

COLUMBIA UNIVERSITY IRVING MEDICAL CENTER

CYSTECTOMY WITH ILEAL CONDUIT SURGERY INSTRUCTIONS

This packet will help you prepare for your upcoming cystectomy. Please review this information before surgery and have it available as a reference after surgery. Should you have any questions, please contact our office at (212) 305-0144. There will be someone available to answer questions 24 hours a day, every day of the week including holidays. For non-urgent issues, please call between 9am and 5pm.

I. IN THE MONTH LEADING UP TO SURGERY

- You must have blood and urine tests within 30 days of surgery. You may also require a chest x-ray and an electrocardiogram (EKG). If you have these tests done locally then you must have the results faxed to us.
- You may be asked to have a clearance letter from your primary medical doctor. In addition, if you have a history of heart or lung disease, you may need a clearance letter from your cardiologist or pulmonologist. If your preoperative clearance is done outside of Columbia, the letter must be faxed to our office at least 5 days prior to surgery.
- Sperm banking: after radical cystectomy, a man is no longer able to ejaculate and will likely have erectile dysfunction. If you intend to have children in the future, you should bank sperm before surgery. Cystectomy in women may also involve removing the uterus, ovaries, and part of the vagina in women, which can impact sexual function.
- We recommend you stop smoking cigarettes as soon as you decide to have surgery.
- Avoid drinking alcohol in the week leading up to surgery. If you use alcohol regularly then stopping suddenly could be dangerous. Let your doctor know if you are a heavy drinker or are unable to stop drinking.
- Please stop taking the following medications **one week** prior to surgery:
 - Any blood thinners, including Plavix, Coumadin, Effient, Brilinta, Ticlid, Persantine, Pradaxa, Eliquis, and Xarelto. **You must discuss stopping these medications with the doctor who prescribes them**
 - You may continue taking low-dose aspirin (81mg) if you have a history of heart disease or stroke.
 - All herbal medications, supplements, and vitamins, including vitamin E, fish oil, garlic, and ginkgo biloba.
 - Ibuprofen-containing medications or other non-steroidal anti-inflammatory medications (NSAIDS). Medications for arthritis often contain these drugs. If you are unsure whether you are taking one of these medications, ask your doctor.
- If you take any of the following medications for diabetes or weight loss, please stop them before surgery:
 - Stop dapagliflozin (Farxiga), empagliflozin (Jardiance), canagliflozin (Invokana) or ertugliflozin (Steglatro) 4 days before surgery
 - Stop liraglutide (Victoza, Saxenda), exenatide (Byetta) or semalutide (Ryblesus) 1 day before surgery.
 - Do not take your injection of dulaglutide (Trulicity), exenatide (Bydureon BCise) or semaglutide (Ozempic, Wegovy) 7 days before surgery.
 - These medications may all be restarted at home after your surgery.

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II. IN THE WEEK LEADING UP TO SURGERY

- Poor nutrition is common before a cystectomy. In order to improve your nutritional status, we recommend preoperative nutritional supplements and consult with a registered dietician.
- You will have an in-person or phone meeting with our registered dietician who will discuss the recommendations for preoperative nutrition.
- You will start an oral nutritional supplement twice daily called **Ensure Surgery Immunonutrition Shake** for 5 days leading up to surgery. <https://ensure.com/nutrition-products/ensure-surgery>.

III. THE DAY BEFORE SURGERY

- You will receive a call from a Milstein Hospital Preoperative nurse the business day prior to your scheduled operation between the hours of 2:30-5:30 PM.
 - If you do not receive this call, please call 212-305-7000. The preoperative unit is open Monday-Friday 6:00AM to 6:30PM.
 - This call will include the following instructions:
 - Arrival time: 2 hours before your scheduled operation
 - Admitting location: 173 Fort Washington Ave, Milstein Heart Center Admitting Desk. The lobby is inside the Milstein Hospital Building and the operating room is on the 3rd floor.
 - What medications to take before your surgery.
- Your surgeon may ask you to perform a bowel preparation by taking laxatives.
- Drink plenty of fluids throughout the day and eat a light diet.
- Wear comfortable loose-fitting clothing. This includes loose underwear and lace-up shoes. Leave all valuables and jewelry at home.
- You must arrange for an adult to transport you to and from the hospital. You cannot be discharged home unless you have an adult to take you home.
- **Do not eat or drink anything after midnight other than what is recommended below.**

