

# Your Child's Life with an Ostomy





#### **Contents**

Introduction	3			
The digestive system	4			
Ileostomy	5-6			
Colostomy	7-8			
After surgery - ileostomy / colostomy 9				
Diet and nutrition	10-11			
Urostomy	12-14			
After surgery - urostomy	15			
Diet and nutrition	16			
Pouch selection	17			
Emptying the pouch	18-19			
Changing the pouching system	20-21			
Going home	22			
At home	23			
Continuing care	24			
Ostomy Youth Camp	25			
Resources	26			

This booklet contains information on multiple types of ostomy procedures - so it's important to note what type of ostomy your child has! Read the anatomy and surgery specific information as highlighted below (based on information addressing either the digestive or urinary tracts). The rest of the booklet is relevant to all surgery types.

**Ileostomy** 

Colostomy

Urostomy

Having a sick child, no matter what age, can be overwhelming. It is natural to experience many different emotions. Each family's beliefs, expectations, and concerns before and after ostomy surgery vary. All feelings are normal and okay. Coping is easier with support from other parents and from hospital staff who have experience with children who have ostomies.

After surgery, your child needs support. Your smiles and the warmth of your touch will help relax your child in this unfamiliar situation. Being patient, supportive and involved from the beginning will also help your child adjust to having an ostomy.

This booklet was designed to help answer some of the most frequently asked questions you may have regarding your child's ostomy care.

At Coloplast, we are dedicated to improving the quality of life for people, big and small, with ostomies. This booklet is a starting point in helping you, your family and your child manage life with an ostomy.

Please note: The materials and resources presented are intended to be an educational resource and presented for general information purposes only. They are not intended to constitute medical advice or in any way replace the independent medical judgment of a trained and licensed health care professional with respect to any patient needs or circumstances. Each child's situation is unique and risks, outcomes, experience, and results may vary. Talk to your healthcare professional about what may be right for your child. Please refer to product 'Instructions for Use' for intended use and relevant safety information.

## The digestive system

When food is swallowed or given by a G-tube or NG tube, it passes through a long narrow tube (esophagus) into the stomach. In the stomach, digestive juices help break down the food before it is passed into the small intestine. The small intestine has three segments: duodenum, jejunum, and ileum. Nutrients needed by your child are absorbed from the food in the small intestine. This is why the small intestine is important. Later, your child's digested food is passed into the large intestine (colon), where water is absorbed and stool becomes more formed. The stool is stored in the rectum and leaves the body through the anus.

The part of the intestine you see on your child's abdomen is called the stoma or ostomy. The stoma is where the stool will now pass from your child's body.

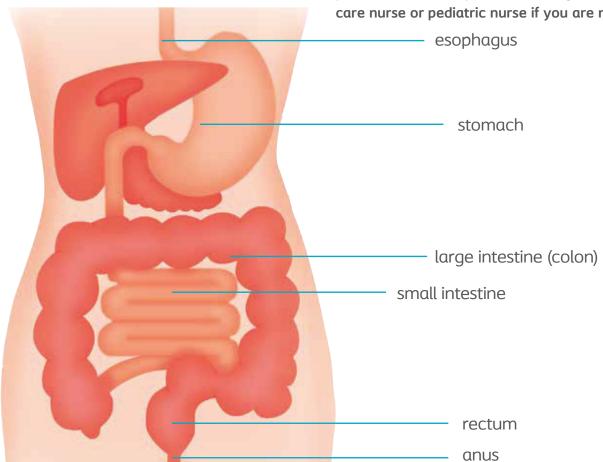
A stoma looks and feels like the inside of your mouth. The stoma is soft, moist and red in color.

Every stoma is different. Stomas can sit at different levels on the skin. Some sit above the skin level, some sit level with the skin, and some stomas sit in a skin fold. Stomas also come in different shapes, sizes, and locations.

There are no nerve endings in the stoma, so the stoma will not hurt when it is touched. It is normal for the stoma to be swollen after surgery. It will usually shrink to a smaller size within 6 – 8 weeks. The diameter of the stoma will grow with your child. You may see the stoma moving slightly at times, appearing slightly longer and wider when this happens. This process helps move the stool through the intestine.

When your child is crying, the stoma may discolor temporarily. Once your child stops crying, the color will return to normal.

Note: It is important to know what type of ostomy your child has. Ask your child's surgeon, stoma care nurse or pediatric nurse if you are not sure.



## **Ileostomy**

If your child has a surgically created opening between the small intestine and abdominal wall, it is a duodenostomy, jejunostomy or ileostomy, depending on what part of the small intestine was involved in the surgery. Your surgeon, stoma care nurse or pediatric nurse can help you understand both the type and reason for your child's ostomy surgery.

A common ostomy surgery involving the small intestine is an ileostomy.

