Wound Ostomy and Continence Nurses Society®

Teen Chat: You and Your Ostomy

Purpose:

This pamphlet was designed especially for you, the teenager. It was designed to help answer some of the questions you may have about your ostomy care. While every individual has specific needs, you will have a lot in common with other teenagers with an ostomy.

Originated By:

WOCN® Society's Pediatric Subcommittee

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Background:

Having an ostomy can be overwhelming. It is normal to experience many different emotions. Each person's thoughts, expectations, and concerns before and after ostomy surgery can be different. Whatever you are feeling is normal and okay. Coping can be easier with support from your family, other teens with ostomies, and from hospital staff who have experience with ostomies.

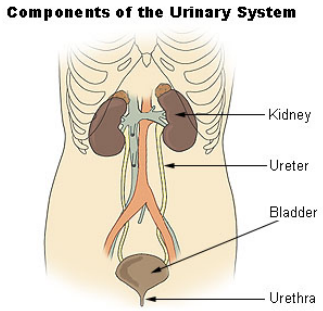
Ostomy surgery happens more often than you might expect. As you become more at ease with the care of your ostomy and establish a network of support, you will also become more comfortable with having an ostomy.

Urinary System

If you have a urostomy (ileoconduit) it may be helpful to understand the urinary system.

The urinary system consists of:

- ***Kidneys.*** Two bean-shaped organs located just below the ribs toward the back. They filter and remove waste from our blood stream and produce urine.



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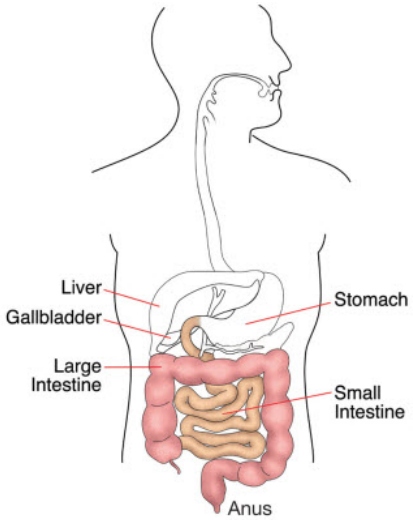
- ***Ureters.*** Tube attached from each kidney draining to the bladder.
- ***Bladder.*** Storage place for urine.
- ***Urethra.*** Drains the urine from the bladder to the outside of the body.

Digestive System

If you have a colostomy or ileostomy, it may be helpful to understand the digestive system. Gastrointestinal system, also known as the GI tract, takes in food, digests it to extract energy and nutrients, and expels the remaining waste.

The following is the flow of the digestive process:

- ***Mouth.*** Where digestion begins.
- ***Esophagus.*** Partially digested food moves from the mouth to the stomach.
- ***Stomach.*** A hollow muscular organ involved in the second phase of digestion.
- ***Small intestine.*** Divided into three parts: duodenum, jejunum, ileum. Each area continues digestion and absorption of nutrients.
- ***Large intestine.*** Last part of the digestive system. Its function is to absorb the remaining water from indigestible food matter, store this unusable food matter (wastes), and then eliminate the wastes from the body in the form of stool.



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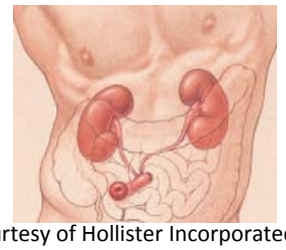
Types of Ostomies or Stomas

An "ostomy" is a surgically created opening in the abdomen. An ostomy is also called a stoma. There are various types of ostomies/stomas. The name of the stoma is determined by what part of the intestine is pulled up to the skin. For example: *col*ostomy is an opening created in the colon.

Stomas for stool or urine are constructed from a part of the gastrointestinal tract or urinary tract and remove waste material to the outside of the body. Stomas are usually moist, shiny, and red in color. It feels like the inside lining of the mouth. All stomas do not look alike. You may have one or two stomas depending on the reason for your surgery.

Urinary ostomies. The stoma for a urinary diversion may be formed from the intestinal tract or may simply involve connecting a section of the urinary system to the skin.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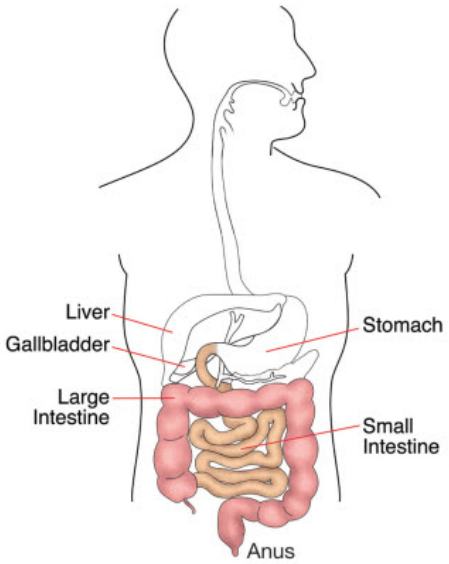
- ***Urostomy.*** (Also called urinary diversion, ileal conduit, or colon conduit.) A short length of intestine (ileum or large bowel) is used to form a stoma in the abdomen. The ureters are implanted into the bowel and this bowel

segment is sewn closed inside the abdomen. Urine drains through the bowel segment (conduit) into an ostomy appliance on the abdomen.

