Caring For Your Ostomy

Introduction
You or a loved one has just had surgery resulting in an ostomy and may feel a little confused and scared. You may wonder how you will ever be able to manage.

An ostomy can be lifesaving for patients with cancer, stomach infections or blockage, or any number of intestinal or bladder diseases. It can improve life for patients with chronic inflammatory bowel diseases such as Crohn’s disease or ulcerative colitis. An ostomy can enable a person to enjoy a normal life and do a full range of activities. People with ostomies can travel, do sports, and have a full family and work life.

This booklet will provide you with information you need to know to take care of your ostomy. We may give you other handouts based on your individual care. We will discuss your ostomy education and needs with you at the hospital.

Ostomy services at Upstate University Hospital at both the Downtown and Community campuses are provided by a specially trained ostomy nurse, who will work with you while you are at the hospital and is available even after you go home.

Call to schedule a post discharge follow-up visit:

Upstate Downtown, 750 East Adams Street, Syracuse – (315) 464-6291
Downtown Ostomy Nurses:
Heidi H. Cross, RN, MSN, FNP-BC, CWON, (315) 464-5124, email crossh@upstate.edu
Jessica Dow, RN, MSN, FNP-C, CWCN (315) 464-5128, email dowj@upstate.edu
Terry Humez, MSN, FNP-C (315) 464-9272, email humezt@upstate.edu
Our website is www.upstate.edu/surgery/healthcare/colorectal/ostomy

Community Campus, 4900 Broad Road, Syracuse – (315) 492-5767
Community Campus Ostomy Nurse:
Patricia Burnham, RN, BSN, CWOCN 315 492-5767, email burnhamp@upstate.edu
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**What is an ostomy?**

An ostomy is a surgically created opening on the front of the abdomen for either stool or urine. A portion of the bowel is brought through the skin to create an opening called a stoma. This allows waste to pass directly out of the body, bypassing a diseased or damaged section of the bowel or urinary system. You must wear a pouch all of the time to collect the waste.

**What types of ostomies are there?**

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<th>Ileostomy- See page 11</th>
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<td>A portion of the large bowel (also known as the large intestine or the colon) is brought to the front. Stool is generally pasty to formed stool.</td>
<td>A portion of the small intestine (the ileum) is brought to the front. Stool is more liquid, usually of thickened consistency.</td>
<td>Also known as a urinary diversion or an ileal conduit. This results when the bladder is removed or is bypassed. Urine is in the pouch.</td>
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**Ostomy videos**

These videos are available in the hospital regarding ostomy care. These will help to reinforce your learning. Interested family members should watch them as well.

**At Upstate University Hospital, Downtown Campus:**

1. Dial 4-4747 from your room telephone.
2. When asked, enter one of the below numbers:
   - #1012 – Living with your ostomy
   - #1014- How to measure your stoma
   - #1018- How to apply and empty a one piece urostomy pouch
   - #1022- How to apply and empty a two piece urostomy pouch
   - #1016- How to apply and empty a one piece drainable pouch
   - #1020- How to apply and empty a two piece drainable pouch
3. The Video order line will confirm your choice, and instruct you to tune your television to a channel number to view this program.
4. If you need help, ask your nurse.

**At Upstate University Hospital, Community Campus:**

Ask your ostomy nurse about watching the ostomy videos and she will obtain the portable DVD player and the DVD for you and your family to view the educational videos.
What to expect after Surgery:

If you need special care after surgery, you may wake up in the intensive care unit. As you feel better, you will be transferred to a regular room for the rest of your hospital stay. The average time that you may be in the hospital is 4 – 10 days.

Possible tubes and attachments you may have:

- **Nasogastric tube**: Goes through your nose into your stomach, used to drain your stomach and intestinal fluids. This is called “decompression”.
- Intravenous (IV) fluid: A small sterile line is put into a vein, and hooked up to a bag of fluid, to make sure you are getting the liquid hydration you need.
- **Drains**: Small rubber drains may be put into the lower part of your abdomen, and are used to drain any fluid that might collect in your surgical site.
- **Foley catheter**: A tube put into your bladder, used to keep your bladder drained of urine, and to keep track of your urinary output.
- **Ostomy pouch**: to contain stool (colostomy or ileostomy) or urine (urostomy).
- **Leg stockings (called “SCD’s”)**: to keep your leg circulation going, and keep you from developing clots. You will feel intermittent pressure on your legs.

Dressings
If you have an open abdominal wound, you will have a dressing, which will need to be changed by the nurses 2-3 times daily. Your wound may have been closed with staples. Staples are removed 1-2 weeks after your surgery.

Deep Breathe
You need to do your **incentive spirometer** (also called Inspirex) every hour while awake to keep from getting pneumonia or other lung problems. Have your bedside nurse show you how.

Pain control
You will be given pain medicine to control your pain, or you may have a “PCA” which allows you to control the pain medicine intravenously by pushing a button. If the medicine from the PCA does not control the pain, tell your nurse or provider.

Activity
Your doctor will let you know when you should get out of bed and move around with assistance at first and until you are stable. You should be up and walking several times a day. This will help you to get better faster, and help prevent breathing and circulation problems. It will help to stimulate bowel function, an important thing after bowel surgery!