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IV. THE MORNING OF SURGERY

- **You should drink one bottle of Ensure Pre-Surgery Clear Carbohydrate Drink 2 hours before your scheduled arrival** <https://ensure.com/nutrition-products/ensure-pre-surgery>
 - You should drink this quickly, within 10-15 minutes.
 - Do not eat or drink anything else including gum, hard candy, and cigarette smoking. You may brush your teeth, but do not swallow any water.
 - If you have any of the following problems, do NOT drink the Clear Carbohydrate Drink:
 - Symptomatic gastric reflux or hiatal hernia
 - Gastroparesis
 - Prior gastric or esophageal surgery
 - Large volume ascites
 - Altered mental status, dementia, stroke with residual deficit, neuromuscular disease, Parkinson's disease
 - Esophageal diverticula
 - Dysphagia
 - Head and neck irradiation
 - Difficult airway
- If you were instructed to take any medications on the day of surgery, you may do so with a small sip of water.
- We recommend that patients wash with antibacterial soap the night before and morning of surgery to decrease the risk of surgical site infections.
- Bring your insurance card and personal identification information to the hospital.
- Consider appointing a healthcare proxy. This is the person who will help make healthcare decisions for you if you are unable to communicate. You may discuss this with your nurse once you arrive at the hospital. If you have already done this, or have an advanced directive, bring this paperwork with you for your surgery.
- If you have obstructive sleep apnea, please bring your breathing mask with you to the hospital. The hospital will provide the machine
- If you wear pants with a belt, please bring these with you the morning of surgery to help with marking your stoma.
- Please remove all metal objects, including jewelry and piercings. You will have to remove hearing aids, dentures, glasses, wigs, and any other prosthetic devices before you are brought to the operating room.
- Surgery times may vary based on emergencies or surgeries that take place before yours. The operating room staff will keep you informed of any changes that may occur on the day of your procedure.
- You will be given a discounted valet parking ticket for your surgery day.
- **Please arrive on time.**

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V. HOSPITAL INSTRUCTIONS FOR FAMILY AND FRIENDS

- Your family may accompany you in the preoperative holding area, and will be directed to the waiting area of the Milstein Hospital building where they can wait during surgery.
 - Your family will receive text updates about your surgery
 - After the surgery is over, the doctor will contact your family.
- The cafeteria is located on the 2nd floor of the Milstein Hospital building.
- Your family will be able to visit you in the recovery room once you are fully awake, usually no more than 2 hours after the surgery is over.
- Your family will be able to visit you when you are in your hospital room and can learn about visiting hours from the nursing staff on the floor.

VI. IN THE HOSPITAL AFTER SURGERY

- After surgery you will spend a few hours in the recovery room as you continue to wake up. You will be transferred to a hospital room later that day.
- When you wake up from surgery, your stoma and ostomy appliance will be on the right lower portion of your abdomen. There will be two stents coming out of your stoma and draining into your ostomy pouch. There will be a Jackson Pratt (JP) drain in the left side of your abdomen, to help remove any excess fluid from the abdomen. The JP drain is usually removed prior to discharge.
- You will be given oral and intravenous pain medications that you can use as needed.
- Most patients can start drinking the day after surgery.
- You should walk at least every 2 hours starting as early as the night of your surgery. This is **extremely important**.
- The nurses will periodically check on you and record your vital signs, urine output, and pain level.
- You will have some blood drawn every day.
- You will practice basic care for your stoma each day in the hospital. In the surgical unit, you will meet with your enterostomal (ET) nurse who will teach you about caring for your ostomy. The ET nurse will tailor your ostomy pouch and accessories to your needs. Many patients feel it is helpful to have a caregiver or family member present during these teaching sessions. Moreover, the nursing staff in the hospital will also enforce stoma teaching.
- Most patients stay in the hospital for 5-7 days, and are then discharged home.

