supplements

The American Cancer Society does not recommend taking vitamins, minerals or herbal supplements during treatment. At this time, there is not enough research to support the benefit or harm of using them during treatment. There is currently no supplement that has shown to lower the risk of cancer getting worse or coming back.

If there is a supplement you are considering using, please talk with your health care team before taking it. They will help you decide which supplements may be used safely and which ones should be avoided because they may be harmful.

Nutrition After Treatment

Some common questions after treatment are:

- What can you do to help keep the cancer from coming back?
- Is there a specific diet you should follow?
- Should you exercise?

The two most common risk factors known to increase your risk of getting bladder cancer are:

- high levels of arsenic in drinking water. If you have well water, it should be tested every year for levels of arsenic.
- tobacco use. People who smoke are at a higher risk of getting bladder cancer than those who have never used tobacco. If you use tobacco, you should stop using to improve your overall health and lower your risk cancers caused by tobacco use.

Food and beverages

Research shows that eating more fruits and vegetables can lower your risk of getting bladder cancer. The American Institute for Cancer Research recommends having at least five servings of fruits and non-starchy vegetables each day. Choose a variety of brightly colored fruits and vegetables for many different health benefits.

It has also found that there may be some benefit in drinking tea (black, oolong or green) to lower your risk of getting bladder cancer.

Make healthy lifestyle changes

You can make lifestyle changes to help lower your risk of getting bladder cancer. These include:

- maintaining a healthy weight
- getting regular physical activity (aim for 150 to 300 minutes each week)
- eating a healthful diet (plant-based foods including whole grains, beans and legumes, fruits and vegetables)
- limiting processed foods and red meat
- limiting or avoiding alcohol.

How to Cope with Side Effects After Treatment

The following symptoms may happen because of having cancer treatment.

Taste changes	■ If you have a metallic taste, eat finger foods or use plastic silverware. Avoid canned foods and drinks. ■ If your food tastes too salty, add a sweet flavor such as honey, agave or real maple syrup. ■ If your food tastes too sweet, add lemon juice, salt or bitters. ■ If your food tastes bitter, try to sweeten it with honey, agave, real maple syrup or another sweetener. ■ If your food tastes bland, try adding herbs to brighten the flavor such as rosemary, basil, mint or oregano. ■ If your mouth is not sensitive and your food tastes bland, you can use: — mustard, barbecue sauce or other marinades to heighten flavors — an acid to help brighten foods such as lemon, lime, orange juice or cider vinegar.
Constipation	■ Drink plenty of liquids (about 8 to 10 large glasses each day). ■ You can drink warm liquids such as coffee, tea and warm juice (prune, pear or apple) to help stimulate your bowels. ■ Be sure to include enough fruits, vegetables and fiber in your diet if able and it is OK with your health care team. Canned fruits and vegetables are generally tolerated well, along with cooked fruits and vegetables. ■ Get regular physical activity – if able – simply walking will help. ■ Eat consistent meals. ■ Try to maintain a regular bowel pattern. ■ Talk to your health care team before you take any laxatives and stool softeners. **Call your health care team if you do not have a bowel movement for more than 3 days.**

Diarrhea	■ Drink plenty of liquids (about 8 to 10 large glasses each day). Liquids that are cool or room temperature are often better tolerated. ■ Eat small meals more often. ■ Eat bland foods higher in salt such as saltines, soups, broth and pretzels. ■ Eat low-fiber foods such as applesauce, bananas, creamy peanut butter, oatmeal, canned pears or peaches. ■ Limit high-fiber foods such as whole-grain breads, fresh and dried fruits, and raw or cooked vegetables. ■ Avoid milk or milk products if they make the diarrhea worse. Yogurt and cheese are generally tolerated well. ■ Avoid fried, greasy, fatty or spicy foods. ■ Avoid caffeine, alcohol and sweets. ■ Avoid sugar-free foods with sugar alcohols such as xylitol, sorbitol or mannitol.
Fatigue (tiredness)	■ Get regular physical activity – if able – activity can reduce fatigue. ■ Eat small meals more often. ■ Eat meals that have protein, carbohydrates and fat. ■ Drink plenty of liquids. Dehydration can make fatigue worse. ■ Plan your day so that you have time to rest. ■ Take short naps instead of one, long rest period. ■ Pace your activities around your energy level.
Sore mouth or throat	■ Eat soft, bland foods. ■ Eat creamy or moist foods such as yogurt, cheese, puddings or custards, ice cream, cooked cereal (cream of wheat, cream of rice) or casseroles. ■ Choose foods and liquids that are cool or room temperature. Eating hot or cold foods may cause some throat or mouth irritation. ■ Moisten food with gravies or sauces. ■ Try frozen fruit ice pops or ice chips to help soothe your mouth or throat. ■ Avoid foods and juices that are highly acidic such as orange juice, tomato sauces and other citrus fruits. ■ Avoid hot, spicy or sugary foods. ■ Avoid rough foods such as dry toast or crackers. ■ Avoid tobacco and alcohol. ■ Avoid mouthwashes with alcohol in them. ■ Try a baking soda, saltwater rinse (¼ teaspoon baking soda, ⅛ teaspoon salt, 1 cup warm water). Rinse 3 to 4 times each day and then rinse mouth with plain water after using the rinse.