Ostomy Care
The ostomy nurse will visit you regularly to teach you how to care for your ostomy pouch.

Food and drink
Depending on your situation and “doctor’s orders”, you may be allowed to drink clear liquids right away, or you may not be allowed to eat or drink (called “NPO”). This depends on your bowel function. A sign that bowel function has returned is when your doctors and nurses can hear bowel sounds (gurgling), and you start to feel gas moving through your
abdomen. With colostomies or ileostomies, gas will cause your pouch to puff up somewhat like a balloon. Eventually, you advance to a more regular diet. Go slow with eating and chew your food well.

Stoma Facts and Care

What exactly is a stoma?
A stoma (from the Greek word for mouth) is what you see when you look at your ostomy. It is the actual opening of the bowel or intestine on the outside skin of the abdomen, allowing the passage of stool (colostomies or ileostomies) or urine (urostomies). It usually sits just below the navel, however may be higher up depending on your surgery. The size of your stoma may shrink for up to two months after your surgery.

What does it look like?
The color of your stoma should be pink or red, somewhat like the inside of your mouth. A little bit of bleeding during clean up is normal.

Stomas vary in size, shape, and location. They usually are about one inch around, but may be smaller or larger. Some protrude, some are flatter. There are two basic kinds of stomas, depending on which kind of surgery was performed:

1. An end stoma, in which the bowel is cut, and the end is brought to the surface. The rectum and the anus may or may not be left in place.
2. A loop stoma, in which a loop of bowel is brought to the front of the abdomen. This is usually done when the stoma is meant to be temporary. Following surgery, it may be temporarily supported by a bridge or rod.

Does it hurt?
The stoma does not hurt. Actually, there is little feeling on the stoma because there are few nerves in the stoma.

Will the stoma get infected?
Infection of the stoma is very rare. Colostomy and ileostomy stomas are meant to have stool on them, so do not be concerned if there is stool on the stoma while changing your ostomy pouch.
Skin Care, Bathing and Swimming

The skin around your stoma should be a healthy and normal skin color.

How do I clean the skin around my stoma?
As a general rule, clean the skin around the stoma using only water when changing your pouch. It is not necessary to use soap, but if you do, be sure to use a gentle, pH balanced soap without lotion or oil, and rinse well. Dry thoroughly before applying your ostomy pouching system. Do not use ointments, powders, or lotions on the skin in the wafer area, because these may keep you from getting a good seal.

What about skin irritations?
Reddened, irritated, and itching skin may be caused by any number of reasons. Most often, it is due to exposure to stool or urine because of a problem with the seal, and leakage problems. This can be the result of cutting the opening of the pouch incorrectly, waiting too long to change your pouch, or uneven skin, wrinkles, or dips and folds around the stoma.

It is possible you may have a fungal infection (called “candidiasis”) if your skin is itchy with a patchy red rash, especially right around the stoma. Fungus loves dark and moist areas. It often occurs if you have been on antibiotics, or if you are a diabetic. It must be treated with anti-fungal medication on the skin. Consult your ostomy nurse.

Sensitivities and allergies to adhesives, skin barrier, paste, tape, or pouch material are rare, but possible. They can develop weeks, months, or even years after use of a product since the body can become gradually sensitized. You can test different products to see if your skin will react to them. You may need to change to a different pouching system. Again, see your ostomy nurse for advice.

You may need to use a barrier film (also known as a skin prep) for added protection of the skin around the stoma. Be sure to use one without alcohol as an ingredient so it does not sting. If you have open, weeping areas around the stoma, use some stoma powder, sealing it with a skin prep.

Whatever the cause, do not live with a leaking ostomy or irritated skin. Call or see your ostomy nurse promptly if you experience difficulty.

Taking a bath or shower
You may bathe or shower with or without your ostomy system on your abdomen. Mostly you will bathe with it on, and can just pat the ostomy wafer and pouch dry when done. When it is time for a change, it is OK to bathe or shower even without the pouching system on, because exposure to air or contact with soap and water will not hurt the stoma. You can prepare the ostomy wafer in advance.
Shaving
Excessive hair around the stoma can get in the way of a good seal, and may be painful if hair is pulled when removing your wafer. Shaving with an electric razor or trimming hair with scissors is helpful. Be careful not to cut the skin or stoma if using a straight edge or safety razor. Always shave in the direction of the hair. A mild soap or shaving cream may be used. Rinse well when you are done shaving.

Diet, Nutrition and Fluids

Food
After surgery, it is not a bad idea to follow a low fiber diet, but then you may gradually increase the amount of fiber you eat. There are no dietary restrictions for people with ostomies, as long as you chew your food well. It is particularly important for people with ileostomies to chew their food well in order to avoid a blockage (see Ileostomy page 11).

You will learn which foods may produce gas and odor and which foods to avoid or decrease. If a particular food causes problems after surgery, wait and try again later.

Fluids
Drinking water is important to avoid dehydration. You should figure on drinking at least eight to ten glasses of water or other fluids each day, unless you have been told by your doctor to restrict fluids.

