

Urology

The Experts in Urologic Care

Radical Cystectomy and Neobladder: A Patient's Guide



UR
MEDICINE

MEDICINE *of* THE HIGHEST ORDER



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Please note: items in this book address both male and female patients.

Female or woman specific items are in a purple font.

Male or man specific items are in a green font.

Detecting and Diagnosing Bladder Cancer

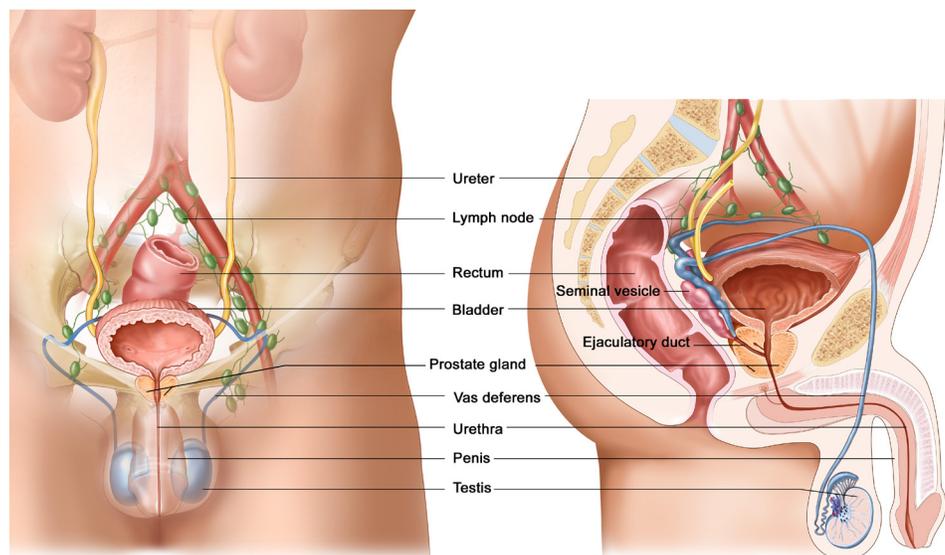
LET US START AT THE BEGINNING. WHAT EXACTLY IS THE “URINARY SYSTEM”?

FOR MEN:

Your urinary system is composed of five main parts. The parts include the kidneys, ureters, bladder, prostate, and urethra. Below you can see where each of these is located in your body.

- **Kidneys:** Most people have two kidneys, one on each side. These are bean shaped organs that filter your blood and make urine. The kidneys are always making urine, even when you are sleeping.
- **Ureters:** Most people also have two ureters. These are tubes that connect the kidneys to the bladder. They help move urine towards the bladder.
- **Urinary Bladder:** This is in your pelvis. It is a hollow organ with a stretchy wall that stores urine. The ureters bring urine into the bladder. The urine is stored here until you chose to urinate and empty your bladder.
- **Prostate:** a small, walnut-sized gland in men that produces most of the fluids in semen. It's located in the pelvis, below the bladder and in front of the rectum, and surrounds the upper part of the urethra
- **Urethra:** the tube that carries urine from the bladder through your penis

The surgery itself involves removing the bladder, prostate, seminal vesicles, part of the vas deferens and nearby lymph nodes.



Detecting and Diagnosing Bladder Cancer

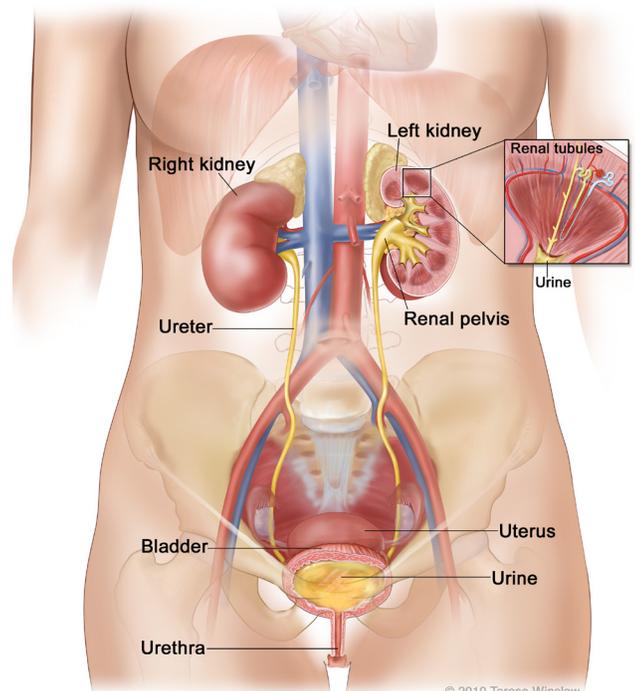
LET US START AT THE BEGINNING. WHAT EXACTLY IS THE “URINARY SYSTEM”?

FOR WOMEN:

Your urinary system is composed of four main parts. The parts include the kidneys, ureters, bladder, and urethra. The female organs below are often removed during the surgery as well as the bladder. There may be occasions where the fallopian tubes, ovaries, and uterus are preserved. Below you can see where each of these is located in your body.

- **Fallopian Tubes:** Part of the female reproductive tract. The long slender tubes through which eggs pass from the ovaries to the uterus.
- **Kidneys:** Most people have two kidneys, one on each side. These are bean shaped organs that filter your blood and make urine. The kidneys are always making urine, even when you are sleeping.
- **Ovaries:** The pair of female reproductive glands in which the ova, or eggs are formed. The ovaries are located in the pelvis, one on each side.
- **Ureters:** Most people also have two ureters. These are tubes that connect the kidneys to the bladder. They help move urine towards the bladder.
- **Urinary Bladder:** This is in your pelvis. It is a hollow organ with a stretchy wall that stores urine. The ureters bring urine into the bladder. The urine is stored here until you chose to urinate and empty your bladder.
- **Urethra:** the tube that carries urine from the bladder out of your body
- **Uterus:** The small, hollow, pear shaped organ in a woman’s pelvis. The organ in which a fetus develops. Also called the womb.

The surgery itself involves removing the bladder and nearby lymph nodes. Some women may also have one or more of the following removed: uterus, cervix, fallopian tubes, ovaries, and part of the vagina.



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What is Bladder Cancer?

Within the body, cells normally grow in an orderly fashion. Cancer is the uncontrolled growth of cells that have forgotten how to function properly. The term cancer also refers to when cells have become malignant. Bladder cancer involves a “malignant” or “cancerous” growth or tumor in the urinary bladder. Additional tests are usually required to determine if the cancer has spread out of the bladder.

What is Metastatic Bladder Cancer?

Metastatic bladder cancer means that the cancer has spread to other parts of the body. When cancer spreads to another part of the body, the new tumor is made up of the same type of cells as the original tumor. When bladder cancer first spreads it generally travels to the lymph nodes in the pelvis. As the cancer progresses it can spread out of the bladder and spread to other parts of the body.

How is Metastatic Bladder Cancer Detected?

The three main imaging tests done to determine if bladder cancer is confined or metastatic include a abdominal and pelvic CAT scan (also known as a CT scan) and bone scan. A CAT scan is used to look for enlarged lymph nodes which may represent metastatic deposits of bladder cancer. It is generally done by laying flat on a table which “travels,” moving the person into a large round scanner. As the person passes through the scanner, multiple pictures of the person’s insides are taken, which are later interpreted by a radiologist. CAT scans are helpful for looking at enlarged lymph nodes. If the lymph nodes are small, as with early cancer, the CAT scan may not show any abnormality.

- A bone scan is a nuclear test done to look at the person’s bones for any abnormal areas which may suggest metastatic cancer. A radiotracer (a bone seeking radioactive material) is injected into the vein. After waiting 3-4 hours for the radiotracer to be absorbed by all the bones, a camera slowly scans a person’s body and takes pictures of how much radiotracer collects in the bones.
- A chest x-ray is done looking for abnormalities in the lungs.
- An abnormal chest x-ray, bone scan, or CAT scan does not necessarily mean that the person has metastatic cancer. Additional tests may be done to further assess any suspicious sites.

Who Gets Bladder Cancer?

You are not alone, in the United States it is estimated over 70,000 Americans are diagnosed with bladder cancer every year. The greatest risk of developing bladder cancer is a history of smoking. Additional risk factors for bladder cancer include exposure to chemicals at work.

What is the Best Treatment for Bladder Cancer?

The treatment for bladder cancer depends on your individual type of bladder cancer. A radical cystectomy is done in an attempt to cure your cancer that has invaded the bladder wall or has come back following initial treatment, or has a high chance of spreading. At this point in your disease, your surgeon has recommended you have removal of your bladder. Some patients may have chemotherapy before or after they have their bladder removed. Your bladder has to be surgically removed to take out the cancer.

Should Everybody have a Radical Cystectomy with Neobladder Urinary Diversion for Bladder Cancer Treatment?

While cystectomies with neobladders are safe and effective, these procedures may not be appropriate for every individual. This patient information booklet describes only one of the surgery options in more detail: radical cystectomy with neobladder. Information about other options is available from your physician.

How Long will Surgery Last?

Surgery usually takes 6 to 8 hours, this is just an estimate. It may take longer with the preoperative and postoperative phases of care.

What research is being done on bladder cancer?

Doctors all over the world are conducting many types of research. Doctors are studying the makeup of bladder cancer, how to better diagnose bladder cancer, and clinical trials.