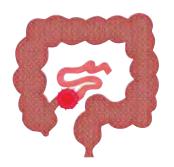
During an ileostomy surgery, the end of the small intestine is brought through the abdominal wall. The part of the intestine you see on your child's abdomen is called the stoma or ostomy. The stoma is where the stool will now pass from your child's body. Depending on the surgical procedure your child has, your child may have one, or more than one, stoma.

Ask your surgeon, stoma care nurse or pediatric nurse to explain how your child's stoma was made during surgery.

Ileostomies can be temporary or permanent. When your child's ostomy is temporary, the small intestine is eventually reconnected and the stoma is closed. When your child's ostomy is permanent, the small intestine is not reconnected, making the stoma permanent.

With an ileostomy, your child will not be able to control when the stool or gas comes out of the stoma. Therefore, your child will wear a pouching system to collect the stool and gas.

#### Types of ileostomies



**End ileostomy** 



Loop ileostomy

#### **Ileostomy (cont.)**

An ileostomy typically begins to function about 1-3 days after surgery. The first output will be mostly gas followed by stool. You may also see some blood in the first output. As your child begins to eat more foods, the stool will vary from a thick liquid to pasty consistency like oatmeal. The consistency of the stool will depend on your child's diet.

This consistency is more liquid to pasty because less water is being absorbed from the stool. The thickness and frequency of the stool will be affected by the location of the stoma in the small intestine.

Stool from an ileostomy contains enzymes that are irritating to the skin around the stoma. This area is called the peristomal skin. Your child's stoma care nurse or pediatric nurse will instruct you on ways to protect the peristomal skin from these irritating enzymes.

With a correctly fitted pouching system and clean peristomal skin, irritation can be minimized. If you have concerns about any irritation of the peristomal skin, contact your child's physician, stoma care nurse or pediatric nurse.

Even with an ileostomy, your child may still have their rectum in place and they may feel the need to have a bowel movement from the rectum. This sensation occurs because the intestine continues to produce mucus, which may pass from the rectum. They can also have mucous or old stool pass rectally, this could happen weeks after the ostomy was created.



## Colostomy

If your child has a surgically created opening between the large intestine (colon and abdominal wall), it is called a colostomy. Your surgeon, stoma care nurse or pediatric nurse can help you understand both the type and reason for your child's colostomy surgery.

During colostomy surgery, the end of the large intestine is brought through the abdominal wall. The part of the intestine you see on your child's abdomen is called the stoma or ostomy. The stoma is where the stool will now pass from your child's body. Depending on the surgical procedure your child has, your child may have one, or more than one, stoma. Ask your surgeon, stoma care nurse or pediatric nurse to explain how your child's stoma was created during surgery.

Colostomies can be temporary or permanent. When your child's ostomy is temporary, the large intestine is eventually reconnected and the stoma is closed. When your child's ostomy is permanent, the large intestine is not reconnected.

With a colostomy, your child will not be able to control when the stool or gas comes out of the stoma. Therefore, your child will wear a pouching system to collect the stool and gas.

#### Types of colostomies



End colostomy



Loop colostomy

### Colostomy (cont.)

A colostomy usually begins to function about 1-3 days after surgery. The first output may be mostly gas and liquid stool. Within the next few weeks, the stool may thicken to a pasty to almost-formed stool. The thickness of the stool will be affected by the location of the stoma in the colon. The closer the stoma is to the end of the colon, the more liquid is absorbed from the stool and the thicker the stool will be.

Stool from the colostomy can be irritating to the skin around the stoma. This area is called the peristomal skin. Your child's stoma care nurse or pediatric nurse will instruct you on ways to protect the peristomal skin. Irritation can be minimized with a correctly fitted pouch and clean peristomal skin. If you have concerns

about any irritation of the peristomal skin, contact your child's physician, stoma care nurse or pediatric nurse.

Even with a colostomy, your child may still have his/her rectum in place and they may feel the need to have a bowel movement. This sensation occurs because the intestine continues to produce mucus, which may pass from the rectum. They can also have mucous or old stool pass rectally, this could happen weeks after the ostomy was created.

Infant: If the stool from the colostomy is thick and infrequent, some parents use a diaper instead of a pouch.





## After surgery - ileostomy / colostomy

After surgery, your child may be wearing an ostomy pouching system. The pouch may be transparent (clear) so the doctors and nurses can look at your child's new stoma. Sometimes, only a piece of gauze will cover the stoma until the stoma begins to excrete stool and gas. After this happens, a pouching system will be applied to collect the stool and gas.

During the first few days, your child will only be given fluids to drink. Food will slowly be added to their diet as intestinal function returns to normal. For babies on breast milk or formula, the stool may be light yellow and seedy-looking. After surgery, when your child has any

discomfort, a medication can be prescribed to help your child feel more comfortable. If your child experiences discomfort, be sure to bring this to the nurse's attention so appropriate treatment can be given. Being comfortable allows your child to move around and do post-surgical activities that speed up the healing process.