Signs of Dehydration
- Dark and/or decreased urine
- Hardened stool in the pouch (“pellets”)
- Feelings of thirst, dry mouth and skin.
- Leg cramps
- Confusion
- Feeling lightheaded, extremely weak/fatigued

Vitamins
You may want to take a daily multivitamin with minerals to avoid vitamin and mineral deficiencies. If you have had a lot of surgery on your small bowel over the years, have your Vitamin B-12 level checked by your physician. Vitamin B-12 deficiencies take years to develop, but can cause a dangerous type of anemia and neurological problems. In this case, only B-12 shots will solve the problem.

Constipation
People with colostomies and urostomies may get constipation at times. To relieve constipation, the first step is to increase fluids (especially water), and fiber foods such as fruits and vegetables. A stool softener may help. See your doctor or ostomy nurse if the problem persists.
Diarrhea
Diarrhea is when your stools become frequent and watery. The first step is to find the cause. Some causes for diarrhea are:
- Viruses or the flu
- Food that does not process well
- Antibiotics or other medications (see your medications side effects)
- Sugary food and drinks

To help you feel better drink more fluid. You can have tea, water, broth, or sports drinks. Sugary foods and drinks may make diarrhea worse. Try eating foods which thicken the stool such as bananas (sometimes, though, these can have the opposite effect and make the diarrhea worse), rice, tapioca, peanut butter, cheese and crackers, and marshmallows. Call your provider if diarrhea persists after trying the diet changes. You may need some medicine to get it under control.

Living a Normal Life

An ostomy is nothing to be embarrassed about, and is no reason for withdrawing from life. People with ostomies have lived many years with active lives. You can live and love life, and travel, dance, golf, swim, join clubs, go to church, continue relationships and intimacy, and enjoy family, children, and grandchildren. Your privacy is important, and only you need to decide whom to tell that you have an ostomy.

Returning to work:
- As your strength returns you can go back to your regular activities, including work, after the appropriate surgical healing time prescribed by your physician.
- You may choose to confide in your employer or co-workers that you have an ostomy. A letter from your doctor to your employer may be helpful should the employer have doubts about your physical capabilities.
- If your job involves heavy lifting, check with your doctor about lifting restrictions. Still, persons who have ostomies do hold jobs that involve lifting, such as firefighters, mechanics, truck drivers, and athletes.
- If you encounter employability or insurance issues, the United Ostomy Associations of America (UOAA) offer advocacy support and advice. Contact the UOAA at www.ostomy.org or at 1 800 826-0826.

Always have a spare ostomy system!
Be prepared for the possibility that you may need to change your ostomy system at any time. Keep a small travel kit with you at all times stocked with a pouch and wafer and all supplies.

Travel
People with ostomies have traveled the globe. Have a well-packed travel kit, and when flying, be sure to store it in your carry-on luggage. Take at least twice the supplies that
you normally use. Your ostomy nurse may be able to provide you with names of ostomy nurses close to your destination.

**Water activities**
Swimming, boating, and even scuba diving are possible!
- Before swimming, empty your pouch, and be sure to empty it regularly.
- Men with ostomies should be comfortable in men’s swim trunks.
- Women may find that tankinis work best, which make it easier to empty the pouch.
- You may want to “picture frame” the wafer with waterproof tape to give you an increased sense of security.
- Wearing a patterned material instead of one in a solid color will help camouflage the pouch.

**Intimacy and sexuality**
- It is normal to feel self-conscious and sensitive about the change in your body. Communication and trust are at the heart of the healing process. It is important to share your feelings with your spouse or loved one, and to respond to their concerns as well.
- It is possible that pelvic surgery can disrupt both the nerves and the vascular supply to the genitals. In addition, other treatments such as radiation, chemotherapy, or medications may interfere with sexual function. Do not be afraid to discuss this with your healthcare team, and seek the advice of a specialist or sexual counselor if needed.
- There are a few things to remember when planning to have sex:
  - Be sure to empty the pouch first.
  - Wear a small pouch such as a closed end pouch or stoma cap.
  - If you or your partner are uneasy about seeing your pouch, cover it with specially designed underwear, lingerie, or pouch covers. Many sites online sell specialty underwear for ostomies.
  - Women may want to use lubrication if they experience vaginal dryness.

**“Phantom” rectal sensation:**
Sometimes people with ostomies feel as if they have to have a bowel movement out of their rectum, or they feel fullness in that area. If you still have your rectum and anus, this could be an accumulation of mucus within the rectum. You may even pass some mucus or stool-colored drainage. The feeling of fullness should subside. You can wear a sanitary napkin to catch any mucus drainage. Sometimes just sitting on the toilet as if to have a bowel movement helps.
Colostomies

A colostomy is a surgical procedure that brings the end of the large intestine (also known as the large bowel or the colon) through the front of the abdomen, and a stoma is created. Stool empties into an ostomy pouch, most commonly on the left side of the abdomen, usually just below your navel.

What will my stool be like?
The consistency of your stools may be pasty to solidly formed, depending on the exact location of your ostomy within the colon. The most common colostomy is a descending or sigmoid colostomy (involving the descending or sigmoid colon). With this type, you may find that you have the same bowel patterns and stool consistency as before your surgery.