Patients who join research studies make an important contribution to medical science by helping doctors learn more about the disease. Although there are some risks with participating in research, researchers take many steps to protect their patients. There are usually many research studies in which the University of Rochester Medical Center is participating. Ask your bladder cancer care team about any studies that are ongoing currently at the University of Rochester Medical Center.

Pre-Assessment Clinic

You will see in our pre-assessment clinic. Here you will meet with an ostomy nurse who will mark a site for the surgeon to put the stoma, if needed in the operating room. You will be counseled on urinary diversion care. Here you will also undergo a comprehensive history and physical exam. You may have to see other specialists in order to get you in optimal condition prior to your surgery. You will be given resources to help speed your recovery and answer any questions you may have.

What is a Neobladder?

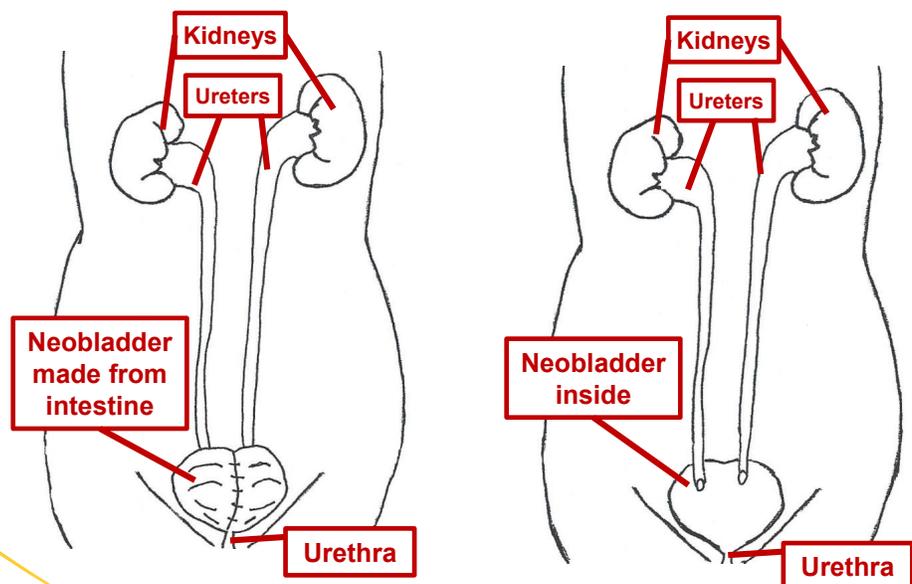
A neobladder is a type of urinary diversion. A neobladder will be the new storage area for your urine once the bladder is removed. This surgery is a lifelong change.

Your intestinal tract is the part of your body that carries and digests food as it moves through your body (from your mouth to your anus). The intestine also carries wastes the body no longer can use. Fortunately a small portion of intestine is a good substitute for the urinary bladder (which also stores wastes your body can no longer use). The ureters will be disconnected from the bladder. Then a section of intestine (bowel) is removed. The intestinal ends are then rejoined so your body can continue to digest your food. The piece of intestine removed will then be positioned inside your body, shaped into a bladder shape and then put in the same place as your original bladder.

After the new bladder is formed with intestine it will be attached to the ureters (tubes that carry urine produced by the kidneys). Once the ureters are hooked up your kidneys will function as normal and deposit urine into the neobladder. The neobladder will be connected to you urethra, allowing you to urinate normally.

This urinary diversion will allow you to preserve as much of your normal function as possible. A sphincter muscle at the base of the bladder prevents leakage of urine when closed and when open it allows urine to empty. This sphincter muscle is left intact during surgery. This will be weak at first, but eventually it should allow you to store urine in your neobladder until you are ready to pass your urine.

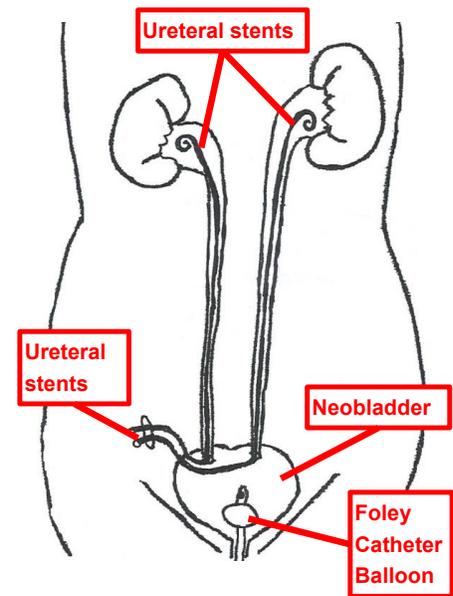
Having a neobladder means your “new” bladder is entirely made of intestine. The intestine normally produces mucus in your body, this is a filmy substance that is excreted with the rest of the waste from the intestines. When the intestine becomes part of your urine drainage system it will still produce mucus. Mucus will collect in your bladder along with urine.



What will be required to care for my neobladder?

WHAT TUBES WILL YOU HAVE AFTER SURGERY?

Initially after the surgery you will have many tubes that prevent the new bladder heal together. These tubes include ureteral stents, which are little plastic tubes that link the neobladder and ureters to the kidneys in order to help the kidneys drain. The ureteral stents will come out of a separate hole in your skin for a few weeks. Additionally you will have a Foley catheter, this is a thin, soft tube, this tube goes through the urethra and into the neobladder. The Foley catheter will drain urine from the neobladder to a bag outside the body, called a urine drainage bag. The Foley catheter is held in place by a water filled balloon.



WILL YOU BE ABLE TO HOLD YOUR URINE AND BE COMPLETELY CONTINENT?

Continence means that you can hold urine and void when you want. Unfortunately this takes time. You will have to work on urinary control. You will likely need an incontinence pad, such as Depends, for the first 3 to 6 months after surgery. Because your neobladder is not wired like your original bladder was, you may have some discomfort when it is full, but it will not be nearly the same. You will need to empty your neobladder every few hours. During the overnight hours you will need to set an alarm so you will be sure to empty your bladder and avoid leakage. Most patients get up at least twice during the night to urinate. Many patients will always leak urine at night, the degree varies from person to person.

HOW IS MY NEOBLADDER GOING TO EMPTY IF THE BLADDER MUSCLE IS GONE?

Your neobladder will be unable to release urine as well as your original bladder. You will urinate by straining your abdominal muscles and relaxing the sphincter muscle. Sometimes you may need to use a catheter to drain your bladder, this is not usually forever, but occasionally you may need to intermittently catheterize your bladder to drain it forever.

WHAT ARE THE RISKS OF HAVING A NEOBLADDER?

All urinary diversion treatment options have associated risks. The most common complications that occur with a neobladder are:

- Urine infections
- Mucus build up and can lead stone formation
- You may have too much acid deposited in your blood when you have a neobladder, this has to be treated with tablets if this develops
- Incontinence, day and/or night
- Inability to empty the neobladder completely and needing to catheterize
- Having to schedule emptying of your neobladder during the night

WHAT HAPPENS IF DURING SURGERY IT IS DETERMINED I CANNOT HAVE A NEOBLADDER?

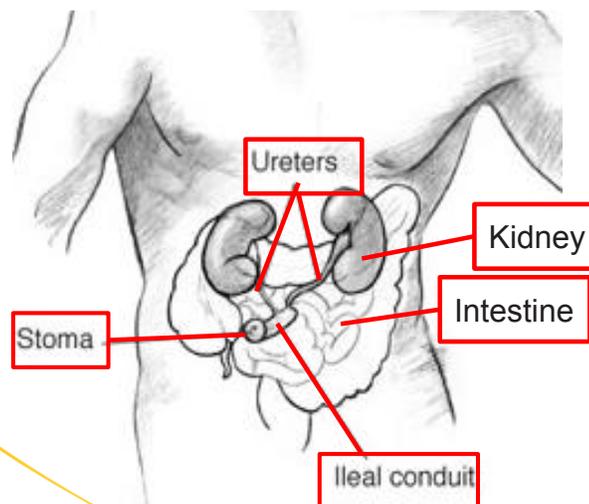
If the surgeon finds any anatomical reasons why they cannot create a neobladder, you will have to be prepared to receive an ileal conduit urinary diversion. Before your surgery, you will meet with your Wound, Ostomy, Continence Nurse (WOCN). For the rest of the booklet this nurse will be referred to as an ostomy nurse, and they will help find a good spot for a stoma if you need one. The ostomy nurse will have you lie flat, stand, sit and bend to determine where the best place for the stoma will be on your belly. This will only be used if the Indiana pouch cannot be done safely or if you decide you do not want an Indiana pouch before surgery.

WHAT IS AN ILEAL CONDUIT?

If the surgeon determines during your cystectomy it is not safe for you to have a neobladder for a variety of reasons, you likely will have an ileal conduit. An ileal conduit is another type of urinary diversion, also known as a urostomy. This ileal conduit is usually lifelong and if you have to have an ileal conduit it is hard to reverse.

The ureters will be disconnected from the bladder. Then a section of intestine (bowel) is removed. The section this is taken from has two ends. The intestinal ends are then rejoined so your body can continue to digest your food. The piece of intestine removed will then be attached to the ureters (tubes that carry urine produced by the kidneys). The end of the intestine that is attached to the ureters will stay in your body. The other end will be brought through your abdominal wall and a stoma is created. A plastic pouch is placed over the stoma to catch the urine that is continuously produced by the kidneys.

The intestine normally produces mucus in your body, this is a filmy substance that is excreted with the rest of the waste from the intestines. When the intestine becomes part of your urine drainage system it will still produce mucus. Mucus will collect in your urinary pouch along with urine.