## Diet and nutrition - ileostomy / colostomy

Your child should be able to eat the same foods as other children, unless the doctor or dietician prescribes a special diet.

#### Gas and Odor

Certain foods may need to be avoided because they may cause gas or odor. Gas can also be caused by swallowing air.

## Gas causing foods include:

- Broccoli
- Cabbage
- Beans
- Onions
- Brussel Sprouts
- Cucumbers
- Eggs

## Odour causing foods include:

- Eggs
- Fish
- Garlic
- Beans
- Turnips
- Mushrooms
- Cabbage family

#### Food Blockage

Some foods are hard to digest and cause a blockage just before the food exits the stoma. Drinking plenty of fluids and chewing food well can prevent this from happening.

#### Foods that can cause blockage include:

- Celery
- Citrus fruits
- Dried fruits (raisins)
- Popcorn
- · Raw fruits and vegetables
- Nuts, seeds in fruits and vegetables
- Meats with casings (hot dogs, bologna)

#### Tips to Prevent Food Blockage:

- Make sure your child chews their food well.
   Cut food into small pieces for younger children.
- Make sure your child drinks plenty of fluids to flush food through the intestine.
- Omit foods that can cause cramping or diarrhea.
- Do not feed your child high fiber foods until approved by their doctor.
- · Add fiber foods one at a time.

#### Signs of Food Blockage:

- Cramping
- Abdominal pain
- Swollen stoma and abdomen
- Watery or NO stool

Call your doctor or go to the hospital if you feel your child has a blockage.

Trust your own judgment when deciding if your child needs medical attention. You know your child best.

Hydration is important! General fluid requirements are: 4 mL/kg/hour for the first 10 kg of body weight +2mL/kg/hour for the next 10 kg of body weight +1mL/kg/hour for each kilogram over 20 kg of body weight.<sup>1,2</sup> For example: If a child weighs 25 kg, they will require 65 mL/hour or 1560 mL/24 hours of fluid. Consult your health care professional regarding fluid requirements for your child.

Some children may have to limit or increase fluid intake due to a medical problem so consult your healthcare provider to discuss fluid requirements for your child. \*Be sure your child drinks extra fluids when exercising or sweating.

#### Dehydration

Dehydration is excessive loss of water. A child can quickly become dehydrated from diarrhea, sweating or vomiting.

Symptoms of Dehydration:

- Dry lips
- Dark urine
- Dry mouth
- Sunken eyes
- Decreased urine
- Sunken fontanelles
- Crying with no tears
- Increased sleepiness

\*If your child displays these symptoms, report them to your child's doctor immediately or go to the hospital.

<sup>\*</sup> Recommendation follows that of CHOC Children's Hospital, affiliated with UC Irvine, https://www.choc.org/programs-services/urology/how-much-water-should-my-child-drink/

<sup>1.</sup> Somers MJ, Endom EE. (2008, May 30). Maintenance fluid therapy in children. (http://www.utdol.com) UptoDate Online 16.3. Maintenance Water Needs section.

<sup>2.</sup> Government of Canada. (2013). Pediatric and Adolescent Care- Chpater 4 - Fluid Management. Retrieved from: https://www.canada.ca/en/indigenous-services-canada/services/first-nations-inuit-health/health-care-services/nursing/clinical-practice-guidelines-nurses-primary-care/pediatric-adolescent-care/chapter-4-fluid-management.html#tbl-1



#### Diarrhea

Diarrhea is the frequent passage of loose, watery stool (more than usual). This can lead to dehydration very quickly. Bacterial or viral infections, diseases, foods, or medications can cause diarrhea. If your child has any symptoms of dehydration, contact your child's doctor.

#### Foods that thicken stool (B.R.A.T. Diet):

- Bananas
- Rice
- Applesauce
- Toast

Snacks that can thicken stool include marshmallows, potato chips, and pretzels

Please contact your physician if you are concerned about dehydration, as children can become dehydrated very quickly. Typically medicine to stop diarrhea is not recommended.

Have your child drink one glass of fluid each time the pouch is emptied.

Encourage plenty of fluids and foods that replace sodium and potassium, such as diluted sports drinks, broth and crackers. Be careful as highly sugared drinks can increase diarrhea.

#### Constipation

Constipation is when the stool is hard or dry, there is a decrease in the number of stools, or your child has difficulty passing stool. Include fruit juices, soft fruits and vegetables to keep stool soft. Notify your child's doctor if constipation continues.

Infant: Infants swallow air when sucking or crying. Gas may need to be released from the pouch more often than stool.