Stool ostomies. Ostomies for stool use a part of the intestine. There are three types:

- ***Jejunostomy.*** A portion of the jejunum is pulled up to the skin of the belly.
- ***Ileostomy.*** A portion of the ileum is pulled up to the skin of the belly.
- ***Colostomy.*** A portion of the colon is pulled up to the skin of the belly.



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Stoma Construction

All ostomies are not constructed the same way. The surgeon constructs the stoma in one of three ways: an end ostomy, a loop ostomy, or a double barrel ostomy.

- **End ostomy.** Is constructed by taking a segment of bowel and then dividing the bowel in two separate pieces. The portion of the bowel that is coming from the direction of the mouth is called the proximal end. The portion of the bowel that is toward the rectum is called the distal end. The proximal end of the bowel is brought through the belly wall and stitched to the skin. The distal portion of the cut bowel is sewn together and left inside the belly.
- **Double-barrel ostomy.** Is fashioned in a similar way as the end ostomy. The proximal end is constructed the same way as an end ostomy. The distal end of the double barrel is also brought through the belly wall. With a double-barrel stoma there are two stomas on the belly. The stomas may be next to each other or separated. The proximal stoma is the stool-producing end. The distal stoma, also called a mucous fistula, only produces mucous.
- **Loop ostomy.** Is constructed by bringing a loop of bowel through the belly wall. This loop of bowel is cut, on the top, halfway through. The cut edges are turned back, like a cuff, and stitched on the skin. The proximal and distal ends are attached at the base of the loop.

What is a WOC Nurse?

A WOC nurse is a nurse with special training in ostomy and stoma care. They can work with your doctor(s) and nurse(s) to help care for your ostomy. They also help you and your family to learn how to take care of your ostomy. Other names for your WOC nurse may include: Enterostomal therapist (ET Nurse), Wound, Ostomy and Continence nurse, or Ostomy nurse.

Having an ostomy is stressful, and the WOC nurse is someone you can trust and lean on for support. If you do not have a WOC nurse, you can use the resources at the end of this booklet to help locate one in your area.

What to Expect After Surgery: First 2 Weeks

After surgery, you might be wearing an ostomy pouch. The pouch collects stool or urine so that it can be easily contained and emptied. It also protects the skin around the stoma from becoming irritated. Usually the pouch right after surgery is clear so that your physicians and nurses can look at your new stoma. Your nurse will likely empty and measure the pouch contents to monitor your hydration and stoma function. You might also have a dressing covering your incision.

Your physician and nurse will be listening to your stomach for "gurgling" or bowel sounds after surgery. As your activity level increases, normal bowel sounds will return, and your stoma will begin to function. During this time, your physician may require that you have nothing to eat or drink to avoid having nausea or throwing up. There may also be a tube that is inserted through your nose and into your stomach, which is called a "nasogastric" (NG) tube. This helps keep the stomach empty to avoid having nausea or throwing up. This tube is gently removed once your stoma begins to function so that you can eat and drink. At first, you may only be given non-carbonated clear fluids to drink. Food will be slowly added to your diet as the intestinal function returns to normal. Depending on the type of stoma, your physician and nurse will inform you of any dietary changes.

You will have an "intravenous line" (IV) that gives fluid through your veins. This will give you medicine, nutrients, and fluids while you are not eating or drinking. You may also have other tubes present, depending on the type of surgery. Ask your physician or nurse about the purpose of these tubes.

When you have discomfort, a medication can be prescribed to help you feel more comfortable. You may get pain medicine through your IV. Once you are able to drink clear fluids and start to eat small amounts of food, you may be given a pain medicine to swallow by mouth. If you are having discomfort, notify your nurse so that the appropriate medication(s) can be given. No matter what type of pain control you have, being comfortable will allow you to move around. Moving around will help keep your lungs clear, prevent soreness, and speed up the healing process. Other things you can do to help your pain include:

- Breathe deeply and slowly.
- Watch videos or TV.
- Listen to music.
- Play your favorite video games.
- Talk with your family and friends.
- Imagine you are in your favorite place.
- Hold a soft pillow on your abdomen, especially when coughing.

You may feel uneasy and afraid about looking at your stoma for the first time after surgery. These are normal feelings, and you may not want to look at your abdomen or participate in care. However, as you participate more in your care, you will begin to feel less anxious about looking at your ostomy. Looking at ostomy teaching booklets with pictures, watching ostomy teaching videos, reading articles about other teens with ostomies, and practicing on ostomy models will help you become more comfortable with taking care of yourself. To prepare you for home, you and/or your family will be taught how to empty and change the pouch. This will allow you to have the skills to take care of your ostomy at home.