What Is Enhanced Recovery?

INTRODUCTION

Understanding of the Cystectomy Enhanced Recovery Program will help you play an active role in your recovery. This program is designed to help you recover from your surgery and regain your independence as quickly as possible. This new program is based on research which showed eating and drinking early, moving around soon after your surgery, and pain control help speed up recovery. Therefore, the program emphasizes how you can focus on helping yourself after surgery. The purpose of the comprehensive care program is to enable you to recover from surgery with minimal stress response from your body.

Planning and actively participating in the steps to success before and after your surgery can help you:

- Feel better, sooner
- Leave the hospital, sooner
- Return to normal living, sooner

The Cystectomy Enhanced Recovery Program is designed to have you in the best possible condition when you come into the hospital for surgery.

This program should help decrease common problems after surgery, such as pain and bowel dysfunction.

Additionally, the Cystectomy Enhanced Recovery Program should help you to get up and move around more easily after surgery and allow you to drink and eat sooner.

As part of this program there will be steps designed to improve your experience through all phases of your surgery, preoperatively, the day of your surgery and postoperatively.

This is a major surgery and will be a big change in your life. It is important to us you are able to return to your lifestyle as quickly as possible. Returning to normal depends on how you feel physically as well as mentally.

Sometimes talking to a patient who previously had this surgery can be helpful. Please let us know if you would like to be connected with a previous patient. There are also resources at the end of this booklet for support.

Preparing for Surgery

HOW CAN YOU SUPPORT MY RECOVERY BEFORE COMING INTO THE HOSPITAL?

Make yourself a to do list. Keep in mind even though you are leaving the hospital you will still be recovering when you go home.

- You will need people to support your recovery when you return home. Make sure that you have family and friends to help you with activities you may not be up to or allowed to do after surgery. It is a good idea to make a list of important phone numbers and bring this with you to the hospital.
- Make sure you have over the counter medications like acetaminophen, Tums or other antacids, and medications to help with constipation such as milk of magnesia.
- Do not be afraid to ask for help.
- Try not to worry
- Spend time with your family and friends

HOW CAN QUITTING OR CUTTING DOWN ON ALCOHOL OR SMOKING CIGARETTES BEFORE SURGERY HELP ME RECOVER?

If you drink or smoke, you can use this as an opportunity to cut down or quit. This will help reduce the risk of complications after your surgery. Even if it is a few days before surgery this will still reduce your risks of wound healing complications. If it is even longer it may help you avoid some of the breathing problems such as pneumonias that occur in smokers more frequently after surgery.

We can help you quit smoking. If this is something you are ready to do, please tell us and we can provide you with the resources to help. You may also find your primary care doctor a resource for help quitting smoking. Additionally, you may always call the New York State Smokers' Quitline at 1-866-697-8487 or visit www.nysmokefree.com

If you drink alcohol consider cutting down the amount you drink or quitting 2 weeks before the surgery.

HOW CAN PRACTICING DEEP BREATHING EXERCISES HELP YOU BEFORE SURGERY?

Using the incentive spirometer before your surgery can help you get your lungs ready for the surgery. You use the incentive spirometer by placing your lips around the mouthpiece and making a tight seal. Exhale out all the air in your lungs. Then inhale a big deep breath through your mouth while maintaining a good seal on the mouthpiece. Hold this breath for 3 seconds, then exhale. Repeat this 10 times every hour.

Preparing for Surgery (cont.)

HOW CAN EXERCISE BEFORE SURGERY HELP ME RECOVER?

It is important prior to coming to the hospital that you increase your physical activity. Doing more physical activity can be as simple as taking a 30 minute walk at least 5 times a week. More activity than this is great, every bit of conditioning you can do for your body will aid in recovery. Increasing your exercise endurance will help your energy level before and after your surgery. Being more physically active before admission will prepare you to walk sooner after your surgery. Increasing your exercise tolerance will also help you lose less muscle mass during the surgery.

WHAT IS A PROBIOTIC AND WHY SHOULD YOU TAKE IT?

A probiotic is a pill that contains “good” bacteria. These supplements can help reduce infections after your surgery. These probiotic supplements also can help regulate your digestive system. You should start taking it two weeks before your surgery. You will continue this in the hospital and after you are discharged. There are many different types sold over the counter. This should be provided for you from the cystectomy preoperative clinic.

DO YOU NEED TO DO A BOWEL PREP?

This will depend on your surgeon, your past medical and past surgical history. There may be certain occasions where you might be asked to do this. If you are asked to complete a bowel prep a handout will be given to you.

WHAT ACCOMMODATIONS ARE THERE FOR MY FAMILY?

If you're from out of town, Strong Memorial Hospital has an affiliation with local hotels that offer low-cost lodging and free shuttle service for you and your family. You may call Strong Guest Services to help you with setting up accommodations, call 585-275-7581. You may also try the Hope Lodge at 1-800-227-2345.

We recommend staying the night prior to your procedure if you are the first procedure the next day.

Visiting hours on the unit are from 11 AM to 8 PM daily. One adult (older than 18) may stay overnight with you if you are in a private room. Most hospital stays after the procedure are 3-5 days.

Preparing for Surgery (cont.)

WHAT SHOULD YOU BRING TO THE HOSPITAL?

During your stay, you may find that you would like to have some of the following items with you

- Sweater or bathrobe
- A few sets of comfortable clothing (sweats, pajamas, underclothes, socks)
- Personal items and toiletries (toothbrush, comb or brush)
- Glasses, dentures, hearing aids
- A favorite pillow or blanket
- Magazines, books, crossword puzzles, Sudoku
- Favorite pictures to put on the wall
- Laptop (wireless service is provided throughout the hospital), DVDs to watch if you bring a laptop
- Credit card for new prescriptions to be filled at discharge. You can conveniently fill all of your prescriptions at our pharmacy. (However for safe keeping we recommend you leave your credit card with a family member or friend until you need it.)
- Your list of important numbers
- Phone calls can be made free to local numbers, the phone receives incoming calls from 8 a.m. to 8 p.m.
- You will have a television in your room
- Sugar free gum

WHAT NOT TO BRING INTO THE HOSPITAL

- Valuables, such as jewelry and money, are best left at home
- Appliances, please do not bring electric appliances such as hair dryers, fans, or other personal items.
- Your own pills and medications, you can leave all your bottles at home.
- Smoking materials, if you smoke, you will be given an alternate form of nicotine. The grounds of Strong Memorial Hospital are smoke free.

Preparing for Surgery (cont.)

HOW CAN YOU IMPROVE YOUR NUTRITION BEFORE THE SURGERY?

Good nutrition may be one of the most important parts of the enhanced recovery process. Good nutrition is promoted by eating a balanced diet before you come into the hospital before your surgery. It is also recommended that you begin to try some different high protein containing drinks to figure out what tastes good. You will be offered these after surgery to help promote your recovery. If you have any nutritional deficiencies based on screening questions and lab values, we will ask you to routinely start taking protein drinks, and possibly supplements, before the surgery. Remember after surgery your taste buds may change for a while, so it is important to try new things in order to keep yourself nourished. The hospital may not have all the flavors or particular drink you like, so you may bring in protein drinks from the outside. Below is a chart of nutritional drinks that will promote healing, along with their protein and calorie contents. We will want you to take 3 drinks a day after surgery, so it helps if you find something you like. All of these drinks can be found at Wal-Mart, Target, drug stores and supermarkets. Many of these stores have their own brand which has the same nutritional value.

Drink	Flavors	Amount	Protein (grams)	Calories	For Diabetic
Ensure®	Vanilla, Milk Chocolate, Strawberry, Butter Pecan, Dark Chocolate, Coffee Late	8 oz	9	250	
Ensure® High Protein	Milk Chocolate, Vanilla	14 oz	25	210	
Ensure® Complete	Milk Chocolate, Vanilla	8 oz	13	350	
Ensure® Plus	Vanilla, Milk Chocolate, Dark Chocolate, Strawberry, Butter Pecan	8 oz	13	350	
Ensure® Clear	Blueberry Pomegranate, Mixed Fruit, Peach	10 oz	9	180	
Enlive® (Ensure Clear)	Apple, Mixed Berry	6.7 oz	7	200	
Boost®	Chocolate, Vanilla, Strawberry	8 oz	10	240	
Boost® Plus	Chocolate, Vanilla, Strawberry	8 oz	14	360	
Boost® Glucose Control	Chocolate, Vanilla	8 oz	16	190	Yes
Glucerna®	Chocolate, Vanilla, Strawberry, Butter Pecan	8 oz	10	200	Yes
(Resource) Boost® Breeze	Orange, Peach, Berry	8 oz	9	250	
Carnation® Instant Breakfast Powder	Milk Chocolate, French Vanilla, Chocolate Malt, Strawberry, Dark Chocolate	1 packet	5	130	*
Carnation® Instant Ready to Drink	Milk Chocolate, French Vanilla	11 oz	14	260	*
Kellogg's® Special K Protein Shake	Milk Chocolate, Strawberry, French Vanilla, Dark Chocolate, Strawberry Banana	10 oz	10	190	
Hormel® Med Pass 2.0	Vanilla, Wild Berry, Butter Pecan	2 oz	5	120	*
Mighty Shakes®	Strawberry, Chocolate, Orange Cream, Plus Chocolate, Plus Vanilla, Strawberry, Vanilla	4 oz	6	200	*
Novasource® (only if instructed)	Vanilla	8 oz	17	475	

*Available in No Sugar Added

What are the risks of your operation?