How often will I have to empty my pouch?
- It depends on your bowel patterns and habits, and on where in the colon your ostomy is located. You may have to empty a few times a day, or maybe daily or even less often. Be sure to empty gas just as if it were stool.
- If your stool is solid and difficult to empty from the pouch, coat the inside of the pouch with cooking spray, mineral oil, or a commercial ostomy lubricant.
- Consider a closed end pouch if you have no more than 2 stools a day. This is a shorter pouch you remove with each bowel movement.

Will my ostomy be permanent?
This depends on the reason for the surgery, and on what surgery was performed. If your anus and rectum are intact, the ostomy is usually reversible. You would need to discuss this with your doctor.

What about odor?
Odor should not be a problem, because the pouches are odor-proof. If you do experience a strong odor, this is usually associated with gas, loose bowels, diarrhea, or food.
Things that may increase odor:
- Foods: eggs, cabbage, cheese, cucumber, onion, garlic, fish, dairy foods, and coffee.
- Medicines such as vitamins and antibiotics.

Things that may decrease odor:
- Parsley, spinach, yogurt, buttermilk, orange juice and cranberry juice.

Tips to control odor:
- Ostomy deodorizing drops may be placed into the pouch for additional odor control.
- Make sure the flange of the pouch and wafer are securely connected.
• Use a spray room deodorizer when emptying, especially when emptying gas.
• Do not poke holes in the pouch; this will allow for escape of odor and seepage.

What about gas?
Everyone expels some gas (also called “flatus”). This is especially true during the early weeks and months after surgery.
Things that may increase gas:
- Foods like cucumbers, cabbage, broccoli, mushrooms, onions, fish, dried beans, milk, cheese, carbonated drinks, and beer.
- Chewing gum.
- Swallowed air. Eat leisurely in a relaxed atmosphere with your mouth closed and chew well.
- Using a straw with drinks.

There are pouches with filters, which vent the gas without releasing odor. There are also commercially available air release vents called Osto-EZ-Vent you can apply into your pouch. Contact us for further information regarding either of these options.

Irrigation:
In the past, irrigation has been used to regulate stool output. This is generally not needed, given today’s modern, disposable supplies. You may need to irrigate if you have frequent or severe constipation. You should first try to stimulate stool naturally by drinking more water, and increasing fiber. Check with your doctor or ostomy nurse if constipation persists despite these measures.
Ileostomy

An ileostomy is a surgical procedure that brings the end of the small intestine, known as the ileum, through the front of the abdomen, and a stoma is created. Stools empties into an ostomy pouch, most commonly on the right side of the abdomen.

What will my stool be like?
- Ileostomy output usually begins the first day or two after surgery. Often, it is liquid at first.
- It is then usually liquid to semi-liquid, depending on what you eat.
- It is rich in digestive enzymes, which can be irritating to skin.
- Foods that may make your stool red:
  Tomato juice, red colored drinks/jello/popsicles, pimentos, beets, red peppers.

How often will I have to empty my pouch?
- Normally you will be emptying your pouch around five to six times a day. Empty gas just as if it were stool.
- If your output is really watery or heavy, try eating foods that tend to thicken stool such as bananas, rice, applesauce, cheese, toast and peanut butter, pasta, or marshmallows. If the problem continues, contact your physician to ask if you can take some medicine to slow it down or follow a more specialized diet.

What about food?
- At first, it is best to avoid hard-to-digest foods such as celery, mushrooms, nuts, popcorn, Chinese food, coleslaw, wild rice, peas, and dried fruits. Add these foods slowly and in small quantities to your diet to see how well you tolerate them, and eat them in moderation. See “Blockage”, below.
- Chew your food thoroughly to help assure that you get the full nutrient value, and to not get a blockage.
- With a lot of output, you may lose sodium and potassium, which are necessary electrolytes. Eat bananas and other fruits and vegetables for natural replacement of these nutrients. Sports drinks are usually not recommended because of the high sugar content.

What about fluids?
- People with ileostomies can easily get dehydrated because they lose more fluids in their stool.
- It is important that you increase your water intake. If possible, drink 8 – 10 glasses of water every day to prevent dehydration.
- See the section Diet, Nutrition, and Fluids on page 6 for more information.

Can I take the same medications?
You should review all your medications with your doctor following your surgery. Do not take any controlled release or extended release medications, because these may
not be properly absorbed. People who have had extensive bowel surgery may want
to consider liquid medications, if this is possible.

What is an ileostomy blockage?
A blockage may be caused by:
- Adhesions (sticky scar tissue on the inside) from other surgeries.
- A mass of undigested food that has become lodged in the bowel, usually caused by
  not chewing enough or eating too fast, especially food with fiber.
- Dehydration (not drinking enough liquids/water).

Signs & symptoms of a blockage:
- Your ostomy output or stool changes from a semi-liquid to thin and watery, and has
  a strong smell.
- Ostomy output amount decreases and then may stop.
- Your stoma becomes swollen.
- You may have cramping or a swollen abdomen.
- You may throw up.