Right after surgery, the stoma is swollen. It will get smaller and change shape over the next 6-8 weeks as the swelling goes down. You may see the stoma move and wiggle slightly at times. This is due to "peristalsis" and helps move the stool through the intestine. It is normal for the stoma to bleed a little bit when it is touched or rubbed.

Your stoma will begin to function several days after surgery. Here is what to expect from your ostomy during the first 2 weeks after surgery.

- ***Colostomy.*** Usually functions 3-4 days after surgery. The first stool output may be mostly gas and liquid. Your pouch may have air in it, and your stoma may make sounds. Bacteria that are normally found in the colon are responsible for the odor and gas. Within the next few weeks, the stool may thicken to a semisolid or formed consistency. Refer to the 'Diet & Nutrition' section for information proper diet and gas minimization with a colostomy. Depending on your diagnosis, you may have one or more stomas. If you have two stomas, one stoma passes stool and gas, and the other stoma passes mucous. The stoma that does not have stool coming from it is called the "mucous fistula stoma." (If you have a mucous fistula stoma, it is typically covered with an absorptive bandage that is changed as needed. It may be pouched if there is a lot of mucous.) With certain ostomy surgeries, the rectum and anus are removed, and there is a "posterior wound." This may result in some temporary normal discharge from the rectum. The discharge usually looks like mucous, and it can be contained by using an absorptive pad in your underwear. Your nurse will teach you how to care for the posterior wound using good hygiene to prevent body bacteria from entering the wound.
- ***Ileostomy.*** Usually functions 2-3 days after surgery. The first stool output may be mostly gas and yellow or green watery stool. Your pouch may have air in it, and your stoma may make sounds. The consistency will depend on where in the small bowel the stoma was created--beginning, middle, or end. This determines how much water is absorbed from the stool and how thin or thick it will be. As you begin to eat more solid food, the stool will thicken to a paste consistency and be light to medium brown in color. Refer to the 'Diet & Nutrition' section for information proper diet and hydration with an ileostomy.
- ***Urostomy.*** Functions immediately after surgery. The urine may have a blood-tinge and contain pieces of mucous. The blood-tinge will gradually clear over 1-2 weeks so that your urine is a pale, clear yellow color. Mucous strands may still be seen in the urine, which is normal. Refer to the 'Diet & Nutrition' section for information proper diet and hydration with a urostomy.

What to Expect after Surgery: At Home (2-8 weeks)

While it is exciting to go home from the hospital, it is also normal to feel uneasy. Some teens are afraid that the seatbelt will hurt the stoma. A seatbelt will not hurt the stoma, it is important to always remember to use your seatbelt. Padding between the stoma and the seatbelt with a towel may be helpful; place a washcloth folded in half between the seat belt and the stoma. You may also be concerned that you will be taking care of your ostomy for the first time away from your nurse. Remember the skills that you and your family were taught. It is helpful to keep printed educational materials and tip sheets on hand. As with any surgery, you will need some time to recover before returning to school and becoming physically active. Be sure to check with your doctor before returning to school or starting strenuous activity. An ostomy should not limit you from what you did prior to surgery.

Your surgeon may order a home care nurse to assist in the transition to everyday activity. The home care ostomy nurse can help with pouching at home which is slightly different than pouching in the hospital because space is different at home. The home care nurse can help you decide where and how is the best way to change your pouch at home. The home care nurse can also help you with supply choices as well as supply companies to ensure you have adequate supplies to care for your ostomy.

Other tips that will help you transition back into normal activities include:

- Letting your school nurse, teacher, and/or responsible adult know of your needs.
- Being independent in your care but ask for help when needed.
- Changing your pouch on a routine basis.
- Transitioning into different pouches (i.e., opaque, closed-ended, filter) that will help conceal the appearance of your ostomy output, minimize gas and odor, and facilitate easy emptying.
- Keeping a positive attitude about your stoma. For example, some teens name their stoma; some teens reach out to connect with other teens with ostomies (i.e., internet resources, Youth Rally – www.rally4youth.org, or support groups).

Over the next 6-8 weeks, you may notice a slight change in the size and/or shape of your stoma. This is normal. As the swelling decreases, your stoma may become smaller. You will need to measure your stoma each time you change your pouch and wafer in order to cut the appropriate sized opening. This is called "downsizing" the wafer opening. After this time period, your stoma should remain the same size, and you can have your wafer opening custom pre-cut from your ostomy supply company.

Just like before your surgery, you can experience diarrhea. This can be caused by many things, including antibiotics, medications, viruses, and intolerance to certain foods. With an ileostomy, you no longer have a working colon. This may cause you to lose water and electrolytes and quickly become dehydrated. Remember to drink at least six to eight glasses of water (64 ounces) or electrolyte replacement fluid each day. A good tip to remember is to drink a glass each time you empty your pouch. Refer to the 'Diet & Hydration' section for more information and signs of dehydration.