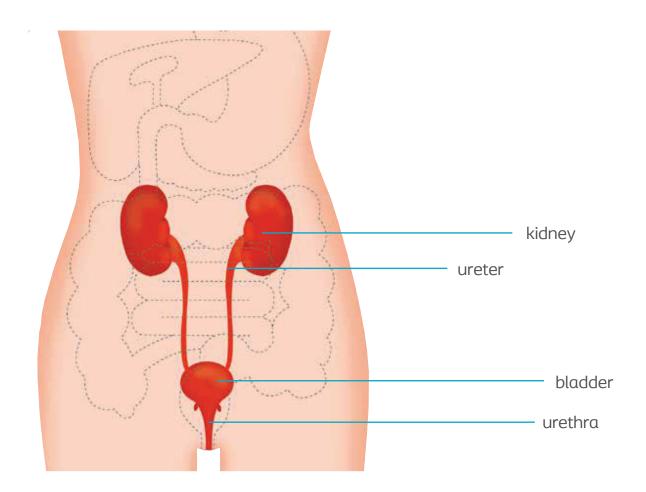
Pre-school and school-age: Air can be swallowed when your child drinks from a straw, drinks carbonated beverages, chews gum or eats quickly.

## Normal urinary function

Looking at how urine is made and passed from the body will help you understand what is involved in your child's operation.

Urine is made by the kidneys and travels through two tubes (ureters) to the bladder. The urine is stored here before passing out of the body through the urethra.

If a problem occurs within the bladder or urinary tract, this process may be changed, leading to the bladder being removed from the body and having to find a new system for urine to be passed from the body.



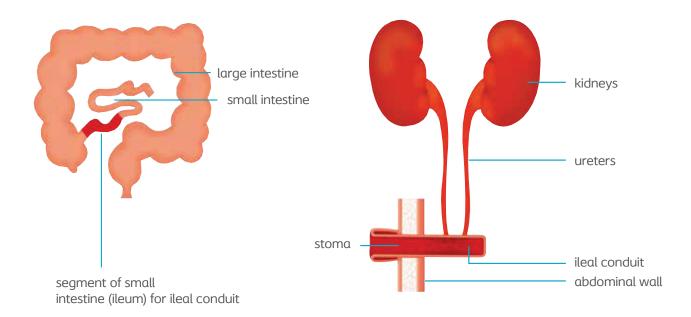
## **Urostomy**

#### What is a urostomy?

During a commonly performed urostomy surgery, called an ileal conduit, the surgeon removes a small piece of your child's small intestine (ileum) and makes it into a conduit (or pipeline) for urine. The remainder of the small intestine is reconnected so your child's bowel will function as it did before surgery. The ureters (tiny tubes that carry urine from each kidney to the bladder) are detached from the bladder and joined instead to the piece of ileum.

One end of the piece of ileum that was removed is sewn closed, and the other end is brought through the abdominal wall. This part of ileum is then folded over like a sock and stitched in place to create an opening on your child's belly called a stoma. The stoma opening may stick out from the abdomen about 1 inch above skin level, but the opening may be flush with your child's skin or slightly below skin level. This is where urine will now drain from your child's body into a disposable pouching system that sticks to your child's skin.

A healthy stoma is moist, and red or pink in color. The stoma has no nerve endings, so it will not hurt when touched. It is normal for the stoma to be large and swollen after surgery, however, it will shrink to a smaller size within a few weeks. You may see the stoma move slightly. This is a normal



#### What is a urostomy? (cont.)

process that had helped push stool through your child's small intestine and now helps drain urine out and into the pouching system on your child's belly.

Just like your gums bleed when brushing your teeth, the stoma may also bleed slightly. However, if your child's urine is cloudy, foul-smelling, bloody, or your child experiences constant bleeding, contact your doctor immediately.

Urine flow will no longer be controlled since the stoma does not contain muscles to stop the flow of urine. Urine will generally drain constantly since the conduit (or pipeline does not replace the bladder or store urine. A pouching system must be worn at all times to collect urine.

Urostomy surgery is performed to cure or alleviate symptoms of a disease. Your child's surgeon or stoma care nurse will explain the type of surgery your child has.





## After surgery - urostomy

When your child wakes up from surgery, he/she will be wearing his/her first pouching system. The pouch will be transparent (clear) so the doctors and nurses can check on the new stoma.

There may be small tubes (stents) placed into your child's stoma during surgery to help keep the ureters open to drain urine. These stents may be removed while your child is in the hospital, or may remain in place for a few

weeks after surgery. Your child's stoma care nurse should show you how to handle applying a pouch around the stents if they are still in place when your child is ready to go home.

In the beginning, your child's urine may be a little red or pink, however it should return to its normal (clear, yellow) color. The piece of small intestine used to create the stoma may still produce some mucus - so it is also perfectly normal to find mucus in the urine.

## Diet and nutrition - urostomy

#### Diet

Eating a well-balanced diet that can include your child's favorite foods is important to his/ her health. Be aware that some foods cause an odor in urine including:

- asparagus
- fish
- onions
- garlic

These foods can still be eaten. However, you may become aware of an unusual odor.