Nausea and vomiting	■ Eat small meals more often. ■ Try eating bland, starchy foods such as crackers, pancakes or toast. ■ Eat foods at room temperature. ■ Try to avoid foods with a strong odor. ■ Avoid fried, fatty, greasy or spicy foods. ■ Drink more liquids: — clear liquids such as water, broth, ginger ale, fruit juices — try Popsicles®, Jell-O®, ice chips and sport drinks. ■ Ginger (such as ginger snaps, ginger ale, crystallized ginger) may help with nausea. ■ Take anti-nausea medicine as prescribed.
Decreased appetite	■ Try eating 5 to 6 small meals each day instead of 3 larger meals. ■ Use a smaller plate instead of a larger plate to help make meals more manageable. ■ Have high-calorie, high-protein food options available such as nut butters, eggs, cheese or trail mix. ■ Avoid drinking liquids during meals. ■ Drink liquids that are higher in calories such as nutrition supplements (Boost, Ensure), lemonade or soups. ■ Try to eat when you are feeling your best. ■ Get regular physical activity – if able – start slowly and increase over time. **If pain is causing your decreased appetite, please talk to your health care team about ways to manage your pain.**
Dry mouth	■ Drink enough liquids. Keep a water bottle or cup with you at all times. ■ If your mouth is not sore, try using sugar-free sour candy, lemon drops, sugar-free gum, and citrus beverages to increase saliva. ■ Moisten food with gravies or sauces to make eating easier. ■ Biotène® is a mouthwash that will help with symptoms of dry mouth.

Chapter 9: Sexual Health and Intimacy

Sexuality and intimacy are important and how each person experiences intimacy will vary.

Tip

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.

Sexual health care be affected by chemotherapy, radiation therapy, nerve damage, hormone level changes, medicines, changes in body image and stress.

Please talk with your health care providers if cancer treatment has affected your sexual health and intimacy or you have any concerns. They can listen, recommend therapies and support groups, or give you a referral to a professional that specializes in sexual health.

Be open and honest with your partner about your feelings and concerns, and how you prefer to be intimate.

Female Concerns

Bladder cancer treatment can affect female sexual health. This may include:

- painful sex
- vaginal dryness
- vaginal narrowing or tightness after surgery
- decreased arousal
- decreased or loss of libido
- changes in body image
- changes in intimacy.

Ways to manage sexual health changes

To help manage sexual health changes, treatments may include:

- **vaginal dilator:** This is a device that gently stretches the tissues of your vagina. It will decrease discomfort during pelvic exams as well as during sex.
- **vaginal lubricants:** These are available to help with vaginal dryness. There are water-based lubricants, oil-based lubricants and silicone-based lubricants. There are pros and cons for each type. Your health care provider can help you decide which type of lubricant is right for you.

- **pelvic floor exercises, physical therapy or both:** Your pelvic floor muscles start at your pubic bone in the front of your body and travel across the floor of your pelvis to your tail bone. These muscles:
  - — support your bladder, uterus and colon
  - — help start and stop urine flow and pass gas and stool
  - — help provide sexual pleasure.

  By doing pelvic floor exercises, you can strengthen these muscles. Your health care provider or physical therapist will give you information on how to do these exercises.

Together, you and your surgeon will decide which type of treatment is right for you.

Male Concerns

Bladder cancer treatment can affect male sexual health. This may include:

- erectile dysfunction
- decreased libido or arousal
- orgasmic dysfunction
- disorders of ejaculation
- changes in intimacy.