Ostomy Pouching Products

There are many options for pouching available to you. There are several companies that make pouches and each company make many different types of pouches. You can often look at them at company web sites and request samples. Try different pouches until you find one that you are comfortable wearing and meets your personal needs.

Here is some basic information about ostomy pouches.

- ***One-piece system.*** The pouch and the adhesive or wafer are a single unit.

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- ***Two-piece system.*** The wafer is separate from the pouch. The wafer is applied to the skin, and then the pouch is connected to the wafer.

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  - There are many ways that pouches connect to the wafers. Some snap on, others clip on, and other pouches have a sticky surface that adheres to the wafer. The wafer is selected mostly based on the size and shape of the stoma and the type of output. There are other features such as borders with and without tape that may be used to select a wafer.
  - When using a two-piece system, a pouch that fits with the wafer will need to be used. Pouches from one company are not mixed with wafers from another company.
  - Advantages of a two-piece system. You can see the stoma as you apply the wafer so it may be easier to get the wafer exactly where you want it. You can also change the pouch without changing the wafer. So, if you want to wear a smaller closed end pouch during the day and a larger drainable pouch at night, you can change pouch without changing the wafer.
- ***Adhesive properties.*** Some wafers are designed to last longer and are better suited for high output stomas or liquid stool. If you are changing the wafer more than one time per

day, talk to your ostomy nurse for advice on other products that may increase the wear time.

- ***Convexity.*** Some wafers are designed with an outward curve to help push flatter stomas into the pouch.
- ***Transparent or opaque.*** Transparent or clear pouches may be easier to use until you get used to putting on the pouch. You can visualize the stoma through the pouch making it easier to place the wafer where you want it. An opaque pouch hides the stool or urine in the pouch.
- ***Backing material on the pouch.*** Some are covered with a thin layer of cloth. The back of the pouch is often in contact with your skin, so you may want something that is comfortable.
- ***Pouches have different closures.*** Some pouches have clips that are separate from the pouch while others have an *integrated closure* or one that is a part of the pouch. Urostomy pouches have spouts on the bottom for easy drainage of liquid. These may also be used for very liquid stool.
- ***Gas filters.*** Pouches may have a filter which will allow gas to pass out of the pouch through a filter that minimizes the odor of the gas.
- ***Belts.*** Some pouches have belt loops for the addition of a pouch belt. Belts help pull the wafer against your body. Not everyone needs a belt. Some people never use them; others wear them all the time, when they are very active, or for a short time after changing the pouch.

Other products that are not a part of the pouch and wafer but may be useful to you:

- ***Adhesive removers.*** Small cloths that help release the glue of the wafer making the wafer easier to remove. They leave oil on the skin so must be carefully washed off your skin before applying the new wafer or it will not stick.
- ***Skin barrier.*** A product that is applied to the skin before placing the wafer. It acts as a barrier between the skin and the wafer to protect the skin from the adhesive of the wafer.
- ***Pastes.*** Pastes come in a tube-like toothpaste form or already formed into strips. They are used around an irregularly-shaped stoma or to fill in areas, such as scars, in order to pouch on a flat surface. They should be thought of as *caulk or filler* and should not be placed all over the wafer. Since pastes in tubes have alcohol in them, one may feel a burning sensation for a few seconds after application if the skin is at all irritated. To minimize this sensation, it may be helpful to apply the paste directly to your wafer and let it sit for 1 minute to allow the alcohol to dry before applying it to your skin.
- ***Powders.*** Powder specifically designed for ostomy care is used on skin around the stoma where the tissue is damaged. The powder absorbs fluid that may weep from the injured skin. Ostomy powders with an antifungal medication are also available.
- ***Absorbent packet.*** This product is placed into the pouch for very liquid stool. It turns the stool into a gel which helps minimize “sloshing” of liquid. It may also help with the wear-time of the wafer by keeping liquid drainage off of the wafer.
- ***Products for odor.*** There are tablets and drops available that go into the pouch to help with odor. Some are also available as a spray for use in the bathroom when emptying the pouch.

- ***Barrier rings.*** A donut shaped moldable adhesive ring that can be added to the back of the wafer to help to get a better seal and prevent leakages.

Gas & Odor Control – Stool Ostomies

You will notice gas in your pouch as your stoma begins to function after surgery. The amount of gas is different with each person. Gas is more common with colostomies but can occur with ileostomies.

Causes of increased gas production include the following:

- Foods that are known to increase gas production (see list).
- Carbonated drinks.
- Chewing gum.
- Drinking through a straw.
- Talking and eating which causes you to swallow more air.

To decrease gas, you may want to limit some of the above when it is important to you. Noise can be muffled a little by putting your arm over the stoma and pouch. Some pouches contain a gas filter. The filter lets the gas go out of the pouch without an odor. It also prevents gas from building up, so the pouch does not look like a balloon under your clothing. Remember that you cannot control gas from your ostomy. However, there should not be an odor if the pouch has a good seal.

