Life After Your Child’s Ostomy
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Introduction

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. Children are very accepting, and after a relatively short period of time, they will become at ease with their 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.

This booklet is not meant to be a substitute for medical care. Always consult your child’s physician, WOC nurse or pediatric nurse for specific health care issues.

ColoKids™ indicates pediatric-focused product

Infant = 0-12 months

Pre-school (includes toddlers) = 1-5 years

School age = 6-10 years
When food is swallowed, 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 cheek. 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.

NOTE: When your child is crying, the stoma may discolor temporarily. Once your child stops crying, the color will return to normal.
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, WOC nurse or pediatric nurse can help you understand both the type and reason for your child’s ostomy surgery.

The most 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.

Ask your surgeon, WOC 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.

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 pouch to collect the stool and gas. Coloplast has odor-proof pouches with built-in filter systems for you to choose from to meet your child’s needs.

Types of Ileostomies

- Double Barrel Ileostomy
- End Ileostomy
Ileostomy (Cont.)

An ileostomy typically begins to function about 2-3 days after surgery. The first output will be mostly gas and yellow or green liquid stool. As your child begins to eat more foods, the stool will thicken to a “toothpaste” consistency that is light to medium-brown.

This is because less water is being absorbed from the stool compared to when your child’s entire intestine was intact. 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 WOC nurse or pediatric nurse will instruct you on ways to protect the peristomal skin from these irritating enzymes.

With a correctly fitted pouch and clean peristomal skin, irritation can be minimized. If you have concerns about any irritation of the peristomal skin, contact your child’s physician, WOC nurse or pediatric nurse.

Even with an ileostomy, your child may still have his/her 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.

Your surgeon or WOC nurse can explain your type of surgery.

*It is important to know what type of ostomy your child has. Ask your child’s surgeon, WOC nurse or pediatric nurse if you are not sure.*
Colostomy

If your child has a surgically created opening between the large intestine (colon) and abdominal wall, it is called a colostomy. Your surgeon, WOC 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. Ask your surgeon, WOC 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 pouch to collect the stool and gas. Coloplast has odor-proof pouches with built-in filter systems for you to choose from to meet your child’s needs.

Types of Colostomies

- End Colostomy
- Double Barrel Colostomy
A colostomy usually begins to function about 3-4 days after surgery. The first output may be mostly gas and liquid stool. Within the next few weeks, the stool may thicken to a soft-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 WOC 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, WOC 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.

It is important to know what type of ostomy your child has. Ask your child’s surgeon, WOC nurse or pediatric nurse if you are not sure.

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

Pre-school: Closed-end pouches work well when your child is at daycare or when emptying the pouch is inconvenient.

School age: Some children prefer to use closed-end pouches so they can throw them away rather than empty their pouch at school.
After surgery, your child may be wearing an ostomy pouch. The pouch may be 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 pouch 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 medications can be given. Your child will not be as frightened if discomfort is minimized. Being comfortable allows your child to move around and do post-surgical activities that speed up the healing process.
Pouch Selection

Ostomy pouches are available in many different styles and sizes. Your child’s WOC 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.

- **One-piece system**
  A one-piece ostomy system refers to a system where the pouch and barrier come as a single unit.
  *(Pictured: 1-piece drainable pouch with clamp)*

- **Two-piece system**
  A two-piece ostomy system has a separate pouch and barrier (these pieces attach to each other).
  *(Pictured: 2-piece drainable pouch and barrier with adhesive coupling and EasiClose™ closure)*

Coloplast offers drainable, closed-end (non-drainable), and spout pouches.

- **Drainable with Clamp**
  A pouch with a clamp or twist-tie to secure the outlet after emptying the pouch.
  *(Pictured: 2-piece drainable pouch with mechanical coupling and clamp)*

- **EasiClose™ Drainable**
  A pouch with an “integrated closure”. No clips or clamps are required due to the Velcro® secure tabs.
  *(Pictured: 2-piece drainable pouch and barrier with adhesive coupling and EasiClose™ closure)*

- **Closed-end**
  A pouch that is removed and thrown away instead of emptying.
  *(Pictured: 1-piece closed pouch)*

- **Spout**
  A drainable pouch that works well with urostomies or very liquid stool. The pouch can be connected to a drainage bag overnight to manage large amounts of urine or stool.
  *(Pictured: 1-piece urostomy pouch)*

It is important that the pouching system fits your child’s stoma size, body size, and the amount of stool 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 gas 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.

