Ostomy: Care at Home

Guidelines for Patients and Families

In Partnership with Primary Children's Hospital
David started having health problems when he was eight years old. It took a year before he was diagnosed with Crohn’s disease. He had various treatments and he would often improve for a while, but then the Crohn’s would come back stronger than before.

The ups and downs of David’s health were hard. David became familiar with many of the staff and procedures at Primary Children’s Hospital. Everyone was positive and encouraging, which helped immensely. When he first started medical testing, David was terrified of being poked and had to be held by his dad, but now he can give blood and have IVs without a fuss.

After exhausting all other treatments, the team decided that it would help David to have an ileostomy. The doctors thought it would be temporary. They hoped that if they disconnected his colon the Crohn’s disease would subside and he would go into remission. David had the ileostomy for about two years before the team decided he would need surgery again and that the ileostomy would be permanent. It took a while to adjust to having an ileostomy, but David can now take care of his ostomy needs by himself.

David enjoys cooking and would like to be a real chef in the future. He also likes video games, camping and scouting activities. David will be fourteen soon and is doing great!
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Introduction

Your child’s condition requires an ostomy. An ostomy is created because your child’s digestive system is not working as it should. The doctor makes an ostomy by bringing part of the bowel through the abdominal wall so it forms a stoma on the outside of the abdomen. The stoma allows body waste (also called stool) to exit the body and collect in a pouch. The pouch is then emptied when it is full.

There are many different conditions or reasons for creating an ostomy. Some of these are Hirschsprung’s disease, imperforate anus, meconium ileus, necrotizing enterocolitis, pseudo-membranous enterocolitis, Crohn’s disease, and ulcerative colitis. Your doctor will discuss with you why an ostomy is necessary for your child. Ostomies can be permanent, but in infants and children they are often created as a temporary solution to a medical problem. This allows time for your child’s bowel to heal or grow before corrective surgery may be performed.

How will I learn to care for my child?

You may feel frightened and overwhelmed with your child’s need for an ostomy. After the surgery, you may also feel anxious about taking care of the ostomy at home. This is normal and many parents feel this way. To help you feel comfortable before you leave the hospital, a specially trained ostomy nurse, will teach you the step-by-step process for caring for the ostomy. We encourage you to practice caring for your child’s ostomy while you are still in the hospital. Do not hesitate to ask questions and get the information needed for you to comfortably care for your child’s ostomy.

What is the purpose of this booklet?

This booklet will help you remember what you learn in the hospital about your child’s ostomy. It’s a reference for when you go home. We start with an overview of normal digestion. Knowing about normal digestion will help you understand how an ostomy works and why stool consistency, skin care, and other daily cares are so important for your child. Then we explain details about an ostomy and instructions for care at home. The instructions in this booklet are intended as guidelines only. Your doctor may give other directions based on the needs of your child. Always follow your doctor’s instructions.
Normal digestion

Digestion is the breakdown of food into very small pieces for the body to use as energy. Digestion starts in the mouth with the chewing action of the teeth. Food particles are then swallowed down the esophagus into the stomach.

In the stomach, food particles mix with enzymes (digestive juices). Next, the food empties into the small intestine, also called the small bowel, where the food breaks down further. In the small bowel, the body begins to absorb nutrients. At the end of the small bowel, water and stool (waste material) pass into the large intestine which is also called the colon or large bowel. Mucus is produced throughout the bowel to help the stool move through it. The large bowel is where water is absorbed and the stool is stored until it is passes through the rectum and then exits the body through an opening called the anus.
Ostomy

If parts of the bowel don’t work correctly or become diseased, they may need to be rested or removed. In these cases a child may need an ostomy. An ostomy is a surgical opening in which part of the large or small bowel is brought to the outside of your child’s abdomen and is turned back on itself like a cuff. The part of the bowel you can see is called a stoma. The stoma allows waste to leave the body without going through the damaged part of the bowel.

Types of ostomies
There are two basic types of ostomies: ileostomy and colostomy.