Erectile dysfunction

Erectile dysfunction means not be able to have or keep an erection. To help manage this condition, treatments may include:

- **medicines:** The most common types of medicines include sildenafil (Viagra®), tadalafil (Cialis®), vardenafil (Levitra®) and avanafil (Stendra®)
- **vacuum erection device:** This is a small pump placed over your penis. The pump is used to remove all the air within the tube and pull blood into your penis to allow you to have an erection.
- **injection therapy:** This is injecting medicines into your penis. A fine needle is used to inject medicine into the base or side of your penis.
- **penile implants:** Implants are placed inside your penis by a surgeon. The devices are inflatable or bendable rods. This type of treatment is more invasive (surgery is done to place the implants).

Together, you and your surgeon will decide which type of treatment is right for you.

Fertility

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

Chapter 10: Cancer Rehabilitation

After surgery, your surgeon may refer you to the Courage Kenny Rehabilitation Institute's 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
- 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.

Chapter 11: Cancer Survivorship

Cancer Survivorship Visit

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 12: 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. They provide an opportunity to talk about your overall well-being and how best to navigate through cancer treatment. 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 nurse navigator for more information on the support services listed and how to make an appointment.

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.

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.

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.

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.

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.

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 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.

Social Services

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.

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.

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:

- **Allina Health**
  - allinahealth.org/cancercare
- **American Bladder Cancer Society**
  - bladdercancersupport.org
- **American Cancer Society**
  - cancer.org/cancer/bladder-cancer
- **American Institute for Cancer Research**
  - aicr.org
- **Angel Foundation**
  - mnangel.org
- **Bladder Cancer Advocacy Network (BCAN)**
  - BCAN.org
- **CaringBridge**
  - caringbridge.org
- **Gilda's Club Twin Cities**
  - gildasclubtwincities.org
- **Jack's Caregiver Coalition**
  - jackscaregiverco.org
- **National Cancer Institute**
  - cancer.gov/types/bladder
- **Open Arms**
  - openarmsmn.org
- **Pathways: A Healing Center**
  - pathwaysminneapolis.org
- **United Ostomy Association of America**
  - ostomy.org

Notes

Notes

Notes

Get connected

Communicate with your Allina Health clinic, hospital and provider

Sign up for your free Allina Health account and get instant access to your health information. You can:

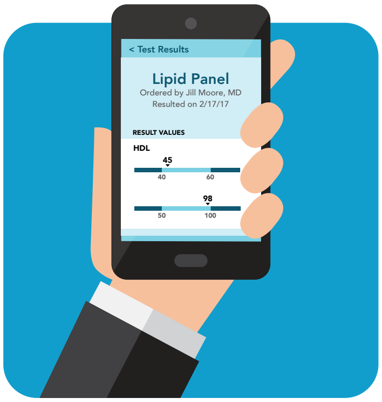
- schedule appointments
- get lab results
- email your care team
- manage a child or another adult's account
- and more!

On the calendar. Off your mind.

- quickly schedule appointments*
- do online visits for common conditions

Fewer steps. Greater access.

- email with your care team*
- view immunizations
- read visit notes* and follow-up instructions

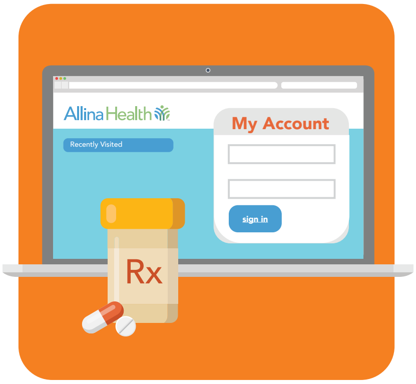


Less waiting. More knowing

- get lab results fast – usually same day

Never run out. We're always open online.

- refill prescriptions at Allina Health pharmacies with the click of a button



Small effort. Big reward.

- take a wellness assessment
- set and track health goals
- create a health care directive

Sign up for your account at allinahealth.org today

Your account is a free service of Allina Health.

Get it on iTunes
GET IT ON Google Play

Allina Health

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*Availability varies by location. Ask your clinic or hospital if this service is available.

Nondiscrimination in Health Programs and Activities

Affordable Care Act – Section 1557

Allina Health complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, gender identity or sex. Allina Health does not exclude people or treat them differently because of race, color, national origin, age, disability, gender identity or sex.

Allina Health:

- provides free aids and services to people with disabilities to communicate effectively with us, such as:
  - ◊ 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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