What do you do for a blockage?
- STOP all solid foods.
- Increase fluids to try to move the blockage through. Try warm liquids, such as tea
  or broth.
- Do not take any laxatives or stool softeners.
- Take a warm shower or bath to relax your muscles.
- Massage your abdomen.
- Lie on your back, pull your knees to your chest and rock from side to side; or
  position yourself on all fours and rock back and forth.
- If a blockage lasts more than 6 hours, or if you start to vomit or the pain increases,
  call your doctor or go to the emergency room.

A note about J-pouch (also known as “ileoanal reservoir”) surgery:
If you have had surgery for a J-pouch, your ileostomy will be reversed at some point,
usually a few months after surgery. Your doctor or ostomy nurse can provide you with
further information.

What about odor?
Odor should not be a problem, because the pouches are odor-proof. If you do experience
a strong odor, this is usually associated with gas, loose bowels, diarrhea, or food.
Things that may increase odor:
- Foods: eggs, cabbage, cheese, cucumber, onion, garlic, fish, dairy foods, and
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Urostomies

The most common kind of urostomy (urinary diversion) is the ileal conduit, so named because a piece of the ileum (a portion of the small intestine) is used to create a “conduit” for the urine.

Always make sure the closure device at the end of your urostomy pouch is closed correctly or attached to a drainage system.

For urinary tract health:

- Drink 8 – 10 glasses of water each day.
- Keep the urine acidic by taking Vitamin C, up to two 500 mg tablets every day.
- If your urine is dark colored or the volume has decreased, increase your fluid intake to make your urine less concentrated. If this persists, call your doctor or ostomy nurse.

Mucus:

Mucus in your urine and pouch and is normal. When changing your pouching system, wipe the mucus off with a washcloth or tissue.

At night:

Connect to a drainage system, using a regular urinary drainage bag. A prescription for this can be obtained from your doctor or nurse practitioner. Attach the tubing to your urinary pouch using an adaptor, included with your box of pouches. Keep the drainage bag off the floor to minimize contamination. In the morning, you can clean the drainage bag with a half-strength white vinegar rinse or a bleach rinse (1:10 ratio, bleach to water). Replace the drainage bag every month with a new one.

For urinary tract infections:

Report promptly to your provider: Cloudy, foul smelling urine, flank or back pain, fever, malaise, anorexia or decreased appetite, nausea, vomiting, abdominal pain, blood in the urine.

If it is necessary to get a urine sample for the laboratory, make sure that the nurse or doctor gets the sample by catheterizing your stoma using sterile technique. A sample taken from your pouch will not be accurate, and may subject you to unnecessary antibiotics.

Normal urinary anatomy:  

After ileal conduit surgery:
Emptying the Pouch:

You should empty your pouch when it is no more than one third full, or it may get too heavy and pull away from your abdomen, causing leakage. Always practice good hand hygiene before and after emptying your pouch.

Emptying colostomy and ileostomy pouches:
- Empty the contents right into the toilet.
- Position yourself a little further back on the seat, or stand and face the toilet.
- Open the end of the pouch.
- If there is a clip, you may want to fold the tail of the pouch inside out before emptying to avoid soiling the inside with stool. Apply the clip as directed; being sure to check that it is firmly clipped.
- If there is an integrated closure (roll down closure), follow manufacturer’s directions.
- With either, clean the inside of the tail of the pouch with toilet paper, or use a baby wipe or moist paper towel. Then be sure the outside is clean.
- Backsplash can be avoided by layering toilet paper on the water in the toilet bowl.
- Emptying formed stool can be a little easier if you coat the inside of your pouch with a few drops of mineral oil or cooking spray oil, or some type of commercial ostomy lubricant. Apply inside each new pouch and with each emptying as desired.
- Do not rinse the pouch with water to empty it, as this may affect the seal and can lead to leakage.
- If odor is a problem, use a room deodorizer before and after emptying. For more on odor and gas information see pages 10 and 13.

Emptying urostomy pouches:
- Empty the contents into the toilet, following the manufacturer’s directions, which vary with different brands.
- For more on urostomy care, see page 14.

When out in public:
- Always be prepared for a change and have supplies with you at all times.
- Include disposable bags (Ziploc bags work great) and wet wipes for easy clean up.
- Look for handicapped stalls, which tend to have more room.
- Pre-cut your wafers, if using a cut-to fits variety.
- Don’t leave supplies in hot cars.
General Ostomy Information

- Change your entire ostomy system on average every 3 – 7 days, or as needed. Do not go longer than 7 days between changes.
- If you cannot keep a secure and predictable seal for at least 3 days, call your ostomy nurse for help.
- The best time of day for changing usually is first thing in the morning, when you have had the least to eat and drink. Before meals is better than after meals, however you will find the time that works best for you based on your bowel and urinary habits.
- Keep all of your equipment well organized in one spot, and assemble it before removing the old wafer and pouch.
- Please see the separate information sheets and booklets for detailed information and pictures about changing one-piece pouches and two-piece pouches. Ask for these from your ostomy nurse if they have not already been provided.
- For the first 6 – 8 weeks after surgery, measure your stoma with each pouch change to make sure that you are sizing the opening of the stoma hole correctly, or use the shape supplied by your ostomy nurse. After that time, measure your stoma every now and then to make sure the size is correct.
- You should have regular follow-up visits with your ostomy nurse as listed in “Support & Resources”.