This is a major operation. One of the well known complications listed below may occur, or you may have no problems at all after the procedure. You should know across the world when a radical cystectomy is performed, there is a 60% chance of one of the below. Additionally, there is a 30% chance you will have to come back into the hospital. If a complication does occur, it can be hard to stay positive, however staying positive will help you recover faster. Our Cystectomy Enhanced Recovery Programs collective interventions are aimed at reducing your risk of the complications below.

COMMON COMPLICATIONS

- Bowels can be slow to return to normal after surgery, you may require a temporary insertion of a stomach tube through the nose to help you feel less sick. Your bowels may not be back to normal for a few months after this surgery.
- Loss of erectile function, this is because the nerves that help with erection are very close to the bladder and in order to try to cure your cancer, these nerves are often removed.
- Dry ejaculation, which does not mean you will not feel pleasure.
- Shortened vagina from having part of the vagina removed, may make sexual intercourse more difficult. Orgasms may be less easy to achieve.
- Cancer may not be cured with removal of the bladder alone.
- Infection of your bowel, urine or wound
- Blood loss requiring you to be given blood products, this may even be a few days after the surgery.
- Mucus build up, stone formation
- Incontinence that usually improves over time
- Needing intermittent catheterization to empty your neobladder
- Having to irrigate your neobladder to drain the mucus

OCCASIONAL COMPLICATIONS

- Anesthesia, lung, or heart problems, possibly requiring intensive care admission (chest infection, heart attack, stroke, death)
- Blood clots in your legs and/or lungs
- Decreased kidney function with time
- Diarrhea
- Narrowing of where the ureter (urine tube) connects to the intestine
- Cancer reoccurrence at the remaining urethra
- Blood contains too much acid, needing pills for treatment
- Vitamin deficiency

RARE COMPLICATIONS

- Needing another surgery
- Bowel or urine leaking from where they were joined together
- Injury to the bowel, major blood vessels and nerves
- Bowel injury requiring bowel diversion
- Bursting of the neobladder if not drained and too full

The day before surgery:

WHAT CAN YOU EAT AND DRINK?

The day before surgery you may eat and drink as you please. If you qualify, you will be given Gatorade PRIME 01 carbohydrate loading drinks. These carbohydrates will help you withstand surgery. Call (585) 275-8256 between 2:30 PM and 7 PM on the day before your procedure to find out the time to arrive to the Strong Surgical Center and the time of your procedure (Please note the surgery start time is approximate.). Please arrive on time. You may want to bring something to help pass the time. If scheduled for a procedure on a Monday, you should call the Friday before. Timing of when you have to take your carbohydrate drinks and when you have to stop drinking are based on what time the Surgery Center tells you to arrive.

- You will be given Gatorade PRIME 01 carbohydrate drinks if you qualify.
- If you receive these drinks, take four containers the night before your surgery (16 ounces). You should drink the remaining two Gatorade PRIME 01s (8 ounces) an hour before you are scheduled to arrive at the Strong Surgical Center (This should be three hours before your scheduled surgery start time, this is considered a clear liquid).

OR

- You should NOT do carbohydrate loading
- You are not allowed any solid food after midnight the morning of your surgery.
- You may drink clear liquids until three hours before your scheduled surgery start time. Clear liquids are: water, apple juice, cranberry juice, broth, black coffee (no cream, no sugar), plain tea (no cream, no sugar), and sodas.

OR

- You may not have anything to eat or drink after midnight (no clear liquids except a sip of water with pills)
- No gum chewing or chewing tobacco after midnight.

Failure to follow these instructions could lead to a delay or cancellation of your procedure

On the morning of surgery you should take your medications you were instructed to take, take these at the usual time or before leaving for the hospital, whichever comes first (unless otherwise instructed). The morning of surgery, you may take the medications you were advised to continue with one of the clear liquids listed above.

The day of the surgery:

WHAT WILL HAPPEN WHEN YOU ARRIVE AT THE SURGERY CENTER THE DAY OF YOUR SURGERY?

The nurses will check you into the hospital system. They will put a little tube in your vein, called an IV, this will help keep you hydrated and get you important medications. You will meet the anesthesiologist and a nurse from our operating room before you are brought back to the operating suite. They will give you a few pills to take before the surgery, these are to help with your bowels and pain control. They will also give you a shot to help prevent blood clots from forming in your legs and lungs during the surgery.

HOW WILL YOUR PAIN BE CONTROLLED?

- Often we offer our patients what is called an epidural anesthetic.
- An epidural is a special drip that goes into your back. A little needle is used to insert it. You may have heard about it because some pregnant women use it to help with their labor pains. Once the drip is positioned in your back it can be used to give some pain killers. These work by numbing the nerves in the back and blocking the feeling of pain from the wound reaching the brain. It is common that other nerves are numbed too. This can mean that you have a numb feeling over your abdominal wall and even in your legs and feet. The epidural will be started in the pre-anesthesia area and continued for 2 days. It should not restrict your mobility or recovery afterwards. The pain killing liquid medicine usually works by dripping into the epidural as a slow continuous flow and by little bursts which you can control with a button. If you are given a button, you should push the button so you are comfortable enough to walk, sit in the chair, do breathing exercises and drink fluids. When you press the button some of the pain killing liquid medicine will flow into the epidural. Use the button as often as you like, don't wait for the pain to get really bad before you use it. If your legs are numb and you do not feel you can walk, let your nurse know so she can call the pain team to evaluate you. In a few patients that have an epidural placed, it can fail to adequately control their pain.
- After the surgery moving and walking about will cause you some discomfort but this is normal.
- If the epidural is not working they may need it repositioning or to use a different form of pain relief. Other options may include having a painkiller pump attached to a drip in your arm vein, with the same type of button as described above, where you push the button when you are in pain.
- You will have pain tablets given to you routinely, usually Tylenol and a strong Ibuprofen through the vein.
- By the morning of the third day after your surgery, if not sooner, your pain should be controlled with tablets alone. The epidural should be removed the morning of the third day after your operation if you are tolerating liquid diet.

What can you expect the night right after surgery?

After your surgery it will be important for you to take an active role in your recovery. You will be given a daily routine outlined in your recovery plan. You will have a journal that outlines your recovery plan, filling this out will help you stay on track. Not everyone recovers at the same rate, you will be treated as an individual and if your recovery is delayed, your care plan will be adjusted.

- Pain control: it is important you speak up if you are having a lot of pain, we can help you recover faster with better pain control. It is important your pain be well enough controlled that you can get out of bed to the chair this night.
- Nausea: Following the surgery you may feel sick (nauseated or feel like you may vomit). Although this is an unpleasant feeling, we have many medications that can make you more comfortable. Let the nursing staff know if you are feeling sick.
- Liquid Diet: Following surgery if you are not feeling nauseated or sick, you will be offered a tray of clear liquids.

WHAT TUBES AND DRESSINGS WILL BE LEFT IN YOUR BODY AFTER THE SURGERY?

- Most patients find the amount of tubes that are left in at the time of surgery surprising. You will have a drain in your abdomen, called a "Jackson Pratt" or "JP" drain for short, this drain removes excess fluid from the surgical site.
- You will have a tube in your vein (IV) for the rest of your hospital stay.
- You often will have a heart monitor on at least the first night after surgery.
- You will have two small plastic tubes (stents) draining your kidneys coming out your abdominal wall, these will stay in until your surgeon decides it is safe for these to be removed.
- You will have an ostomy bag over the ureteral stents.
- You will have a Foley catheter
- You may have oxygen placed in your nose.
- You will have anti-thrombosis massaging stockings on at all times.
- For the first two days you will have dressings over your incision, once the dressings are removed you will often find your incision was closed with staples.
- We encourage you to wear tight stockings to help keep swelling down. We try to prevent swelling of the legs, leg swelling can be very uncomfortable and even inhibit walking.
- Additionally you may have some swelling of your genitals, this is normal.
 - For **men**, if this happens we would like you to support your genitals with a rolled up towel to elevate your scrotum while sitting. Swelling can become painful and this also can prevent you from walking.

WHEN CAN YOU EXPECT TO START THE IN HOSPITAL PORTION OF YOUR ENHANCED RECOVERY PROGRAM?

After you have had your surgery, there will be many people involved in your care. You will first be transferred to the postoperative care unit (PACU). Here you will be monitored by your nurse as you come out of anesthesia to an arousal state. Communicate any needs or information you would like the nurse to know. This stay is usually a short one and soon you will go to your floor for your post-op recovery. You will then start your Cystectomy Enhanced Recovery Program, this is outlined further here, keep in mind your body's response to the surgery could be different from what we hope. If this happens we may have to change the eating schedule we have outlined here. This sometimes includes inserting a tube in your nose to drain your stomach. If this happens, you will not be allowed to eat or drink anything and you may have to have nutrition through the vein.

WHAT WILL YOUR ROOM BE LIKE IN THE HOSPITAL?

After surgery your nurse will show you around the room. Each room has a shower or bathtub. Bathrooms in your room are for patient use only, there are bathrooms in the hall for friends and family. There is an area right outside your room where you can walk around the nurses' station.

WHEN WILL YOU KNOW IF ALL THE CANCER WAS REMOVED?