Ileostomy
An ileostomy is an ostomy located in the small bowel. Stool here will be loose and watery. There is minimal odor, and gas may or may not be present.
Colostomy

A colostomy is an ostomy located in the large bowel or colon. A colostomy is called ascending, transverse, descending, or sigmoid, depending on the area of the large bowel where it is located. Stool gets firmer as it travels up, over, and back down in the large bowel. This means that what comes out of the stoma is different based on where the colostomy is.

- **Ascending colostomy:** An ascending colostomy is located in the part of the large bowel where stool travels up, or ascends. It is found on the right side of the abdomen. The stool will be loose or watery. Gas and odor are present.

- **Transverse colostomy:** A transverse colostomy is located in the middle section of the large bowel, where stool travels from the right side to the left side. It may be located anywhere in the middle section of the abdomen. The stool will be loose or soft, but not formed. Gas and odor will be present.

- **Descending colostomy:** A descending colostomy is located in the large bowel where stool travels down again, or descends. It is found on the left side of the abdomen. The stool will be formed and soft. Gas and odor will be present.

- **Sigmoid colostomy:** A sigmoid colostomy is located in the sigmoid section (the last section) of the large bowel. It is found on the left lower side of the abdomen. The stool will be formed and soft. Gas and odor will be present.
Stomases

A stoma is created during your child’s surgery. A stoma is the part of the bowel that you can see when it is brought through the surface of the abdomen.

Normal appearance of the stoma

The stoma should be pink or red and should be moist like the inside of your cheek. Stomas do not have nerve endings, so touching it is not painful for your child. You might notice that the stoma moves. This is normal and is called peristalsis. Peristalsis moves the stool through the bowel.

The stoma will be swollen for six to eight weeks after surgery. Over time, it will get smaller. The stoma may bleed easily. If the stoma has a large amount of bleeding, gently apply pressure to the area with a clean finger. If it does not stop within five minutes, call your child’s doctor.

Shortly after surgery, you may notice dark tissue around the stoma. This is normal and the dark tissue will come off. Usually this happens before your child goes home from the hospital. After the stoma heals, if it becomes black or dark purple in color, call your child’s doctor. This could be an emergency.

Everyone’s stoma is different. It is important to recognize the normal appearance of your child’s stoma. It may be flat, oval, or round. It may be large or small. Also, some stomas will be very large right after surgery, but will slowly become smaller over the first month or two. The opening through which waste drains is usually in the center of the stoma, but it could be somewhere else on the stoma.
Types of ileostomies and colostomies

There are several types of ileostomies and colostomies. The stoma will look different depending on the type of ostomy. The doctor will decide what type is best for your child.

End ostomy

An end ostomy is made by cutting the bowel in two pieces. One end of the bowel is brought to the abdomen and sewn in place making one stoma with one opening. The other end of the bowel is sewn closed and left inside your child.

Double-barrel ostomy

A double barrel ostomy is made by cutting the bowel and bringing both ends to the skin surface. This type of ostomy has two stomas and two openings. Stool comes from one stoma. Small amounts of mucus come from the other stoma. This stoma is called a mucus fistula.

Loop ostomy

A loop ostomy is made by bringing a loop of bowel above the skin surface. A plastic or rubber tube is placed under the loop of bowel to hold it above the skin level until the abdominal wall has healed. The tube will be removed after your child’s incision heals (five days to two weeks). The loop of bowel above the skin may have one or two openings.
Ostomy pouches

What is a pouching system?

A pouch (also called an appliance) is a small bag placed over the stoma that collects stool and helps prevent odor. Some pouches have an opening at the bottom used for emptying the stool. The skin barrier, also called a wafer, attaches to the pouch and protects the skin from waste that comes from the stoma. A pouching system includes both a pouch and a wafer. Your ostomy nurse will help you choose a pouching system that will work well for your child. Your child’s pouching system may also include tape (used to help the wafer stay in place) and stoma paste (used to fill in gaps and creases on the skin).