Support and Resources

- Before discharge from the hospital, talk with your doctor and ostomy nurse about the need for a home care nurse.
- The most important support is that of your family and close friends. Do not be afraid to talk with them about your concerns.
- Be sure also to talk to your doctors and nurses, especially your ostomy nurse. Call at any time if you are experiencing ostomy problems.

Outpatient Follow-up

- Schedule a follow-up visit with your ostomy nurse at the same time as your first post-operative visit with your physician.
- It is recommended that you be seen every 6-8 weeks for the first 6 months after discharge and then yearly to have your stoma remeasured. Your ostomy nurse is the best resource to find out about any new development in ostomy supplies.
- Check with your insurance company before your visit to confirm coverage for ostomy outpatient care and to receive proper authorization.

Local support groups
The Crouse Hospital Ostomy Support Group meets at 6:30 pm on the second Tuesday of every month. For more information, call (315) 470-7300. A newsletter is sent out every other month. Call to be added to the mailing list.

Helpful groups and web sites for your information:
• The United Ostomy Associations of America (UOAA), 2489 Rice St., Suite 275, Roseville, MN 55113-3797  1-800-826-0826  www.ostomy.org

• Crohn’s and Colitis Foundation, 733 Third Ave, Suite 510, New York, NY 10017.  1 800-932-2423  www.ccfa.org

• National Institute of Diabetes, Digestive, & Kidney Diseases (NIDDK), Office of Communications and Public Liaison, Building 31, Room 9A04 Center Drive, MSC 2560 Bethesda, MD 20892-2560.  301 496-3583  www.niddk.nih.gov

• American Cancer Society , 6725 Lyons St., PO Box 7, East Syracuse, NY  13057 315 437-7025   1800-ACS-2345 (National Number)  www.cancer.org

• Other helpful websites:
  www.convateclink.com.  Information about Convatec ostomy products, with lots of consumer education
  www.hollister.com/us  Information about Hollister ostomy products
  www.j-pouch.org   A website with information about ileoanal anastamosis (J-pouch), including a chat group
  www.ostomyinternational.org.  International Ostomy Association
  www.ostomycanada.ca.  Canada United Ostomy Association
  www.ostgroup.org.  For ostomies without insurance in the U.S.
  www.glo-uoaa.org.  For gay and lesbian ostomies.

• Websites oriented toward ostomy issues of children:
  www.rally4youth.org.  A camp for youth with bowel and bladder dysfunction.
  www.pullthrunetwork.org.  Pull Through Network

### Ordering Ostomy Supplies

**Prescriptions**
Generally, ostomy prescriptions are written after discharge, when you have had a chance to try the new supplies yourself, and when your stoma has settled into a more permanent shape. Ostomy nurse practitioners or your medical provider can provide those prescriptions.

**Insurance**
Ostomy supplies are paid for under Medicare Part B and Medicaid. Most private insurance policies pay for them. You need to call your insurance company to find out about your coverage. Inform them that you are a new ostomy patient, and ask them if they have a
“preferred provider” for ostomy supplies. Reimbursement at different vendors will often vary.

**If your insurance does not require you to go to a particular vendor,** contact your local pharmacy where you normally buy prescriptions, if that is your preference. Pharmacies can usually order most of the supplies you need if you have a prescription. The questions to ask are:

- Do you have the supplies that I need?
- If not, can you order them, and how long will it be before they come in?
- Do you take my insurance for ostomy supplies?

**If you have no preference or your local pharmacy cannot meet your needs,** contact one of the vendors listed below. All information supplied below regarding the vendors (address, hours of operation, reimbursements, supplies available) is subject to change, so be sure and call ahead to verify all information.