Unfortunately, here, there is no quick answer. All specimens your surgeon removes are sent to our pathologist. The pathologist will look at the bladder, surrounding organs, and lymph nodes under a microscope. The microscope allows them to see where the cancer cells are within the specimens. This usually takes 5 to 7 business days to come back. If you leave the hospital before the final pathologist report comes back, this will be discussed when you follow up in the office with your surgeon.

HOW CAN YOU PREVENT ACQUIRING INFECTIONS WHEN YOU COME INTO THE HOSPITAL?

If you have not seen a member of the healthcare team who cares for you either wash their hands or use hand sanitizer, ask them to do so. Same applies to visitors. Wash your hands and use alcohol rub often. This is one of the most important ways to prevent infections.

WHAT WILL YOUR HOSPITAL STAY BE LIKE?

The hospital is a very busy place and unfortunately it can be hard to get rest. However, in order for you to heal, you need a restful space. Every patient will receive a personal comfort kit with ear plugs, eye masks and ear buds to listen to the TV between 8 PM and 7 AM. Things that can help you get better sleep are having the door closed to your room, be aware of side effects medications may have. We suggest during the day you raise your window shade. Get as much physical activity as you can during the day. Limit your daytime napping to only 30 to 45 minutes. Turn off the TV and computer screens at night.

What will be your daily routine?

HOW OFTEN WILL THERE BE BLOOD DRAWS AND VITALS SIGNS TAKEN?

We will be monitoring you very closely after your surgery. You will have your blood pressure, heart rate, pain score, and temperature taken every 4 hours. You will have your blood drawn every day, usually between 3am and 6am, this enables your doctors to have the results when they come see you on medical team rounds. We will also want to have you help us record how much fluid you are taking in and how much fluid is coming out.

WHAT CAN YOU EXPECT FROM DAILY MEDICAL TEAM ROUNDS?

The members of your medical team will be in to see you every morning. Our team often consists of medical students, residents, nurse practitioners and physician assistants. Sometimes they may visit as early as 5am, before they go to the operating room for the day. Your attending surgeon or one of their partners will be in to see you every day. The team will likely ask you if you have passed gas or had a bowel movement, this is nothing to be embarrassed about, this is a sign your intestine is working and you are recovering. After the team comes to see you, if you are not clear on the plan for the rest of the day, ASK!

WHAT SHOULD BE YOUR DAILY GOAL FOR ACTIVITIES AND EXERCISE?

- In the morning you can expect you will have help with personal hygiene, including oral care.
- On the third day after your surgery, we encourage you to take a shower.
- Walking and being out of bed are very important.
- It is also important to do deep breathing exercises, using the incentive spirometer as you did preoperatively. The nurse will provide you with a cough pillow, if you hold this tight to your belly during this exercise, it will reduce your pain.
- Walk laps around the hospital floor at least four times daily.
- Your goal is to sit in a chair for 6-8 hours a day after your surgery. This will be hard work, but this will keep up your muscle strength.
- Chew gum at least 3 times daily. Sugar free is the best kind of gum, you may bring your favorite flavor.

HOW WILL YOU LEARN TO TAKE CARE OF YOUR NEOBLADDER?

Hopefully starting before you come into the hospital for this surgery you had an idea of what to expect. When you are out of bed, we encourage you to be disconnected from the night bag and put on a leg bag. Start emptying the bags yourself. Start flushing the catheter yourself. Over the first few days the nursing staff will teach you how to care for neobladder. There will be two small plastic tubes (stents) coming out abdomen with an ostomy bag over then, you will also need to learn to flush the stents. These tubes help drain urine from your kidneys. It is essential you participate in caring for your neobladder. The staff will also teach whoever will be helping care for you at home.

RECOVERY CARE PLAN JOURNAL

This journal is designed to outline your care plan for you. These are goals that you should try to meet daily. Please fill this out daily. One of the urology team members will be available to go through this with you if you have any questions.

What should you be doing postoperative day 1?

DRINKING

You may have clear liquids today. If you found a protein drink you liked before you came into the hospital, ask the team to order this for you. Your team can prescribe almost any drink for you, let them know if you do not like the drink you are getting, this can always be changed. We would like you to take three protein drinks a day. You should try to take in about 1500ml to 2000ml of fluid by mouth. If you are feeling nauseated, or sick, tell someone. If you begin to feel nauseated, slow down on the drinking, when you feel better then try again.

ACTIVITY

You will likely be visited by a physical therapist today. They will assist you in getting the support you need to walk, such as a walker. You should aim to be out of bed in the chair for 6 to 8 hours today. You should walk at least four times around the hospital floor. Make sure you are using your incentive spirometer.

PAIN CONTROL

You will receive Tylenol scheduled every 6 hours. You may also get a strong Ibuprofen type pain medication if your kidneys are working well enough. Pain control is an important key to getting you up and about. Pain control also aids in deep breathing, drinking and sleeping well, all of which will help promote recovery. You will continue to have an epidural for pain control.

HOSPITAL STAFF

When anyone that works for the hospital comes to see you, please do not send them away. If you have visitors, you should tell them before they come to see you in the hospital, if a therapist or ostomy nurse comes while they are here, you are expected to work with that team member. We are all here to help you recover quickly, keeping on pace with daily visits and goals you have to meet will only advance your recovery.

BLOOD CLOT PREVENTION

You will have a shot, usually once a day, administered for blood clot prevention. You will also wear the massaging stockings when you are not walking. You should begin to learn how to do the injections yourself. You will be going home with this medication for 28 days after your surgery.

INCISION AND DRAINS

You will continue to have an IV, JP drain, Foley catheter, and the ureteral stents.

What should you be doing postoperative day 2?

DRINKING

You may have full liquids today. This means more soups and puddings are available, your nurse will give you a full list. If you have started passing gas or have had a bowel movement you may start on some regular food. When you start your diet, try starting with things that are easy to digest. We encourage 6 smaller meals with protein drinks, rather than 3 large meals a day. Your appetite may not be the same, this is okay, as long as you can keep yourself hydrated and nourished. Again today we would like you to take three protein drinks. You should try to take in about 1500 ml to 2000 ml of fluid by mouth, this is about 6 to 8 glasses. If you are feeling sick or nauseated, tell someone. If you begin to feel sick or nauseated, slow down on the drinking, when you feel better then try again. If you are drinking enough, the fluids through your vein can be shut off.

ACTIVITY

You may be visited by a physical therapist again today. You should aim to be out of bed in the chair for 6 to 8 hours today. You should walk at least 4 times around the hospital floor. Continue doing your deep breathing exercises with the incentive spirometer to prevent pneumonia. Depending on your activity level before admission and your strength after surgery, the physical therapist may recommend to you a rehabilitation facility before going home.

PAIN AND NAUSEA

Please let someone know if you are having pain. Your pain should be controlled well enough that you can do the deep breathing exercises, walk, and drink. If you are feeling sick or nauseated you should also let someone on your care team know. You will still have your epidural today.

NEOBLADDER

You should be starting to feel more comfortable flushing your ureteral stents and Foley catheter. You should be able to disconnect and reconnect to the overnight bag,. You should be able to disconnect and reconnect to the leg bag.

HOSPITAL STAFF

Talk with our nursing staff. Start to get visiting nurse services coordinated for when you return home. Let the team know how we can assist you in planning to return home. If the physical therapist feels you may need rehabilitation, now is the time to start planning with your family.

INCISION AND DRAINS

Your dressings will be removed today. It is normal for there to be bruising and slight redness around the incision for 1 to 2 weeks. Occasionally there is a bit of fluid leaking from the incision. Your drain will have the fluid sent off today and test if there is urine leaking from the new connections. The output from the drain will continue to be monitored. Your fluids running in the IV should be removed by today, the IV should remain. You will continue to have a Foley catheter, JP drain and stents.

What should you be doing postoperative day 3?

DRINKING AND EATING

You will likely be advanced to a light diet today whether or not your bowels are working, unless you are really not feeling well. If you begin to feel sick back off from the food and take a rest until you feel better. Let the team know if you are having a lot of gas pains. Try to keep yourself hydrated and continue to take three protein drinks a day. You should try to take in about 1500 ml to 2000 ml of fluid by mouth.

ACTIVITY

You should start thinking about how you will move around at home when you return. You should aim to be out of bed in the chair for 8 hours today. You should walk at least four times around the hospital floor. Continue doing your deep breathing exercises with the incentive spirometer and the cough pillow.

PAIN CONTROL

You will continue to take Tylenol. The epidural will be removed this morning. You will then have pills available for pain control every 6 hours once the epidural is out. All of your pain control should be by mouth today. You may have episodes of 'gripping' abdominal pains during the first week or so. The pain usually is from the small bowel and lasts for a few minutes and will go away between spasms.

RECOVERY CARE PLAN JOURNAL

Continue to record your progress.

PLANNING FOR HOME

Make sure your family and friends know you are progressing and when you might be able to go home. Your family and friends will play an important role in your recovery. Our aim is for you to continue your recovery process at home as quickly and safely possible.

INCISION AND DRAINS

The output from the drain will continue to be monitored. Your IV should remain without fluids running. You will continue to have a Foley catheter, JP drain and stents.

What should you be doing beyond postoperative day 3 and beyond?

Everybody that has surgery is different and their body responds differently. The goal of your care plan is to have your return to home in 3 to 5 days after your surgery. Do not be discouraged if you are not going home by hospital day 5, everybody recovers differently and keeping a positive attitude will help. If you are doing well and the team feels you are ready for discharge they will tell you. There is a list of things that have to be achieved before you may be discharged:

- Taking regular diet
- Having bowel function
- Ambulating enough to function at home
- Pain controlled with all medications by mouth
- Be able to care for your neobladder

What do you need to know about going home?