Odor is a concern for people who have ostomy surgery. Modern ostomy pouches are made with odor-barrier film, so odor of stool should be contained inside the ostomy pouch if you have a good seal. It may be hard to adjust to emptying the pouch as the smell is closer to you than when you sat on the toilet for a bowel movement. All stool has an odor, but this is more evident with stool sitting in the pouch outside your body before it is emptied. You should notice odor only when you are emptying or changing your pouch. Some important tips on managing stool odor include the following:

- Odor is worst right after surgery because of old blood that is mixed with stool.
- Odor does vary with foods that you eat in your diet. (See list of foods that produce increased odor.)
- Keeping the bottom of your pouch and tail closure clean will eliminate odor when the pouch is closed.
- Empty your pouch regularly to help reduce the risk of leakage.
- If you notice an odor, check and make sure you do not have a stool leak.
- Deodorants are available to neutralize the odor of stool in the pouch, and others can be sprayed in the air when emptying the pouch.

Odor Control – Urine Ostomy

Odor is also a concern for people who have had urostomy surgery. Just as the ostomy pouches for stool are made with odor-barrier film, so are urostomy pouches. Odor can especially be a concern if your urine is very concentrated (dark and small amount from not drinking enough fluids). Some important tips on managing urostomy odor include the following:

- Drinking plenty of water each day will help decrease urine odor.
- Carbonated drinks will increase odor of urine.
- Asparagus and seafood may cause urine odor.
- Make sure that the bottom of the pouch drainage spout is clean.
- If you rinse out a two-piece pouch system, make sure to use lukewarm water. Hot water will open the pores and make the odor worse.
- When urinary equipment is not in use, white vinegar and water (1:1 ratio) can be used to cleanse the urinary tubing and dependent nighttime drainage bag. There are also commercially available products to cleanse the tubing and bag.

Diet and Nutrition – Stool Ostomies

Colostomy. Having a colostomy does not restrict you from foods unless you have a specific medical condition that requires a special diet. If your stoma is low in the colon, you could have issues with constipation (hard balls of stool), and you may need to increase intake of foods high in fiber and drink more water. There are some foods that can cause odor or gas. If that is a concern for you, then you may want to eat those foods in moderation.

Foods that may increase odor.

- Asparagus
- Broccoli
- Brussel sprouts
- Cabbage
- Cauliflower
- Certain spices
- Eggs
- Fish
- Garlic
- Onions

Food and beverages that may increase gas.

- Beans
- Broccoli
- Brussel sprouts
- Cabbage
- Carbonated beverages
- Certain spices
- Cheese
- Corn
- Eggs
- Fish
- Garlic
- Onions

Ileostomy. The actual digestion of food takes place primarily in the small intestine, not in the colon. Certain foods are harder to digest and can build up and block the passage of stool. You may also need to pay more attention to certain foods that you eat that may cause a blockage of the bowel.

Foods that may contribute to a food blockage (high fiber foods).

- Chinese vegetables coconut
- Citrus fruits
- Coleslaw
- Corn
- Dried fruits
- Mushrooms
- Nuts
- Popcorn seeds
- Vegetable or fruit peelings (potatoes, cucumbers, grapes, apples)

Everyone responds differently to foods, so it is important that you learn what works for your body and which foods you may need to avoid. Try one new food at a time so you can see how your body responds. You most likely can eat all foods, but you may want to try foods listed high in fiber one at a time in small amounts. Chewing food well and drinking plenty of fluids helps reduce the risk for a blockage.

Signs of obstruction.

- Pain and/or cramping in the belly, especially near your stoma, with little or no stool output. You may have increased watery output.
- Stoma swelling.
- Belly distention (swollen belly).
- What may help:
    - Sitting in a warm tub of water to relax your muscles.
    - Sitting in a knee-chest position may also help to relax your belly muscles.
    - Walking.
    - Heating pad on low setting placed on your belly for a short time.
    - Drinking more fluids.
    - Removing your pouch and putting on one with a larger opening as your stoma may swell.
- Contact your doctor or WOC nurse if this does not improve in ____ hours or sooner if you are in severe pain. You may need to go to the emergency room.

Diet and Nutrition – Urine Ostomy

There are usually no food restrictions with a urinary diversion. If you do have food restrictions, as with End Stage Renal Disease or stone formation, your doctor and nutritionist will discuss your diet needs. Some foods will increase the odor of your urine (i.e. asparagus and seafood), but this is usually very temporary. It is important to drink plenty of fluids (6-8 glasses) daily. This will decrease the odor of your urine. Foods and fluids that make your urine alkaline can cause you to have crystals form around your stoma.

Dehydration

Signs and symptoms of dehydration.

- Urine is dark and concentrated.
- You don’t urinate very frequently.

- Thirsty.
- Dry lips, mouth, gums.
- Feeling weak, nauseous, loss of appetite.