<table>
<thead>
<tr>
<th>Vendor Name</th>
<th>Address</th>
<th>Telephone</th>
<th>Hours</th>
<th>Reimbursement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rothschild Medical Supply</td>
<td>5 E. Genesee St., Syracuse NY 13210</td>
<td>475-5181</td>
<td>Mon-Fri: 8:30-5. Sat: 9 – 2.</td>
<td>Require upfront payment; will process claims for most insurances. Medicare Part B only.</td>
</tr>
<tr>
<td>Rite-Aid (Large variety of ostomy supplies)</td>
<td>9 W Genesee St. Syracuse, NY 13204</td>
<td>488-2799</td>
<td>Mon-Sat: 8 am – 9 pm Sun: 9 am – 5pm</td>
<td>Accept assignment for Medicaid and Medicare.</td>
</tr>
<tr>
<td>Gifford &amp; West Pharmacy</td>
<td>300 Gifford St. Syracuse, NY 13204</td>
<td>471-4139</td>
<td>M-F: 8:30 am – 7 pm Sat 8:30 am – 5</td>
<td>Accept Medicare and Medicaid.</td>
</tr>
<tr>
<td>Brewerton Pharmacy</td>
<td>9679 Brewerton Road, Brewerton, NY 13029</td>
<td>676-4441</td>
<td>Mon-Fri 9 – 9 Sat 9-5 Sun 9-2</td>
<td>Accept Assignment on Medicare and most insurances</td>
</tr>
<tr>
<td>Kinney Drugs</td>
<td>41 Albany Street Cazenovia, NY 13035</td>
<td>655-3451</td>
<td>Mon-Fri: 8 - 8 Sat 8 - 7 Sun 9 - 5</td>
<td>Do not accept assignment</td>
</tr>
<tr>
<td>Bolton’s Pharmacy</td>
<td>128 West Main St. Watertown, NY 13061</td>
<td>782-5961</td>
<td>M - F: 8:30-6 Sat 8:30-4 Sun 8:30-1</td>
<td>Accept Assignment</td>
</tr>
<tr>
<td>Village Pharmacy</td>
<td>792 N. Main St., N. Syracuse, NY 13212</td>
<td>458-0500</td>
<td>Mon-Fri. 8:30 – 6 Sat. 8:30 - 12</td>
<td>Accept Assignment</td>
</tr>
<tr>
<td>Nunn’s Hospital Supply</td>
<td>407 Erie Blvd., W.Rome, NY 13440</td>
<td>339-4084</td>
<td>Mon-Fri. 8-5:00 Sat. 9 - 1</td>
<td>Accept Assignment</td>
</tr>
</tbody>
</table>
Mail Order Companies
Mail order companies deliver directly to your home. Most will bill insurance companies for you, including Medicare, and some have free shipping. Many more can be found online.

Edge Park Medical 1 800-321-0591  www.edgepark.com
American Ostomy Association (AOS) 1 800-858-5858
Byram Medical 1 877 902-9726  www.byramhealthcare.com
Express Medical Supply, Inc. 1 800-633-2139  www.exmed.net
AARP Pharmacy Services 1 800-707-3918  www.aarppharmacy.com/medicalsupplies
Liberty 1 800 -705-5797.  www.LibertyMedical.com
UroMed 1 800-841-1233  www.uromed.com
CCS Medical. 1 888 724-4357  www.ccsmed.com
Total E Medical 1 877 750-5252 x7801.  www.totalemical.com
180 Medical 1-877-688-2729,  www.180medical.com

Do not have any insurance coverage for your ostomy supplies?
1. You may qualify for free supplies from one of the ostomy manufacturers (Convatec or Hollister). Contact your ostomy nurse for an application.
2. Shop around! Make telephone calls and explain that you have no insurance coverage, and ask for a discount if possible.
3. OstoGroup is a nonprofit organization that provides FREE ostomy supplies to the uninsured for the cost of shipping and handling, or can help you find products at a substantial discount. Contact them at 877-678-6690 or at www.ostogroup.org.
4. Sometimes your ostomy nurse may have extra supplies on hand to tide you over until a permanent source can be found.

When you Should Call the Doctor:

- Cramps lasting more than 2-3 hours.
- Severe unusual odor lasting more than one week.
- Unusual change in stoma size and appearance
- Obstruction at the stoma and/or prolapsed.
- Excessive bleeding from the stoma opening, or a moderate amount in the pouch.
- Injury to the stoma.
- Continuous bleeding at the junction between the stoma and skin.
- Severe watery discharge lasting more than five or six hours.
- Any other unusual occurrence regarding the ostomy.
- No ileostomy output for at least 6 hours.

**When you Should call your Ostomy Nurse:**

- You are having any difficulty with your pouching system such as:
  - Inability to keep a seal for at least three or four days.
  - Your pouching system repeatedly leaks.
- You have skin breakdown around your stoma that does not heal within two or three changes of your pouching system.
- You have a question about where to get ostomy supplies.
- You are unable to get ostomy supplies for whatever reason.
- You do not have insurance coverage, and may qualify for free supplies from one of the manufacturers.

**Glossary & Terms**

**Accept Assignment:** The vendor or supplier accepts the Medicare approved amount as payment in full. Your insurance company or Medicare will be billed, leaving the consumer to pay the deductible.

**Adhesions:** Strands of scar tissue between two or more organs, which commonly develop after abdominal surgery. May lead to bowel obstruction.

**Appliance:** Refers to the pouching system to collect stool or urine. May be a 1-piece system (pouch) or a 2-piece system (pouch and wafer).

**Barrier Film:** A polyurethane film, usually in pad form, used to protect skin from stool and irritation underneath the ostomy wafer. Acts as a “varnish”. Also called a “skin prep”.

**Colectomy:** A surgical procedure to remove part or all of the colon.

**Colon:** Part of the intestine that stores digestive material and absorbs water and minerals. Also called the large intestine or the large bowel.

**Colonoscopy:** A diagnostic test that lets the physician look inside your entire colon. Looks for early signs of cancer in the colon and rectum, diagnoses the causes of unexplained changes in bowel habits, and lets the physician see inflamed tissue, abnormal growths, ulcers, and bleeding.

**Colostomy:** A surgical opening in which a portion of the colon is brought out onto the abdomen. Results in a stoma with stool output which is fairly formed. May be permanent or temporary.