Hydration is important! General fluid requirements are: 4 mL/kg/hour for the first 10 kg of body weight +2mL/kg/hour for the next 10 kg of body weight +1mL/kg/hour for each kilogram over 20 kg of body weight.1,2 For example: If a child weighs 25 kg, they will require 65 mL/hour or 1560 mL/24 hours of fluid. Consult your health care professional regarding fluid requirements for your child.

Some children may have to limit or increase fluid intake due to a medical problem so consult your healthcare provider to discuss fluid requirements for your child. \*Be sure your child drinks extra fluids when exercising or sweating.

#### **Urinary Tract Infections (UTIs**

UTIs can occur with a urostomy. Signs and symptoms of a urinary tract infection include:

- · increased amount of mucus in the urine
- · cloudy and strong-smelling urine
- fever
- confusion
- loss of appetite
- back pain
- · nausea and vomiting
- blood in urine

# If you experience these symptoms, contact your physician.



<sup>\*</sup> Recommendation follows that of CHOC Children's Hospital, affiliated with UC Irvine, https://www.choc.org/programs-services/urology/how-much-water-should-my-child-drink/

## Types of pouching systems

Ostomy pouches are available in many different styles and sizes. Your child's stoma care nurse or pediatric nurse can help choose the pouching system that suits your child best at different stages in your child's life. There are one-piece and two-piece ostomy pouching systems.

#### **Baby pouching systems**

#### Baby pouch

A small pouching system designed to gently adhere to a baby's delicate skin.

(Pictured: SenSura® Mio Baby 2-piece pouch and barrier)



#### Toddler / pre-school pouching systems

2-piece drainable system
A 2-piece pouching system
enables you or your child to
change the pouch more
frequently (if desired) than
the barrier.

(Pictured: SenSura® Mio Kids Flex 2-piece drainable pouch and barrier)

#### 1-piece drainable system

A 1-piece pouching system refers to a system where the pouch and barrier come as a single unit. (Pictured: SenSura® Mio Kids 1-piece drainable pouch)



#### Spout outlet

Available in 1-piece and 2-piece options, this is a drainable pouch designed for urostomies.

The pouch can



be connected to a drainage bag overnight to manage large amounts of urine, e.g. while they sleeps.

(Pictured: SenSura® Mio Kids 1-piece urostomy pouch and SenSura® Mio Kids Flex 2-piece urostomy pouch and barrier)

#### School-age to adult pouching systems

Older kids have access to the full adult range, which includes a number of larger options of the same types of pouching systems, plus new options including:

#### Convexity

A stoma that doesn't stick out from the abdomen, or which has lots of creases and folds around it, may need extra support to reduce leakage. In these cases, a rounded shape – "convexity" – may be suggested – either created with accessories or built-in to the product.

(Pictured: SenSura® Mio Convex 1-piece drainable pouch)

#### Closed system

A "closed" or "closed-end" system refers to a system where the pouch is removed and thrown away instead of emptying. It is available in 1- or 2-piece options. (Pictured: SenSura® Mio Click 2-piece closed pouch and barrier)

Please note that you may come across different terms referring to the same parts of an ostomy appliance. For instance:

- A barrier may be referred to as a flange, baseplate or a wafer.
- A pouch may be referred to as a bag.
- A drainable pouch can also be referred to as an open pouch.

It is important that the pouching system fits your child's stoma size, body size, and the amount of output coming from the stoma. Remember to measure the stoma frequently for the best fit. Just as children can outgrow their clothing, they can also outgrow their pouching system.



## **Emptying the pouch**

You or your child should empty the pouch when it is 1/3 full of urine or stool, or whenever you change your child's diaper. A full pouch is more difficult to empty and can become heavy and pull loose from the skin.

For colostomies and ileostomies: In between emptying the pouch, it may inflate with gas. If this happens, you may press gently on the pouch to accelerate airflow through the filter.

#### Steps:

- 1. Empty the drainable pouch (or throw away a closed pouch) when it is 1/3 full of stool or urine.
- 2. Hold the end of the pouch up before opening the closure.

For a drainable pouch: unfasten the VELCRO® Brand tabs and unroll the closure. Lower the outlet toward the toilet and smooth the contents toward the outlet to empty.

For a urostomy pouch: pinch the end (like you would the nozzle on a beach ball), unplug the outlet, then direct the outlet toward the toilet. Unpinch to drain.

3. After emptying, wipe the end of the pouch with toilet tissue or a baby wipe.

4. Close the pouch.

and replacing the plug.

Colostomy / ileostomy: by rolling up the drainable outlet and refastening the VELCRO® Brand tabs.