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VII. BEFORE YOU ARE DISCHARGED

- You will be taught how to care for your urostomy and any other drains that you go home with.
 - Before you leave the hospital you will practice how to:
 - Empty the pouch into the toilet
 - Connect to bedside drainage bag
 - Remove the pouch
 - Clean around the stoma
 - Measure your stoma
 - Cut the flange
 - Apply the pouch
 - Discuss how to clean the night-time drainage pouch
 - How to order your urostomy supplies
- During your hospital stay you will meet with a social worker who will arrange home care visits by a registered nurse to help you transition home safely. Prior to discharge, your social worker will provide you the name and phone number of the home health agency and the medical supply company. Please keep all contact information in a safe place to refer to if a problem arises.
- The Home Health care agency will send a visiting nurse usually one or two days after discharge. At home, the visiting nurse will perform an assessment and determine how many visits you qualify for in a given week. Your visiting nurse will continue stomal education at home and address any medical questions. Since your home nurse visits are limited, please work with them closely to troubleshoot any problems that may occur. It is important you discuss with your visiting nurse how to obtain your first urostomy supplies from your medical supply company.
- Some patients who need additional support after surgery will be discharged to a rehabilitation facility.
- If you have a long trip home, make sure you stand up and walk every 45 minutes.
- You will receive a copy of your discharge instructions.

VIII. YOUR UROSTOMY SUPPLIES

- It is the patient's responsibility to order his or her ostomy supplies. Urostomy pouches and accessories are distributed from a medical supply company such as Edgepark, Byram or McKesson. Your inpatient social worker will help start the process of ordering supplies. Please retain the invoice from the medical supply company to reorder. Prior to discharge you will receive one week's worth of ostomy supplies from your nurse until your one-month supply arrives to your house.

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IX. AT HOME AFTER SURGERY

ACTIVITY

- No heavy lifting (more than 10 pounds) for 6 weeks. This includes pets and children.
- No vigorous activity for 6 weeks, such as running, tennis or golfing. You may not push anything heavy, such as a lawnmower.
- You should walk regularly and you may walk upstairs.
- You may ride in a car, but no driving for 4 weeks.
- You may shower but no tub baths or swimming. You may take a shower with the urostomy pouch on or off. Do not shower with your pouch off if you have stents in place.

DIET

- You may eat a normal diet and should stay well hydrated.
- If your appetite has not returned to normal, it is still very important to eat. We recommend eating small, frequent meals throughout the day.
- It is normal to lose 10-20 pounds after this surgery. Most people will gain this weight back after several months.
- If you are unable to eat or drink, contact your doctor immediately.

WOUND CARE

- Your incisions are either closed with skin glue, which will slowly flake off over several weeks, or staples. If you have staples, these will be taken out after 1-2 weeks.
- You may shower after leaving the hospital and gently wash the incisions with warm soapy water. The water will not harm the incision.
- You may have drainage from your incisions and your penis or vagina after surgery. This can either be clear fluid or blood tinged fluid, which is generally not worrisome and will eventually stop.
- If there is redness, heat, or whitish drainage from the incision, contact the office as there may be an infection.
- Incisions can sometimes open slightly. If an incision opens larger than 1 cm, contact the office.
- Bruising around your incisions is common. This is typically not an issue and will resolve with time.

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POSTOPERATIVE ISSUES

- **Digestive problems:**
 - *Bloating:* after a cystectomy the intestines can take a while to return to their normal working state. Sometimes if the intestines stop working normally, patients can become bloated, distended, have nausea and vomiting, and stop passing gas from below. If this occurs, please contact your doctor.
 - *Dehydration* is a common cause of readmission after surgery. It is critical for patients to remain well hydrated upon hospital discharge. Dehydration can cause weakness, poor appetite, nausea, and low urine output.
 - If you experience *diarrhea* after surgery do not take over-the-counter anti-diarrhea medication unless instructed by your doctor. Drink extra fluids to avoid dehydration. Call your doctor's office if diarrhea last longer than 48 hours.
 - If you experience ongoing diarrhea consider a BRAT diet (Bananas, Rice, Applesauce, Toast) to slow your bowel movement.
- **Clots in the legs:** During the first 4-6 weeks after surgery, there is the risk of a clot forming in a vein in your leg (deep venous thrombosis, or DVT). This can produce pain in your calf or swelling in your ankle or leg. These clots may break loose and travel to the lung, producing a life-threatening condition known as pulmonary embolus, or PE. Symptoms of a PE include chest pain (especially when you take a deep breath), shortness of breath, the sudden onset of weakness or fainting, and/or coughing up blood. You will be discharged from the hospital with a medication to prevent this from occurring. If you develop any of symptoms of a DVT or PE, call immediately and/or seek local medical attention.
- **Infection:** there are many possible sources of infection after radical cystectomy, including the urinary tract, wound/skin, lung, and abdomen. These types of infections have different symptoms, but many will cause a fever of greater than 101.5°F. Abdominal and urinary infections can cause pain, fatigue, nausea/vomiting. If you develop a fever or have any concerning symptoms, please notify your doctor.
- **Pain:** Abdominal pain is common and generally resolves with time. Pain can normally occur around incisions or abdominal muscles. You may notice firm areas under the incisions, which is usually part of the normal healing process. Discomfort in the testicles is very common for men, and this can last for several weeks.
- **Swelling:** It is common to have swelling and discoloration of the genitals. This is usually fluid that has not yet been absorbed by the body or bruising. If the scrotum is swollen, put a rolled hand towel underneath the scrotum to elevate it when lying down.
- **Fatigue:** It is very common to be fatigued for the first several weeks after surgery, and this typically resolves in time.
- **Sexual function:** This surgery may substantially impact your sexual function. You may discuss any bothersome sexual side effects from surgery in clinic after surgery.
- If you experience fevers >101.5 degrees, nausea, vomiting, redness around your incisions, thick drainage from the incisions, chest pain, shortness of breath, leg swelling, or any other concerning symptom, **call the office immediately or come to the emergency room.**