**Crohn's Disease:** An inflammatory bowel disease (IBD), most frequently in the small and large intestine, but can occur anywhere in the gastrointestinal tract. Most frequent signs and symptoms include fever, pain, and frequent stools with mucus.

**Dehydration:** Loss of water from the body tissues due to poor fluid intake, diarrhea, vomiting, or excessive sweating.
Diverticulitis: An inflamed diverticulum (see diverticulosis). Diverticulosis and diverticulitis are also called diverticular disease.

Diverticulosis: A condition in which there are small pouches in the colon that bulge outward through weak spots, like an inner tube that pokes through weak places in a tire. Each pouch is called a diverticulum. Pouches (plural) are called diverticula.

Electrolytes: Salts and minerals needed by the body. The most common ones are sodium and potassium.

Enzymes: Chemicals in the body involved in chemical reactions. Digestive enzymes, present in stool, help to break down food. Can be irritating to skin.

ET Nurse: “Enterostomal Therapy” Nurse. Also called WOCN (“Wound, Ostomy & Continence Nurse”). A nurse who has received formal training in the care and education of patients and families with ostomies, wounds, and incontinence. A board certified WOCN (CWOCN) has successfully completed national certification board exams.

Flange: The ring on the ostomy wafers where the pouch attaches. Varies based on stoma size.

Gastrointestinal tract: (GI tract) Mouth to anus; the part of the body involved in taking in food, digesting food, absorbing nutrients, and eliminating waste (stool).

Hernia: An abdominal hernia is a bulging of the bowel through the abdominal muscles under the skin; can occur around stomas.

Ileal conduit: A type of urinary diversion, which is usually done as a result of removal of the bladder. A segment of small intestine (ileum) is used as a conduit (pathway) between the ureters and the front of the abdomen. Results in a stoma with urinary output.

Ileum: The lowest part or the end of the small intestine.

Ileostomy: A surgical opening in which a portion of the small intestine (the ileum) is brought out onto the abdomen, resulting in a stoma with stool output which is liquid to semiliquid, with lots of digestive enzymes, and irritating to the skin around the stoma.

Inflammatory Bowel Disease: General name for two diseases that cause inflammation in the intestines, Crohn's disease and ulcerative colitis.

Irrigation: An enema through a colostomy (never an ileostomy!), done for constipation or as preparation for diagnostics or surgery.

Laparotomy: Open abdominal surgery.

Laparoscopic surgery: Surgical instruments, including a camera, are inserted through small holes in the abdomen. Eliminates the need for open incisions during surgery.

Malignancy: A cancerous growth.

Mucosa: The inner membrane of the bowel, including the portion that is the stoma. Will be red and glistening, and bleeds easily. A little bleeding is normal.

Obstruction: Any blockage in the digestive tract. Symptoms include no ostomy output over several hours, or spurts of watery stool, combined with abdominal cramping and nausea.

Os: The actual opening in the stoma (Latin: opening or mouth), where the stool or urine comes out.

Ostomy: Surgically created opening on the abdomen. Refers to ileostomies, colostomies, and urostomies.

Peristalsis: A wavelike motion of the intestines and bowel which propels food and stool through the intestinal tract.

Peristoma: The skin surrounding your stoma, called “peristomal skin”.

Pouch: In a two-piece ostomy system: attaches to the wafer and collects the stool. In a one-piece system: usually refers to the entire appliance.
Preferred Provider: A vendor, supplier, or a health care provider which has an agreement with insurance to provide services or goods, usually at a discount to the insurance company.

Prolapse: A protrusion of the stoma in which the stoma becomes longer.

Rectum: The lowest portion of the large intestine.

Retracted stoma: A stoma that is flat as opposed to protruding.

Stenosis: Narrowing or tightness of the stoma that may cause obstruction.

Stent: A narrow tube placed at the time of surgery which extends from the upper ureter down through the ileal conduit and out the stoma. It helps to support the connection where the ureter is sutured to the conduit and maintains urine flow through the ureter until swelling as subsided.

Stoma: Greek word for “mouth”, it is the actual opening of the bowel or the intestine onto the abdomen. Allows the stool or the urine to pass directly out of the body. Has no nerve endings, but is rich in blood vessels and may bleed slightly if irritated or rubbed (a small amount of blood is normal).

Ulcer: An inflamed lesion on the skin.

Ulcerative Colitis: A disease that causes inflammation and sores, called ulcers, in the top layers of the lining of the large intestine. The inflammation usually occurs in the rectum and lower part of the colon, but it may affect the entire colon. Rarely affects the small intestine except for the lower section, called the ileum. Ulcerative colitis may also be called colitis, ileitis, or proctitis.

Ureter: The two tubes that drain urine from the kidneys, normally going into the bladder. In the case of a urostomy, they drain urine out the stoma.

Urostomy: Surgical opening involving the urinary tract. See ileal conduit. Is a type of urinary diversion.

Wafer: Part of two-piece system. It is the part that goes on your abdominal skin and holds the pouch in place. Comes in different flange sizes, based on the size of your stoma.

References:


Nursing Information Modules: Living with an Ostomy. United Ostomy Associations of America.