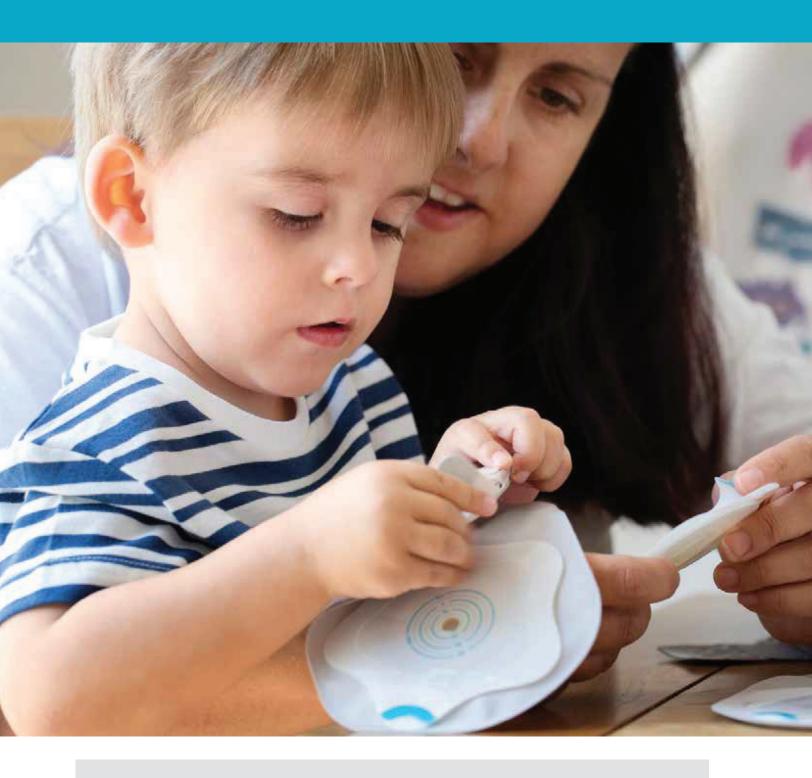
Urostomy: by pinching the outlet closed

- 5. If using a 2-piece pouch, you can replace the soiled pouch with a new one without replacing the barrier every time.
- 6. Wash your hands and your child's hands if they were involved in emptying the pouch.

NOTE: Never flush a pouch or baby wipes down the toilet. It will clog your plumbing system.

Having your child help with emptying the pouch will promote self-confidence.

Please refer to product labeling for complete product instructions for use, contraindications, warnings, precautions and adverse events.



Infant: Empty the pouch into an extra diaper, then throw it away.

**Pre-school and school-age:** Your child can sit on the toilet and place the end of the pouch between their legs. Place toilet paper on top of the toilet water to prevent splashing.

**NOTE:** Empty the pouch before your child naps to help avoid leakage. Your child can sleep in any position that is comfortable.

## Changing the pouch

Plan a regular time to change the pouching system. Do not wait for it to leak. If your child feels burning, itching or is picking at the barrier, there may be a leak. Always check the skin around the stoma (peristomal skin) for skin irritation (similar to diaper rash). If skin irritation occurs, contact your stoma care nurse - but in the meantime, DO NOT apply creams or ointments to your child's skin (unless your stoma care nurse directs otherwise) as this will cause the pouching system to not adhere. The best time to change the pouch is when the stoma is less active (before your child eats or drinks in the morning).

#### Steps:

- 1. Gather all supplies:
  - Pouching system (if using a 2-piece, be sure you have both the pouch and barrier)
     Soft cloth (paper towel or wash cloth and warm water)
  - Stoma measuring guide, pen and scissors
  - · Plastic bag for trash
  - Pouching accessories, if using (i.e. protective ring, ostomy powder)

Your stoma care nurse or pediatric nurse will help you decide if additional items will be needed.

- 2. Gently remove the pouch from the skin using the push-pull technique.
  - Never rip or tear the pouch when removing. This can injure your child's skin. Use an adhesive remover if required.
- 3. Use the plastic bag to throw away the soiled pouch.
- 4. Clean the stoma and the skin around the stoma with a soft cloth and warm water. Do not be alarmed if you see slight bleeding from the stoma this is normal.
- Check the skin for any redness or irritation. If you see a rash or have concerns, call your child's stoma care nurse or doctor immediately.

- 6. Measure the stoma using the stoma measuring guide.
- 7. Trace the measurement onto the back of the barrier.
- 8. Cut the opening to match the pattern.

Check to make sure the hole you cut fits your stoma exactly, without squeezing your stoma or leaving loose gaps. This will help prevent output from the stoma from touching your child's skin and causing irritation.

- 9. Warm the barrier between your hands.
- 10. If the stoma becomes active, wait for the stoma to take a break and then proceed. Re-cleanse the skin if it becomes wet or soiled.
- 11. Remove the backing from the barrier.
- 12. Apply the new barrier by centering the opening over the stoma. Gently press in place, smoothing your fingers around the stoma and then outward toward the edges. Hold the full barrier in place with your hands for a minute or two.
- 13. Close the pouch outlet.
- 14. Wash your hands.

Do not use baby wipes or soaps with moisturizers to clean around the stoma; they will prevent the barrier from sticking to the skin and leave residues.