To prevent dehydration, you should drink more fluids than you normally do, especially water. A general guide is to drink one 8 ounce glass of water each time after you empty your ostomy pouch. This replaces the fluid you have lost through your ostomy. Discuss with your nurse or nutritionist the amount of fluids you need to take in each day. Additionally, caffeinated drinks, energy drinks, and tea can actually cause you to lose more fluid through your urine. Drink these in limited amounts.

It is important to increase your fluid intake right away.

Stool ostomies. Dehydration occurs when you are putting out more fluids than you are taking in. You are essentially 'drying out.' The colon's job is to reabsorb water; this function is lost when the colon is bypassed or removed. With an ileostomy, you will lose a lot of water through your ostomy. This is common soon after your surgery, during hot weather and during periods of activity.

It is important to increase your fluid intake right away.

Diarrhea and Constipation – Stool Ostomy

After you go home, you will notice that your stool will begin to thicken. You will usually have to empty your pouch 3-4 times a day, depending on the type of ostomy you have, the amount of food you eat and the types of food.

- Diarrhea is when you have increased liquid output in your pouch.
- What is diarrhea when you have an ileostomy? The need to empty your pouch more than *your* usual amount.
- If you notice your stool is more liquid you need to drink more water.
- Call your primary care doctor or your WOC nurse if you continue to have loose, liquid stools. During this time, avoid foods and beverages that can cause loose stools.

Foods that may help thicken your stool.

- Applesauce
- Bananas
- Cheese
- Creamy peanut butter
- Noodles
- Pretzels
- White rice
- White toast
- Yogurt

Constipation is when your stool is hard, small balls or pasty, small stools. This may happen when you have a colostomy. You can also have watery stool that makes you think you have diarrhea, but it may be water coming around hard stool. This is usually only a concern if you have a stoma in the lower part of the colon. Drinking more water will help keep your stool soft.

Eating foods high in fiber will help, but you must drink the water to make the fiber work. If you continue to have problems with constipation, call your primary care doctor or your Ostomy nurse.

Medication

Stool ostomies. Some medications or nutritional supplements may change the color, odor, or consistency of your stool. Some medications may not be completely absorbed. Make sure your doctor or nurse knows that you have a colostomy or ileostomy when they give you a new medicine. With an ileostomy, you cannot take time-release capsules as they will come through your stoma without breaking down. You may need to take some medications in liquid form to get the full benefit.

Urine ostomy. Some medications will cause your urine to change color. Call your doctor or nurse who gave you the medication to ask about it if your urine changes color.

Activity and Living with Confidence

Skin care. It is important for the skin around your stoma to remain healthy without irritation. The skin around your ostomy (*peristomal skin*) should look just like the skin elsewhere on your belly. Each time you remove your pouching system, look carefully at your skin. If you notice any swelling, redness, discoloration, or rash, you could have irritated skin. This may also be itchy or painful. Contact your doctor or WOC nurse for further guidance.

Bathing and showering. Showering with an ostomy is easy with a few modifications. Empty the pouch first so that it is not so bulky. Try standing with your back to the shower spray to protect wafer seal. After showering, dry the pouch, its backing, and any tape border well with a towel.

- Some people like to remove their pouch before showering so they can cleanse the skin around the stoma in the shower and then apply a fresh pouch afterwards. Soap and water will not flow into your stoma or hurt it in any way. Some leakage may occur during the time the pouch is off, though, so you may prefer to change the pouch after showering.
- Taking a tub bath is fine. Just remember that a long soak loosens the adhesive. If you don't want to loosen the wafer, then use a bit less water in the tub.
- Do not apply lotions or oils to your skin around your stoma. This will interfere with your wafer and cause it not to adhere as well.

Routine care. You will get used to your pouching system and develop an emptying and changing schedule. Below are a few guidelines when taking care of your ostomy:

- Empty your pouch when it is 1/3-1/2 full.
- Keep yourself, friends and family safe by washing your hands often.
- Replace the skin barrier (the part that sticks to your skin) routinely every 3-7 days, or as determined by your WOC nurse, rather than waiting for it to leak.
- Do not 'patch up' a loose or leaking pouch system. This may result in skin irritation.

- If you use soap when cleansing your skin around your ostomy, make sure it doesn't contain oils or lotions.
- Rinse your skin with water after cleansing it with soap, and dry it completely before applying the new pouching system.
- Cut the opening(s) in the skin barrier to fit the size of the stoma(s). Cutting an opening too large could cause skin irritation, and cutting an opening too small may harm your stoma(s).
- After applying your skin barrier, hold it against your body for 30-60 seconds. The pressure and warmth will help activate the adhesive.

Exercise and sports. Your surgeon will give you permission when you can resume full activity, usually six weeks after surgery. Activities include sports, swimming, dancing, and other forms of exercise and fun.

People have participated in all sorts of exercises with an ostomy, so you don't have to worry that you won't be able to do the things you enjoy. However, you will probably want to take some precautions.