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MEDICATIONS

- You will have mild to moderate pain for the first several days after surgery. This may include abdominal pain, bloating, or pain around the incisions. You may treat mild pain with ibuprofen or acetaminophen, and more severe pain with the prescribed narcotic medication. If you have severe pain despite these medications, let your doctor know.
- To prevent blood clots, you will be sent home with 30 days of **Eliquis**, or a similar medication.
- You should take a laxative (Miralax 17g daily) while you are taking narcotic pain medication, and for as long as necessary to avoid constipation after surgery. You should avoid straining with bowel movements. If you become constipated despite taking Miralax, you may use an over-the-counter oral laxative, such as milk of magnesia, Senna, or Dulcolax. Follow the dosing directions on the medication packaging.
- If you are discharged home with ureteral stents in place, you will be given one antibiotic tablet to take **one hour** before your stents are removed in clinic.
- If you were taking blood thinners before surgery, you may resume them one week after surgery, unless directed otherwise.

X. FOLLOW-UP

- You will be seen in clinic 1-2 weeks after surgery. Please call your doctor's office to arrange a time for this appointment, or arrange a time with your surgeon's office prior to the surgery.
- The pathology report is available to review at the time of the first follow-up visit.
- **Return to work:** most people will require at least 6 weeks off work to recover from surgery.

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ILEAL CONDUIT POUCHING TIPS

GETTING TO KNOW YOUR STOMA

- It is normal for your stoma to secrete mucus. You may notice mucus or sediment in your pouch and in your bedtime drainage bag. The amount of mucus will decrease with time; however, it will never go away.
- There are certain foods that can increase the odor of your urine including asparagus, fish, beer, garlic, and broccoli. You may continue to eat these foods.
- Your stoma is soft, moist, and healthy red/pink. It may remind you of a rosebud. When you touch your stoma you may notice it does not have a touch sensation. With this in mind, be sure to place your seatbelt and pant belt either above or below your stoma and never over the stoma.
- We recommend drinking 8 -10 cups of 8oz of non-caffeinated fluids a day to keep your urine clear yellow.

UROSTOMY APPLICATION TIPS

- Emptying your pouch
 - Empty the pouch when it is ½ full to decrease the chance of ballooning
 - If you are having a difficult time remembering to empty your pouch, you can set a phone alarm every 2-3 hours to remind yourself.
 - Empty your pouch while sitting down on the toilet
- Changing the pouch
 - For the first 6-8 weeks after surgery, cut the flange up to 1/8 inch larger than your stoma to decrease the chance of skin irritation. Once the swelling of the stoma has decreased, it may get smaller.
 - Once the size has stabilized, you may order your barriers pre-cut from your medical supply company.
 - Apply the flange to clean **dry** skin.
 - Pull your skin upward with one hand and apply the flange with the other hand. If you apply the flange/barrier over wrinkled skin it may stretch off when you start moving.
 - We recommend cleaning around the stoma with tap water and paper towel (Viva® paper towels are absorbent and soft for your skin). If you choose to use soap, try soap without a moisturizer, oils, or fragrance as they may interfere with the adherence of the flange; this includes baby wipes.
 - Do not use alcohol or peroxide to clean around the stoma.
 - The best position to view your stoma as you apply your pouch is standing in front of mirror. Also, the best time to change the pouch in the morning before drinking fluids.