Warming the barrier can be the key to successful barrier adhesion. Place the barrier against your skin to warm the barrier while you gather the supplies. You can have your child help by asking them to warm the barrier.

Naming the stoma is not uncommon and can help your child adapt to living with an ostomy. Some children have a stuffed bunny or other toy that has a stoma. It is also common to have your child put an ostomy pouch on a stuffed bunny.

Coloplast offers a complimentary stuffed bunny with a stoma as a teaching tool for babies and kids with a stoma\*

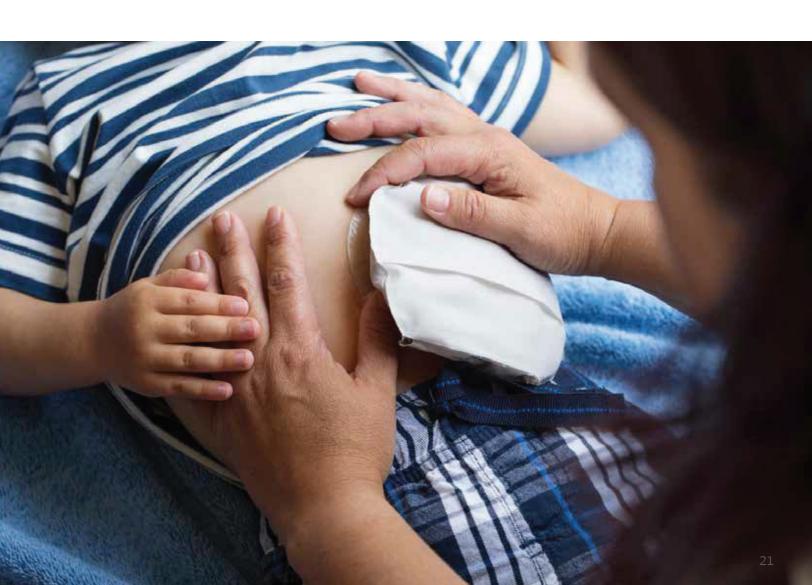


**Infant:** Distract your infant when changing the pouch. Using a mobile, a toy with music, or a pacifier to soothe can be helpful.

Pre-school and school-age: As your child grows, teach them simple tasks such as gathering supplies and warming the barrier. This will encourage acceptance and increase comfort and security with their ostomy.

Your child may surprise you by what they can do, some 2-3 year olds can empty the pouch (and sometimes will even empty in the toilet) and some 4-6 year old's have been able to change the pouch.

\*Coloplast offers a training bunny complimentary for product education use with both Sensura® Mio Baby & Kids. Contact your stoma care nurse for more information. Limitations apply; the Sensura® Mio bunny is provided for teaching purposes only, and should be used only with Coloplast products.



## Going home

Taking your child home from the hospital is an exciting, as well as apprehensive time. You may have questions concerning supplies, diet and nutrition, medications, activities, bathing, clothing, and travel. We will try to answer some of these questions to facilitate a smooth transition home.

#### **Supplies**

Before leaving the hospital your stoma care nurse or pediatric nurse will provide you with information on how to obtain ostomy supplies, along with written documentation from your doctor.



#### Parent's Supply Checklist:

- ☐ Barriers / pouches
- ☐ Stoma measuring guide
- ☐ Pen / marker
- ☐ Scissors
- ☐ Soft wipes (can use moistened paper towels in a zip-lock baggie)
- ☐ Plastic disposal bag
- ☐ Accessory items (only if needed)
  - Protective seal
  - Adhesive remover
  - Ostomy powder
  - Belt or Brava® Elastic Barrier Strips
  - Pouch deodorant
  - Skin barrier

Re-order pouching system when you open the last box. Re-measure the stoma before ordering to make sure your child's pouch is still an accurate fit.

Store your supplies in a cool, dark place (do not carry them in the trunk or glove box of the car; heat can damage the adhesive barrier, causing it to not stick properly).

Infant: Keep all supplies needed for a complete pouching system change with you at all times. Pack a diaper bag including ostomy supplies.

Pre-school and school-age: Keep extra supplies, clothes, and written instructions at the daycare, school, grandparent's home and places you visit frequently.

## At home

#### Medications

Let your pharmacist know your child has an ostomy. Your child's medicine may need to be in liquid or chewable form, so it can be absorbed. If you notice pills in your child's stool or pouch, notify your child's doctor or pharmacist. Only give medications prescribed by your doctor, including vitamins. Carry a list with you when visiting your doctor or hospital.

#### Activity

Many parents wonder if activities will be limited because their child has an ostomy. Your child should be able to participate in all of his/her activities as long as the stoma is protected from injury. Follow your doctor's recommendations for your child. Protective belts are available online for contact sports.

#### **Toilet Training**

Teach your child to empty the pouch into the toilet when preparing for toilet training. Common phrases like 'let's go potty' can be used when it is time to empty or change the pouch.