- Empty your pouch before you start.
- Be sure that you have spare pouching supplies/change of clothes in locker/sports bag in case of accidental leakage.
- Use a belt for added security, either the type made by the pouch company or a special support belt with or without a protective flap, over the stoma area.
- Depending on the sport/type of clothing or uniform worn, you can camouflage the pouch using snug shorts worn under the uniform and over the pouch area.

Swimming is an activity that most people enjoy, and having an ostomy is no reason to stop.

- Limit the length of time spent submerged in the water to an hour or so at a time and increase the time as you find what your pouch system can tolerate.
- Change your pouch at least 12 hours before you plan on water sports so the adhesive has a chance to adhere well.
- You may want to add waterproof tape to the edges of your skin barrier before swimming.
- Modify your suit selection. Boys can add a dark colored tank or A-shirt. Girls may try a one-piece suit with gathers or a skirt over the lower abdomen. Tankinis are an excellent option for a one-piece style suit with two-piece tanning options. For bikinis, you can use boy-cut short or high waist for good tanning with coverage over the ostomy area.
- Emptying the pouch on time can reduce bulging. Carrying zip-lock baggies make it easier on beach areas with little bathroom access.
- With a two-piece ostomy pouching system, try a closed-end, shorter pouch. It doesn't have bulky clip, and you can snap it off to change back into your regular system later.
- Opaque pouching systems can help to conceal your ostomy and output.

School. If there is no health reason to stay home, it is best to get back to school as soon as you and your doctor feel you are ready. It usually helps one feel better to get back to normal

routines and be around the support of friends. When you first start back to school after ostomy surgery, it helps to plan ahead a bit.

- How much and when you will want to share with your teachers and classmates is entirely up to you.
- Your absence will have been noticed, and you may want to practice what you would like to tell people ahead of time.
- A simple statement will handle most casual situations when you first return.
- Keep spare supplies and clothing at the nurse's office, which usually has a private bathroom available.
- Be prepared in whatever bathroom you end up having to use – a pencil style case can hold deodorizer drops, wipes, hand sanitizer, and any other supplies you use discretely.

Clothing. Dressing with confidence may require less adjustment for boys than girls since most boy outfits cover the area of the stoma naturally. Having an ostomy doesn't mean wearing totally loose baggy clothes unless that is the style that you prefer.

- More fitted clothing is mostly a challenge in terms of the length of the top and how snugly it is to fit over the pouch – layering shirts can help conceal an ostomy pouch.
- Add a looser fitting long vest.
- Use a lightweight wide belt over the entire pouch area with the buckle worn off center on the other side.
- Wear tops that are snugger at the top and looser around the waist.
- Scarves, sashes, and other waist-to-hip wear can help conceal an ostomy pouch.
- Pouch covers are a fun option, especially for girls. These can be made to go on the outside of your pouch using soft cloth with lace, beads, and ribbon to coordinate with underwear, clothing, and your personal fashion style.
- Specialty clothing items are available, such as body wraps and body bands.
- Be flexible with trends or styles that aren't your usual style.
- In terms of pants:
    - Tight or snug-fitting pants will not prevent the ostomy from functioning, but they might prevent stool or urine flow into the lower part of the pouch. Try a different waist height or style of slim pant that accommodates the pouch better, or you might wear the pouch over the pants with tops that are longer at least in the front.
    - For girls accustomed to having midriff open, there are other areas of the body that can peep for appeal, such as off-the-shoulder tops, low-cut or peek-a-boo backs, and sheer or cut-out sleeves.

Most importantly, as you gain confidence with your new body, you will be able to develop your own style that accommodates fashion, your personal taste, and your need for concealment

Social Relationships

Ostomy surgery and what leads up to it are a very big life experience and one that most other family members and friends have not experienced.

- Some common feelings are anger and resentment at the situation, asking or wondering "why me?" and feeling even more sensitive about things than usual.
- Some people feel very tired, sad, frightened, depressed, or even hopeless.
- Some may cycle in and out of all of these feelings over and over for a while.
- Your doctors, nurses, friends, relatives, and other community supports can help you by listening and helping your family to help you. Some people find counseling useful; others use chat rooms or web forums or ostomy support groups (when available) helpful.

Family relationships. Being part of a family is stressful for most teens, but at the same time, it can provide a lot of love and support.

- There is often strain in relationships totally separate from the issues around illness, injury, or ostomy surgery.
- Having an ostomy and learning to manage it independently is a big deal. A lot of feelings may overlap with feelings that already exist, and might be harder to cope with the usual activities of family life.

Friends. If your ostomy is temporary and very short term, you might want to hold off on telling lots of people all the details. It may be enough to simply indicate that you are going through some surgeries.

- There is no way up front to anticipate how any given person will handle information you choose to share with them.
- Close friends may be very helpful to you after ostomy surgery. Teens sometimes find it easier to talk to close friends than parents about feelings. Think about your friends and decide who you feel comfortable enough with to share information about your operation and your stoma. You may even decide to show them your stoma.