DRINKING AND EATING

Continue to take 3 protein shakes a day for at least 2 weeks after your surgery. If at the end of the 2 weeks you are still not taking enough food, continue these drinks and let your doctor know. Continue to take 5 or 6 smaller meals and frequent snacks for 2 weeks and then return to a regular diet. Make sure you stay very well hydrated at home. Your urine should be clear, if it is dark or has an odor, you need to drink more.

ACTIVITY

At home you should continue to be out of bed at least 8 hours a day. Over the next 6 weeks after you go home you will continue to recover. Some people do not feel back to normal for up to 3 months after having this surgery. Continue to walk at least 4 times daily, stairs are encouraged. You should keep walking and try to increase the distance you walk every day. Continue doing your deep breathing exercises with the incentive spirometer to prevent pneumonia. You will need help with things like shopping, mowing the lawn and shoveling snow. You should plan for help after surgery at home in advance before you come in for surgery.

PAIN AND SICKNESS

You may need to continue to take pain medications for a few weeks. You will be given a prescription for this at discharge. If you are feeling sick or nauseated you should let us know. Contact numbers are at the back of the book.

What happens after you go home?

PAIN AND SICKNESS

You may need to continue to take pain medications for a few weeks. You will be given a prescription for this at discharge. If you are feeling sick or nauseated you should let us know. Contact numbers are at the back of the book.

BLOOD CLOT PREVENTION

You will give yourself a shot usually once a day for 4 weeks after your surgery. You will have this training before you go home.

WHEN SHOULD YOU SEE YOUR PRIMARY CARE DOCTOR AFTER YOU GO HOME?

It is a good idea to follow up with your primary care doctor in the office the first week you are discharged after your surgery. They can look over your medications and see if there are any medications that need to be restarted.

WHAT OTHER TESTS DO YOU NEED IN ADDITION TO THE CYSTOGRAM AFTER SURGERY?

You should get lab work drawn prior to coming to your appointment, your visiting nurse can likely draw this for you.

WHAT MEDICATIONS SHOULD YOU TAKE WHEN YOU GO HOME?

You will get a list of medications you should continue and medications you should stop taking. You will also get prescriptions for new medications. You should take the probiotic until it is gone.

You should take the antibiotics as directed before stent removal and Foley catheter removal. The prescription for this should be given to you when you are discharged.

WHAT LONG TERM PRECAUTIONS SHOULD YOU TAKE WITH YOUR NEOBLADDER?

You should put a card in your wallet explaining the surgery you had and the fact you have a neobladder. You can consider getting a medical alert bracelet. Both of these things would be useful in the case that you would be hospitalized and would be unable to communicate with those caring for you. If you have one of these items they will know and be able to care for you appropriately.

How do you take care of your neobladder at home?

FOLEY CATHETER

- It is important to make sure the catheter in you neobladder is always unblocked and the bladder is being drained.
- You will need to flush your neobladder with 30ml of sterile normal saline every 4 hours and allow it to drain out.
- You will also have to flush your ureteral stents with 3 to 5ml of sterile normal saline twice daily.
- Your indwelling Foley catheter will be attached to a large overnight bag. If your urine is pink or red, you need to drink fluids, you will begin to see the urine's color diluting back to yellow with time.
- You will learn how to convert your overnight catheter bag to a smaller, more portable leg bag. Wearing this leg bag will allow you to be less restricted and more active throughout the day.
- Empty the leg bag every 2 hours during the day.
- You can sleep through the night when you are connected to the night bag because it has a bigger capacity.
- To prevent discomfort and tugging, keep your catheter secured loosely to your thigh using a cath-secure at all times. Some cath-secures do not stick very well. You can use tape or a self-sticking Ace bandage, or a medical supply store near your home may have a better product. The goal is to prevent tugging of the catheter. The catheter will not come out as it is secured within the bladder by a small balloon filled with water, which prevents it from dislodging.
- To ease urine drainage, always keep your catheter bag lower than your neobladder.
- Wear the leg bag when you're active. Use the larger bag overnight.
- To prevent infection, clean around the catheter site at least twice daily with warm soapy water. Do not use alcohol, surgilube or K-Y Jelly! You may only apply an antibiotic ointment (Polysporin, Neosporin) at where the catheter inserts to help with irritation.
- You may wash your leg bag with mild soap and water or one-teaspoon of vinegar and water. Be sure to recap all ports.
- Do not drive while catheter is in place.
- Call the office if the catheter stops draining or you feel your bladder is distended and you cannot relieve the pressure or obstruction with flushing the catheter.

How do you irrigate and empty your catheter?

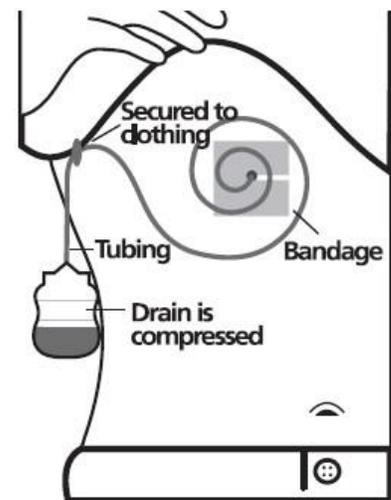
CATHETER FLUSHING

- Flush with sterile saline every 4 hours and if your catheter is not draining.
- Supplies for flushing
 - 60ml catheter tip syringe (you can reuse the syringe, clean the syringe after every use by pulling the plunger out of the casing and washing both with warm water and soap. Let them air dry on a clean surface)
 - Sterile normal saline
 - A small container for saline
- Procedure:
 1. Wash your hands
 2. Open bottle of saline
 3. Pour saline into one of the containers
 4. Pull up 30ml of saline into the syringe
 5. Disconnect the drainage bag from the Foley catheter
 6. Place the tip of the syringe into the Foley catheter
 7. Gently push the saline into the tube (also called flushing)
 - A. Sometimes we will ask you to pull back on the stopper of the syringe, this is called aspiration, you should know how to do this too.
 8. Remove the syringe and reconnect the Foley catheter to the drainage bag
 9. Get up and walk around, you will likely see bits of mucus in the Foley catheter tubing if you are watching the tubing

How will you manage your Jackson Pratt (JP) drain at home?

JACKSON PRATT (JP) DRAIN

- This is a small collapsible chamber that will be on your either the left or right side, which gently suctions fluid as a result of your surgery. This needs to be drained periodically. You may go home with this drain depending on the output.
- It works by the suction so if it is full, it is not able to remove the fluids.
- When it is closed, it will be squeezed so the suction can start working again.
- You will go home with the drain in your belly.
- You will have to empty the JP drain every 8 to 12 hours and record the amount that is coming out each time.
- Bring your JP drain amounts to your follow up appointment for review.
- Change the dressing around the JP site daily or as frequently as needed.



HOW TO EMPTY YOUR JACKSON PRATT (JP) DRAIN.

- Supplies: measuring container and JP drainage recording sheet.
 1. Wash your hands
 2. Unplug the stopper on the top of your drain, the bulb should then expand.
 3. Do not touch the inside of the stopper or the inner area of the opening in the bulb
 4. Turn the JP drain upside down, gently squeeze the bulb and pour the drainage into the measuring container.
 5. Turn the JP drain right side up
 6. Squeeze the bulb until you fingers feel the palm of your hand.
 7. Continue to hold the squeeze while replugging the stopper.
 8. Check to see if the bulb is fully compressed to ensure a gentle suction.
 9. Pin the drain to the inside of your clothing
 10. Record the amount of drainage and then flush the drainage down the toilet and rinse the measuring container with water.

When does my catheter come out?

CATHETER REMOVAL

- Take the antibiotics that were prescribed for you prior to your appointment for the test on your bladder, specific instructions should be given to you when you are discharged.
- At 2 to 3 weeks after surgery you will get an x-ray after dye is put in your neobladder through the catheter. This is called a “pouchogram” or “cystogram.”
 - If the picture looks okay, and the neobladder has healed together, then you will get your stents out on that day.
 - If the neobladder is not healed together it will be repeated before the stents can be removed.
- About 4 days after the stents are removed if you are doing okay, your Foley catheter will be removed.
 - The same day as long as no leak is detected after removal of the Foley catheter you will also get your JP drain out.
- Once the catheter is removed you will need to empty your bladder around the clock, even at night, every 2 hours.
- Remember to bring an absorption product and brief underpants to that appointment. (Male guard pads work fine.)

INCISION HEALING AND PERSONAL CARE

- Bruising is normal around the incision sites and will resolve over time.
- Your urethra may become irritated from the catheter. You may apply a thin coat of Polysporin or other antibiotic ointment to the irritated area up to three times a day. Do not use alcohol, surgilube, or K-Y Jelly.
- For **men** and **women**: Bluish discoloration and swelling of the genitals can be seen at times.
 - For **men**, it might help to place a small rolled up towel under the scrotum for elevation when sitting up or lying down.
 - You may leak fluid from your vagina, this is normal and can continue for up to 6 weeks, and can seem like a lot of fluid at times, you should buy pads before surgery for home.

WHAT ARE THE RECOMMENDATIONS FOR AFTER CATHETER REMOVAL?