#### **Bathing**

Bathing will not hurt the stoma. Therefore, your child can bathe with the pouch on or off. If you choose to keep the pouch on, you may wish to "picture frame" the edges of the barrier with waterproof adhesives or Brava® Elastic Barrier Strips.

Choose a soap that is free of oil, residue and fragrance. Soaps containing moisturizers, oils and deodorants, most bubble baths, as well as some brands of baby wipes containing lanolin, will leave a film on the skin that interferes with barrier adherence.

#### Clothing

Your child should not have to wear special clothes because of their ostomy. Pouches are lightweight and may not be seen under clothing. Most children tuck the pouch into their undergarments. Empty the pouch when it is 1/3 full. (An emptier pouch is less noticeable.)

One-piece outfits can prevent unplanned pouch removal. Examples include "onesies" and overalls. If the stoma is above the beltline, use a soft layer of clothing next to the body (to keep the pouch secure) as well as a loose outer shirt.

Infant: Babies are very active and curious. Your child's ostomy will not slow them down. As your baby's curiosity and activity increases, he/she may pull off the pouch or get it caught under a knee when crawling.

**Pre-school**: Toddlers are very curious and enjoy exploring their body. They may also enjoy pulling off their pouch.

# **Continuing care**

To be completed by stoma care nurse

After surgery, it is important that your child begins enjoying life as quickly as possible. Your child's physician or stoma care nurse is available to help you with any problems or questions. Organizations are also in place to provide information and support for you and your child. Ask your child's stoma care nurse or pediatric nurse for information about local groups and chapters.

Nursa		Phone:			
Surgeon:					
		Type of Stoma:			
Date of Surgery:		Stoma Size:			
Coloplast ostomy products given upon discharge:					
Product Code	Description				
This information should be used at your pharmacy:  Ostomy product supplier:		om your ostomy supplier; you may need a prescription			
Phone:					
Address:					
Coloplast Consumer Care Specialist 1-866-293-6349  Notes:					



Pictures courtesy of Ostomy Canada Society. Used with permission.

## Ostomy Youth Camp

The Ostomy Canada Youth Camp provides an opportunity for children between the ages of 9 and 18, from across Canada who have had or will have bowel or bladder diversionary surgery (such as an ostomy) or who have related special needs (i.e. self catheterization, bowel and bladder incontinence, internal pouch, cecostomy tube, mitrofanoff), due to birth defects, trauma or disease (IBD, Cancer, Spina Bifida etc.) to attend camp and participate in camp activities under professional supervision.

Camp takes place for six (6) days each summer in the beautiful foothills of the Rocky Mountains in southern Alberta. Activities include arts and crafts, swimming, rafting, archery, outdoor education and both formal and informal education sessions. Camp mentors and specialized nurses encourage independence and self-confidence with personal care and camp activities. Additionally, camp can provide individual mentorship on stoma care and ostomy related needs (physical and psychosocial).

No child is ever denied the opportunity to attend camp due to financial limitations, and full or partial sponsorship is available.

For camp information & application forms, please contact Ostomy Canada Society Inc.

Email: info1@ostomycanada.ca www.ostomycanada.ca/camp

## Resources

Use the contact information below to find a support group most suitable for you.

Ostomy Canada Society is a non-profit volunteer organization dedicated to all people with an ostomy, and their families, helping them to life to the fullest through support, education collaboration and advocacy.

#### **Ostomy Canada Society**

5800 Ambler Dr., Suite 210 Mississauga, ON L4W 4J4 1-888-969-9698 www.ostomycanada.ca

#### Nurses Specialized in Wound, Ostomy and Continence (NSWOC)

1-888-739-5072 office@nswoc.ca

#### **Ostomy Canada Youth Camp**

A summer camp for young people, between the ages of 9 and 18, with an ostomy or related special needs.

www.ostomycanada.ca/camp

#### Crohn's and Colitis Canada

www.crohnsandcolitis.ca

#### International Foundation for Gastrointestinal Disorders

404-964-1799 www.iffgd.org

#### Spina Bifida and Hydrocephalus Association of Canada

1-800-565-9488 www.sbhac.ca



#### **Coloplast Consumer Care Advisor**

A team of dedicated, trained individuals prepared to answer a broad range of questions about Coloplast ostomy products.

Coloplast Consumer Care Advisors are available to assist you with questions regarding insurance coverage of ostomy supplies and locating product suppliers. They can also send samples\* to your home.

For further assistance, call 1-866-293-6349 or visit casupport@coloplast.com

\*Limitations apply

# Notes

Coloplast develops products and services that make life easier for people with very personal and private medical conditions. Working closely with the people who use our products, we create solutions that are sensitive to their special needs. We call this intimate healthcare.

Our business includes ostomy care, urology and continence care and wound and skin care. We operate globally and employ more than 12,000 people.