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- Change your ostomy appliance every 3-4 days. If your pouch is leaking, change it immediately and do not reinforce with tape. If the integrity of the seal is compromised, reinforcing with tape will only allow urine to sit on your skin which may cause skin irritation.
- When applying the flange preform a “Stomassage”: press around the stoma for up to 30 seconds to activate adherence of appliance to skin.
- Bedside drainage bag/ Leg bags
 - You may connect to a bedside drainage bag at night to decrease trips to the bathroom. Empty your nighttime drainage bag every morning and rinse the bag with a 3:1 ratio of water to vinegar. There are also Appliance Cleaners detergents available. Please note you will need a urostomy adaptor to connect to a bedside drainage bag. There are two adaptors in each box of pouches. Most insurance companies will pay for 1-2-night time bag per month
 - If you going on a long trip you may connect your urostomy pouch to a leg bag. Cleanse your leg bag as you would your night time drainage bag
- Consider using an ostomy belt to help extend ostomy wear time during the daytime.
- After your stents are removed you may shower without your pouch on days you are planning to change your pouch. Then reapply your pouch once you are out of the shower.
- You must **always** wear a pouch when taking a tub bath or going into a pool as water can travel into your stoma and into your kidneys.

TRAVELING

- Always carry an extra pouch and paper towels when going out in case of leakage. This includes doctor visits.
- Airline Traveling: consider obtaining a Transportation Security Administration (TSA) travel card to discreetly alert TSA agents of your ostomy during screening. While the card does not preclude the possibility that you will be searched, it tells the TSA agent you have stoma and you are carrying ostomy supplies
- Precut your extra “carry on flanges” to avoid carrying scissors on to the plane.

ORDERING SUPPLIES

- During your hospital stay your social worker and ET nurse will help establish your first order of supplies when you return home. Please contact the medical supply company listed in the discharge papers when you are home to authorize the first shipment. The medical supply company must receive verbal consent from the patient at home. If you have home visiting nurse services they can assist with the first ostomy supply order.
- Initially your supplies will arrive in one-month increments. When you are comfortable with your pre-cut pouches you can request a 3-month supply from your medical supply company.
- When you notice you are down to one-week supply, call your medical supply company to request the next shipment. Some companies do not automatically send the next shipment. It is your responsibility to reorder your supplies.
- Keep your ostomy pouches and ostomy accessories in one place so you know where to find them if need to change your pouch urgently. Keep supplies in a dry and cool place.

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ACTIVITIES

- You must wear an ostomy appliance when *swimming*. Empty your pouch before entering the water. Barrier extenders are available to provide extra protection from leakage. Contact your ET nurse for more information.
- There are companies who make underwear, swimwear, stoma covers, and intimacy garments. Contact your ET nurse for more information

CONTACT YOUR ET NURSE IF YOU ARE HAVING

- Peri-stoma skin irritation
- Leakage issues
- Problems obtaining supplies
- Would like to try new ostomy appliance

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Support Organizations

American Cancer Society

www.cancer.org

Inspire

Bladder cancer support group and online discussion community <https://www.inspire.com/groups/bladder-cancer-advocacy-network/>

Bladder Cancer Advocacy Network (BCAN)

Survivor 2 Survivor program to connect with a volunteer who knows about having a radical cystectomy. Dial 888-901-BCAN

www.bcan.org

United Ostomy Associations of America

www.uoaa.org

Wound Ostomy Continence Organization

www.wocn.org

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SUPPORT FOR THE COLUMBIA UNIVERSITY DEPARTMENT OF UROLOGY

Patients often ask how they can help support the mission of our Department. Not only are we committed to providing excellent patient care, but also to advancements in prostate cancer research and teaching the next generation of prostate cancer experts. Our Department relies on private support to maintain and advance our research, education, and patient care goals.

If you are interested in learning more, please contact Cynthia Gorey at cg3334@cumc.columbia.edu, or you may contact your surgeon directly.

If you wish to opt out of receiving fundraising communications, please contact the CUMC Office of Development at fundraising.opt.out@columbia.edu 212-305-7315.