- The urine may also be tinged with blood for about one or two days because of irritation from the catheter. This is normal and will stop. Continue to drink a lot of fluids.
- You will now have to void by contracting your abdominal muscles. Try sitting to urinate as this is often easier. Rest your elbows on your thighs and curl over, contract your abdominal muscles 3 to 4 times.
- You should try to urinate every 2 hours until you are instructed by your surgeon to increase time intervals between voids. You should not go longer than 4 to 5 hours without emptying your neobladder.
- Call the office if you inability to urinate, abdominal/pelvic pain, or fever and chills.
- Be sure to drink fluids.
- On average you will change your pads 7-10 times a day.

Gaining control of your urine

Urinary leakage is normal after a catheter is removed, especially when you do any weight-bearing activity. This could be a small amount to a large amount as every patient is different. Patients have reported male guards or female pads work well in brief underpants for daytime use and diapers work well at bedtime. This will lessen over the next 3 to 6 months.

WHAT ARE KEGEL EXERCISES AND HOW DO YOU DO THEM ?

- Kegel exercises are pelvic floor exercises to regain urinary control, you must do Kegel exercises to strengthen the pelvic floor muscles. The floor of the pelvis is made up of layers of muscles and other tissues. The pelvic floor supports the bladder and bowel, thus they will play an important role in your urinary control of your neobladder
- Once you have decided to have a neobladder you should start practicing these. Practice these exercises prior to surgery and restart postoperatively when your catheter is removed. Do not perform them while you have a catheter in place. The best time to learn them is during urination before you have the cystectomy, try to stop the flow of urine for approximately five seconds, and then resume urinating.
- Pay attention to the muscles that are contracting during this exercise until you're confident you can tighten them even when you're not urinating. Keep your leg and buttock muscles loose as you do the exercise.
 - For **Men**: If you are doing them correctly you may feel and see the base of your penis move slightly towards your abdomen.
 - For **Women**: It sometimes helps to imagine trying to hold a tampon in your vagina, and keep it from falling out.
- Now that you can feel the muscles you can start to exercise them.
 - Tighten and imagine lifting them up inside. Try to hold the contractions for 5 seconds, then slowly release, relax for a few seconds. Repeat and relax. Eventually try to hold the contractions for 10 seconds
- Once the catheter is removed after surgery, establish a routine time to do the exercise. Pick a time that will be easy for you to remember! Over time your urine control will improve.
- Do 10 repetitions 3-6 times a day.
- Remember, do not hold your breath during the exercises, keep your tummy muscles, buttocks and thighs relaxed while doing the exercises.
- Results of urine control improvement take time. The muscles have to be built up over time. Stay positive and continue the exercises.

What about sexuality and sterility?

- Talk to your doctor about when it is safe to have sex. Generally it is recommended you wait until after your incision is healed, this usually takes 6 to 8 weeks.
- **FOR MEN:**
 - Many men are unable to achieve erections after surgery due to nerves necessary for erections being damaged in order to try and get all of their cancer out at surgery. Treatments are available. Talk to your doctor.
- **FOR WOMEN:**
 - As a result of this operation, you are likely to experience pain or difficulty with sexual intercourse due to the narrowing or shortening of your vagina.
 - If you have not gone through menopause, (also known as the “change”) this operation will start menopause for you if your ovaries and/or uterus is removed.
 - Just because the vagina is smaller, does not mean you cannot have orgasms. Many women who have had a cystectomy with part of the vagina removed still have orgasms, some may be less able to have an orgasm. You may have damage to some of the nerves that help you have orgasms.
- If you or your partner have any worries or concerns regarding sex, or if you are having pain or difficulty with sex, talk to us. Do not be afraid to bring these issues up with your doctor or nurse, they will understand and be able to offer help and advice.
- If you have a stoma , it should not be used as a sexual orifice.
- If you have a stoma, remember, because physical beauty can be important to us, sometimes the stoma and the idea of ostomy surgery can be threatening. For some returning to a normal sex life will be normal. This is usually after you become more comfortable with having a stoma. Do not assume your partner is turned off by your stoma. Try to stay intimate with your partner.

If you are having any hesitation about being intimate, talk to your ostomy nurse or your doctor. Whatever questions you may have regarding intimacy and your stoma, they likely have heard the question many times before, so ask!

What are recommendations for when you go home?

- If you live alone or are elderly you should have a friend or relative stay with you for the first few days
- Make sure you are staying hydrated, drink 6 to 8 glasses of water a day
- You may have constipation, this often is relieved with an over the counter laxative or enema. We recommend something like milk of magnesia
- Continue to take Tylenol (and if instructed ibuprofen) at home to help with pain control
- You may shower when you are home. Pat your incision dry, do not rub. No tub baths, hot tubs, or swimming until the wounds have completely healed for 30 days post surgery.
- We encourage you to be active. Walk and climb stairs, but do not walk on a treadmill or use a Stairmaster.
- Avoid heavy lifting (over 10 pounds) for 6 to 8 weeks.
- No driving for at least 4 weeks, while your Foley catheter is in place or if you are taking narcotic pain medications. Your doctor will have to clear you before you can drive
- Plan on being out of work for at least 6 to 8 weeks, your doctor will have to clear you to go back to work.
- Reasons to call us:
 - Stents become dislodged early
 - Chills or a fever greater than 101°f
 - Incision becomes red, swollen or drainage of pus
 - If your incision opens up
 - Urine becomes very bloody or cloudy, or if you are passing blood clots
 - Nausea and vomiting
 - Severe pain not relieved by medications
 - Catheter is clogged and obstruction cannot be relieved
 - If you have swelling of your lower extremities
 - Watery (unformed stool), foul smelling diarrhea
 - Calf pain, noticeable warmth and/or leg swelling which are signs and symptoms of blood clots in your legs
 - Chest pain and/or shortness of breath, jaw pain
 - Any other major medical concerns

WHAT DO YOU DO IF PROBLEMS ARISE?

Call us. During business hours (Monday-Friday 8 a.m. to 4PM) please call 585-275-0998. If it is outside of business hours contact your surgeon. If it is an emergency call 911.

Glossary

- **Abdomen:** The part of the body that contains the pancreas, stomach, intestines, liver, gallbladder and other organs.
- **Anesthesia:** Loss of feeling or awareness. Local anesthetics cause loss of feeling in a part of the body. General anesthetics put the person to sleep.
- **Bacteria:** A large group of single-cell microorganisms. Some cause infections and disease in animals and humans.
- **Benign:** Not cancerous; does not invade nearby tissue or spread to other parts of the body.
- **Biopsy:** The removal of cells or tissues for examination under a microscope.
- **Bladder:** organ that stores urine.
- **Bone scan:** A technique to create images of bones on a computer screen or on a film. A small amount of radioactive material is injected into a blood vessel and travels through the bloodstream; it collects in the bones and is detected by the scanner.
- **Cancer:** a term for a disease in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.
- **Carcinoma in situ:** cancer that only involves the cells in which it began and that has not spread to neighboring tissues.
- **Catheter:** a flexible tube used to deliver fluids into or withdraw fluids from the body.
- **Cervix:** the lower part of the uterus.
- **Chemotherapy:** Treatment with anticancer drugs.
- **Clinical Trial:** A research study that tests how well new medical treatments or other interventions work in people. Each study is designed to test new methods of screening, prevention, diagnosis or treatment of a disease.
- **Continent reservoir:** A pouch formed from a piece of small intestine to hold urine after the bladder has been removed.
- **CT scan:** a series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. They may also be called a CAT scan.
- **Cystectomy:** Surgery to remove the bladder.
- **Cystogram:** dye gets put in through a catheter to fill the bladder, then an x-ray is taken to make sure all the dye stays in the bladder.

- Cystoscope: Thin lighted instrument used to look inside the bladder and remove tissue samples or small tumors.
- Cystoscopy: examination of bladder and urethra using a thin, lighted instrument inserted into the urethra. Tissue samples can be removed and examined under a microscope to determine whether disease is present.
- Deep venous thrombosis: Also called a DVT. Blood clots that have formed in the veins and lungs
- Dry orgasm: Sexual climax without the release of semen from the penis.
- Enterostomal therapist: A health professional trained in the care of persons with urostomies and other stomas.
- Epidural: A special drip that goes into your back with a small little tube that carries pain liquid to the nerves that sense pain and take the pain signals to your brain, this should help control pain. A little needle is used to insert it.
- External radiation: Radiation therapy that uses a machine to aim high energy rays at cancer. Also called external beam radiation therapy.
- Fallopian tubes: Part of the female reproductive tract. The long slender tubes through which eggs pass from the ovaries to the uterus.
- Foley catheter: Thin, flexible tube which exits from the urethra. It drains the area where the tip sits inside you.
- Fulguration: Destroying tissues with an electric current.
- Grade: The grade of the tumor depends on how abnormal the cancer cells look under the microscope and how quickly the tumor is likely to grow and spread. Grading is different for each type of cancer.
- Ileal Conduit: This is the most common type of urostomy. The ureters are connected to a small section of intestine used to create a stoma.
- Ileal loop: you may hear your surgeon use this term, this is the same thing as an ileal conduit.
- Imaging: Tests that produce pictures inside of areas inside the body.
- Immune system: The complex group of organs and cells that defends your body against infection.
- Impotent: Unable to have an erection for sexual intercourse.
- In situ cancer: Early cancer that has not spread to neighboring tissue.
- Incision: A cut made in the body during surgery.
- Intravenous or IV: into a vein.
- Invasive cancer: Cancer that has spread beyond the layer of tissue in which it developed and is growing to surrounding, healthy tissues. Also called infiltrating cancer.
- Jackson Pratt or JP drain: small collapsible chamber that will be gently suctioning fluids as a result of your surgery. This needs to be drained periodically. It works by suction so when it is full, it is not able to remove the fluid. This may or may not be removed prior to discharge.
- Kidneys: A pair of organs in the abdomen that remove waste from the blood (as urine). They also produces a substance that stimulates red blood cell production, called erythropoietin.
- Local therapy: Treatment that affects cells in the tumor and the area close to it.
- Lymph node: A rounded mass of lymphatic tissues that is surrounded by a capsule of connective tissue. Also known as a lymph gland. Lymph nodes are spread out along lymphatic vessels and contain many lymphocytes, which filter lymphatic fluid.