Intimacy. Teens experience intimacy with peers in many different ways from friendship to companionship to romance. Part of intimacy is sharing, and you can decide each time and every time how much you want to share. Intimacy at any level involves risk, so take things at your own pace

Travel

Travel doesn't have to be a problem with an ostomy as long as you plan ahead.

- Short trips mean you need to pack enough supplies for a complete change or two as well as some zip-lock bags for emptying if you think bathroom access will be an issue. Some ostomy supply companies provide opaque disposable plastic bags in their boxes of ostomy supplies. It is very helpful to carry hand sanitizer with you in case you are not near a water source.
- If the ostomy is new, and you are still getting used to figuring out your normal wear-time, include another extra change of clothes.

- For longer trips, you may want to plan ahead and ship some extra supplies to where you will be staying so you don't need to pack everything.
- Check for back up medical care in the area where you will be staying.
- Teens that travel between parents for joint custody need extra supplies and back-up medical care at both locations. Your nurse may be able to help you make those arrangements.

Continuing Care

Now that you have "lived" with your ostomy, you may have additional questions. There is much information that can be obtained from many resources. The WOC nurse at your local hospital can answer questions and direct you to any local support groups in your area.

It's important to have an extra set of supplies on hand in case of an emergency. Many of the ostomy supply companies provide a carrying-case that can be used, or you may use a make-up bag or toiletry-type bag. Do not store extra supplies in the car while at school or work because the heat may cause some products to melt.

Usually insurance companies will allow supplies to be shipped to you monthly. You need to know what medical equipment company your supplies are coming from and call them each month to place an order. Make sure you re-order before you run out of supplies.

Remember to check with your doctor before taking any medications including anti-diarrhea medications. If you take a medication and later see the pill or tablet in the pouch, then it has not had time to absorb. You will need to ask your doctor to change the prescription to a liquid form.

If you have a urinary stoma (urostomy), and there is a question of a urinary tract infection, the stoma should be catheterized to get a sterile specimen for the lab. If urine is taken directly from the pouch, it will show contamination. Remember, it is normal to see mucus in the pouch mixed with urine.

It is not normal to have skin rashes or red, sore skin around the stoma. Call your doctor or WOC nurse if this occurs.

There are many different styles of ostomy products available, and companies often make new products. Most of the companies that make ostomy supplies will provide samples. You can contact them through their toll-free number or website. Many of the companies also have a WOC nurse available to answer questions and suggest particular products that may work for you.

National Resources

Association for the Bladder Exstrophy Community (ABC)
6737 West Washington Street, Suite 3265
West Allis, Wisconsin 53214
USA
Email: admin@bladderexstrophy.com

Phone: 414-918-9002 (US)
519-679-8774 (Canada)
Website: www.bladderexstrophy.com

Coloplast US Headquarters
1601 West River Road North
Minneapolis, Minnesota 55411
USA
Email: usmedweb@coloplast.com
Phone: 1-800-533-0464
Website: www.us.coloplast.com

ConvaTec Inc.
Professional Services
100 Headquarters Park Drive
Skillman, New Jersey 08558
USA
Email: CIC@convatec.com
Phone: 1-800-422-8811
Website: www.convatec.com

Crohn's & Colitis Foundation of America, Inc. (CCFA)
386 Park Avenue South, 17th Floor
New York, New York 10016
USA
Email: info@ccfa.org386
Phone: 1-800-932-2423
Website: www.ccfa.org

Hollister Incorporated
Consumer Programs Team
2000 Hollister Drive
Libertyville, Illinois 60048
USA
Phone: 1-888-740-8999
Website: www.hollister.com

Pull-thru Network, Inc. (PTN)
2312 Savoy Street
Hoover, Alabama 35226-1528
USA
Email: Info@PullthruNetwork.org
Phone: 205-978-2930
Website: www.pullthrunetwork.org

Spina Bifida Association (SBA)
4590 MacArthur Blvd. NW, Suite 250
Washington, DC 20007-4226
USA
Email: sbaa@sbaa.org
Phone: 1-800-621-3141 or 202-944-3285
Fax: (202) 944-3295
Website: www.sbaa.org

United Ostomy Associations of America, Inc. (UOAA)
P.O. Box 512
Northfield, Minnesota 55057-0512
USA
Email: info@ostomy.org
Phone: 1-800-826-0826
Website: www.uoaa.org

UOAA Teen Network
Website: www.ostomy.org/forum/viewforum.php?f=9

UC and Crohn's Teen Network
Email: info@ucandcrohns.org
Website: www.ucandcrohns.org

Wound, Ostomy and Continence Nurses Society (WOCN)
15000 Commerce Parkway, Suite C
Mt. Laurel, New Jersey 08054
USA
Email: wocn_info@wocn.org
Phone: 1-888-224-WOCN (9626)
Website: www.wocn.org

Youth Rally Committee, Inc. (YRC)
424 Bradford Avenue
Westmont, New Jersey 08108
USA
Email: laukett@rally4youth.org
Phone: 856-854-3737
Website: www.rally4youth.org

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