Steps:
1. **Empty the drainable pouch (or throw away a closed pouch) when it is 1/3 full (gas, stool or urine).**

2. **Hold the end of the pouch up before opening the closure.**

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

4. **Close the pouch using a clamp or the integrated closure.**

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 changing 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.

**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 tissue in the water to prevent splashing.

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

Plan a regular time to change the pouch. 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) for skin irritation (similar to diaper rash). 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:
   - Pouch and barrier (if using 2-piece)
   - Soft cloth (paper towel or wash cloth and warm water)
   - Stoma measuring guide, pen and scissors
   - Plastic bag for trash
   - Pouching accessories (i.e. paste, powder)
   Your WOC nurse or pediatric nurse will help you decide if additional items will be needed.

2. Gently remove the pouch from the skin. Never rip or tear the pouch when removing. This can injure your child's skin.

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.

5. Check the skin for any redness or irritation. If you see a rash or have concerns, call your child's WOC nurse or doctor.

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. Measure to fit the same size as the stoma. This will help prevent stool 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.

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

Warming the barrier can be the key to successful pouch adherence. 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.
12. **Apply the new barrier** by centering the opening over the stoma. Gently press in place.

13. Close the pouch outlet.

14. Wash your hands.

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

**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 him/her simple tasks such as gathering supplies and warming the barrier. This will encourage acceptance and increase comfort and security with

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**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 WOC 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:
- Pouches/barriers
- Stoma measuring guide
- Pen/marker
- Scissors
- Soft wipes (can use moistened paper towels in a zip-lock baggie)
- Plastic trash bag
- Accessory items (only if needed)
  - Moldable ring
  - Strip paste or tube paste
  - Ostomy powder
  - Belt or special tape
  - Pouch deodorant

Re-order pouches 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 of the car; heat can damage a pouch).

Diet and Nutrition

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.

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)
Infant:
Infants swallow air when sucking or crying. Gas may need to be released from the pouch more often than stool. Some pouches have built-in gas filters.

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

Tips to Prevent Food Blockage:
• Make sure your child chews his/her 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.

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
• 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.

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

Do not take diarrhea lightly, as children can become dehydrated very quickly. 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. Some pouches have built-in gas filters.

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

Toilet Training
Teach your child to empty the pouch into the toilet when preparing for toilet training. Common words 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 tape.

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

Clothing
Your child should not have to wear special clothes because of their ostomy. Pouches are lightweight and cannot 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

After surgery, it is important that your child begins enjoying life as quickly as possible. Your child’s physician or WOC 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 WOC nurse or pediatric nurse for information about local groups and chapters.

To be completed by WOC nurse

Nurse: ___________________________ Phone: ___________________________
Surgeon: ___________________________
Patient Name: ___________________________ Type of Stoma: ___________________________
Date of Surgery: ___________________________ Stoma Size: ___________________________
Physician Signature (if needed): ___________________________

Coloplast ostomy products given upon discharge:

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<tr>
<th>Product Code</th>
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This information should be used when obtaining product from your ostomy supplier; you may need a prescription at your pharmacy:

Ostomy product supplier: ___________________________
Phone: ___________________________
Address: ___________________________

Coloplast Consumer Care Specialist 1-888-726-7872

Notes:

__________________________________________
__________________________________________
__________________________________________
__________________________________________


Resources

The United Ostomy Associations of America (UOAA) is a nationwide organization whose aim is to provide information, advice and support to anyone who has, or is about to have an intestinal or urinary diversion and their caretakers. Numerous local chapters operate throughout the country, where meetings are held to share news and views with other members. The UOAA also has a Parents Discussion Board.

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

Wound, Ostomy, Continence Nurses Society
1-888-224-WOCN (9626)
www.wocn.org

United Ostomy Associations of America, Inc. (UOAA)
1-800-826-0826
www.uoaa.org

International Foundation for Functional Gastrointestinal Disorders
1-888-964-2001
www.aboutkidsgi.org

Spina Bifida Association of America
1-800-621-3141
www.sbaa.org

Pull-Thru Network
1-205-978-2930
www.pullthrunetwork.org

Coloplast Consumer Specialists
A team of dedicated, trained individuals prepared to answer a broad range of questions about Coloplast ostomy products, including the ColoKids™ one-piece and two-piece pouches.

Coloplast Consumer Specialists 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.

If you need further assistance, please call 1-888-726-7872 and ask for a Consumer Care Specialist. You can also visit our web site at: www.us.coloplast.com
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 7,000 people.