- **Lymphatic system:** The tissues and organs that produce, store and carry white blood cells that fight infection and other diseases. This system filters impurities (such as bacteria) from the body. The lymphatic system is a fine network of thin tubes that carry lymph and white blood cells. These tubes branch, like blood vessels, into all the tissues of the body.
- **Magnetic resonance imaging: MRI.** A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.
- **Malignant:** Cancerous. A growth with a tendency to invade and destroy nearby tissue and spread to other parts of the body.
- **Medical Oncologist:** A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy and biologic therapy. A medical oncologist often serves as the main caretaker of someone who has cancer and coordinates treatment provided by other specialties.
- **Menopause:** The time in a woman's life when she undergoes changes that are from her hormones changing. A woman will no longer have periods and she will no longer be able to have children after menopause. Often associated with hot flashes, inability to sleep, vaginal dryness.
- **Metastasis:** The spread of cancer from one part of the body to another. Tumors formed from cells that have spread are called "secondary tumors" and contain cells that are like those in the original or primary tumor. The plural is metastases.
- **Metastasize:** Cancer spreading from one part of the body to another. When cancer cells metastasize and form secondary tumors, the cells in the metastatic tumor are like those in the original or primary tumor.
- **MRI:** Magnetic resonance imaging. A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.
- **Mucus:** sticky, thick fluid that looks like cloudy material in the urine. This is normal to see in the urine from a urinary diversion made of bowel or intestine.
- **Nasogastric tube: NG tube.** A tube inserted through your nose into your stomach. It is put there to drain gastric secretions and help prevent you from getting sick. It may have to be put in if your intestines do not wake up after surgery.
- **Ostomy:** An operation to create an opening from an area inside of the body to the outside. Urostomies carry urine from the inside to the outside of the body. Colostomies carry stool from the inside to the outside of the body.
- **Ovaries:** The pair of female reproductive glands in which the ova, or eggs are formed. The ovaries are located in the pelvis, one on each side.
- **Pathologist:** A doctor who identifies disease by studying cells and tissues under a microscope.

- Pelvis: The lower part of the abdomen, located between the hip bones.
- Pouch: the bag that collects drainage from the stoma.
- Pouching System: includes the skin barrier and the pouch. Options are a one or two piece system. Right after the operation you will have a two piece system.
- Primary tumor: The original tumor.
- Prostate: A gland in the male reproductive system just below the bladder. It surrounds part of the urethra, the canal that empties the bladder and produces fluid that forms part of semen.
- Pulmonary embolus: a blood clot that has formed as a clot in the leg (DVT) and traveled to the lungs.
- Quality of life: the overall enjoyment of life. Many clinical trials measure aspects of an individual's sense of well-being and ability to perform various tasks to assess the effects of cancer and its treatment on the quality of life.
- Radiation Oncologists: A doctor who specializes in using radiation to treat cancer.
- Radiation Therapy: The uses of high energy radiation from x-rays, gamma rays, neutrons and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body in the area near cancer cells (internal radiation therapy, implant radiation, or brachytherapy).
- Radical cystectomy in men: Removal of the bladder, prostate, seminal vesicles, and part of the vas deferens.
- Radical cystectomy in women: Removal of the bladder, uterus, ovaries, and sometimes urethra.
- Rectal: Having to do with the rectum. The rectum is the last 8 to 10 inches of the large intestine and ends at the anus.
- Recur: To occur again. Recurrence is the return of cancer, at the same site as the original tumor or in another location, after the tumor has spread.
- Risk factor: A habit, trait, condition or genetic alteration that increases a person's chance of developing disease.
- Semen: the fluid that is released through the penis during an orgasm. Semen is made up of sperm from the testicles and fluid from the prostate and other sex glands.
- Seminal vesicles: Glands that help produce semen.
- Side effects: Problems that occur when treatment affects healthy cells. Common side effects of cancer treatments are fatigue, nausea, vomiting, and decreased blood cell counts
- Skin Barrier: The portion of your pouching system that fits around your stoma and sticks to your skin. The pouch is then connected to the skin barrier (in a two piece system) or may come already connected (in a one piece system.)
- Small intestine: Part of the digestive tract that is located between the stomach and the large intestine.
- Squamous cell carcinoma: Cancer that begins in squamous cells. Squamous cells are found in the tissue that forms the surface of the skin, lining the hollow organs of the body and the passages of the respiratory and digestive system.
- Squamous cells: Cells that cover internal and external surfaces of the body.
- Stage: The extent of cancer, especially whether the disease has spread from the original site to other parts of the body.

- Staging: Performing exams and tests to learn the extent of the cancer within the body, especially whether the disease has spread from the original site to other parts of the body.
- Stents: Small tubes that are inserted during surgery. They come out of your abdomen or stoma and drain into your a pouch. They are temporary and will be removed later.
- Stoma: A surgically created opening from an area inside the body to the outside.
- Transitional cells: cells that vary in shape depending on whether the tissue is being stretched. The cells may be stretched without breaking apart. They line hollow organs such as the bladder.
- Tumor: an abnormal mass of tissue that results from excessive cell division. Tumors perform no useful body functions. They may be benign (not cancerous) or malignant (cancerous).
- Ureter: the tube that carries urine from the kidney to the bladder.
- Urethra: The tube through which urine leaves the body. It empties urine from the bladder.
- Urinary diversion: general term for a surgical procedure to reroute the urinary system. Also called a urostomy.
- Urine: Fluid containing water and waste products. Urine is made by the kidneys, stored in the bladder and leaves the body from the urethra. Also called pee.
- Urologic oncologist: A doctor who specializes in treating cancers of the urinary system.
- Urologist: A doctor who specializes in diseases of the urinary system.
- Urostomy pouch: a disposable bag that connects with the wafer in a two piece system. It attaches over the stoma to collect urine.
- Urostomy wafer: the part of the urostomy appliance that sits directly on your skin around the stoma.
- Urostomy: An operation to create an opening from the inside of the body to the outside of the body, making a new way to pass urine.
- Uterus: The small, hollow, pear shaped organ in a woman's pelvis. The organ in which a fetus develops. Also called the womb.
- Vagina: The muscular canal extending from the uterus to the exterior of the body. Also called the birth canal.
- Vas deferens: A coiled tube that carries sperm out from the testes.
- Wafer: part of a two piece urostomy pouching system that is cut to size to fit your stoma. This then connects to the pouch.
- Wear time: the length of time a pouching system can be worn before it fails.
- WOC: (wound, ostomy, continence) Nurse: A nurse with additional training and specializing in ostomy care. Sometimes called a stomal therapist.
- X-ray: energy radiation that is used in low doses to diagnose conditions and take pictures inside the body.

Additional Support

- American Cancer Society: The American Cancer Society provides a variety of resources and programming to patients and care givers with a cancer diagnosis. They can be reached at 1-800-227-2345. www.cancer.org.
- Bladder Cancer Advocacy Network: (BCAN). Offers up to date information on bladder cancer. Has online support community 24 hours a day. Lists multiple websites you can access to learn more about bladder cancer treatment and surgery. BCAN.org.
- Bladder Cancer Webcafe: www.blcwebcafe.org
- CancerCare: www.cancercare.org. 1-800-813-HOPE.
- Gilda's Club of Rochester: Gilda's Club provides a meeting place for men, women and children living with cancer, along with their caregivers to build social and emotional support networks as a supplement to medical care. They can be reached at 585-432-9700.
- Hope Lodge Hospitality House: Provides temporary housing care for patients and caregivers undergoing treatment and surgery. They do not have shuttle service. They can be reached at 585-224-4951.
- Human Touch Initiative: Offers massages at little or no cost to individuals touched by cancer. Referral form to be completed and sent in, they then notify you if you have been accepted. Contact Kim Ross 585-672-6222. www.humantouchinitiative.com
- Integrative Oncology Group: Held on the third Tuesday of the month. This group is a URMCM support group that focuses on individuals with a cancer diagnosis and ways to cope with the diagnosis and treatment. Call 585-275-6490.
- Monthly caregivers support group: Held the second Wednesday of the month. This is a URMCM support group for caregivers dealing with the stresses of care giving. Call Catherine Thomas 585-273-3895.
- Ostomy Resources: offers support to individuals who have or will undergo any kind of ostomy surgery. Meetings held at Brighton Memorial Library. Call 315-237-8407.
- National Cancer Institute: www.cancer.gov. 1-215-690-0300.
- Strong Behavioral Health: (585) 275-8321
- Strong Family Therapy Services - Marriage Counseling: (585) 275-0320.
- United Ostomy Associations of America: uoaa.org.
- Urology Care Foundation. 1000 Corporate Boulevard, Linthicum, MD 21090, Phone: 410-689-3700 or 1-800-828-7866. E-mail: info@urologycarefoundation.org, website: <http://www.urologyhealth.org/>.

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