Types of pouching systems

There are many types and sizes of pouching systems available. They fall into two basic categories:

- A **one-piece pouching system** has a pouch that is connected to the wafer.
- A **two-piece pouching system** has a pouch that is separate from the wafer.

The type of pouch your child uses is determined by the size of your child, the size of the stoma, and where the stoma is located.

With many pouching systems, you have to cut the wafer to fit the stoma. The wafer and pouch must connect securely to prevent leaking and limit odor. The wafer will stay on better if the skin area around the stoma is flat. To further prevent leaking, you can use stoma paste. Stoma paste is used like caulk to fill in gaps and creases on the skin around the stoma.

There are two types of stoma paste:

- **Tube stoma paste** contains alcohol and may sting if placed directly on red or tender skin. To apply tube stoma paste, squeeze it into a syringe and push from the syringe onto a wafer. Keep the stoma paste open to air for 30 to 60 seconds before placing the wafer on the skin. This allows the alcohol to evaporate.
- To apply **strip and ring stoma paste**, pinch off a small amount and roll it into a thin rope. Then place the stoma paste at the base of the stoma and shape it like putty to make a tight fit. Strip and ring stoma paste do not contain alcohol and may be placed directly onto the skin.

*Keep in mind that stoma paste is not glue.* It should not be used to stick the wafer to the skin. Using stoma paste as glue can actually prevent the wafer from sticking well and make it painful to remove. This might require more frequent pouch changes and cause more skin irritation.
The basics: pouches and wafers

The pouch and wafer are the two basic supplies for caring for an ostomy. Together they prevent odor and protect the skin around the stoma. There are a few different types to choose from.

**The pouch** holds waste.
- A **drainable** pouch has an opening at the bottom. It can be emptied and re-used for 3 to 5 days.
- A **closed** pouch does not open at the bottom. It is thrown away after each use.

**The wafer** (also called the skin barrier) seals the pouch to the skin around the stoma.
- On a **one-piece** system, the wafer is already attached to the pouch. They seal to the skin at the same time.
- On a **two-piece** system, the wafer is placed on the skin and the pouch is attached afterwards.

Both one-piece and two-piece systems can be used with either drainable or closed pouches.
Emptying and cleaning the ostomy pouch

You will need to empty the pouch when it is ⅓ full of stool or air. You may also need to empty the pouch if it begins to pull away from the skin. If you allow stool or air to build up, the pouch will balloon and pull the wafer away from the skin. You should only notice odor when changing and emptying the pouch or if the pouch is leaking. If odor is a problem, odor reducers are available to put in the pouch.

In the hospital, your child’s nurse will wear gloves when emptying the pouch. At home, you don’t need gloves. Before you begin, gather your supplies. This includes a small container, a diaper or catheter tipped syringe to collect the stool, a bottle of water, and tissues.

A pouch can be emptied in a few different ways:

- You can drain the pouch using a syringe or small container, which you either throw away or empty into the toilet.
- You can drain a baby’s pouch into a diaper, which you then throw away.
- An older child can sit on the toilet and empty the pouch directly into the toilet. Placing a piece of toilet paper in the toilet before emptying the pouch will reduce the amount of splash back.

Helpful tips

- Attach the pouch so the opening points in the direction you want it to empty. For babies, you can position the pouch to the side so it is easy to empty into the diaper. Older children usually like the pouch angled between their legs, making it easier to empty when sitting on the toilet.
- Cut at least one extra pouch for emergency pouch changes.
- Always keep supplies for one pouch change with your child.
- There will be more stool output after your child has eaten. If possible, change the pouch before a meal.
- Distract young children with toys during a pouch change. Try hanging a mobile over the changing area.
- Be aware that products containing alcohol will sting when applied to irritated skin. Read the label of any unfamiliar product.

Benefits of proper ostomy care:

- Maintain normal bowel function
- Protect the skin from stool
- Control odor and maintain cleanliness
Emptying and cleaning

1. Hold the bottom of the pouch upward so the contents don’t spill out.

2. Undo the closure on the pouch. Open the pouch and make a cuff on the opening to keep it clean.

3. Slowly lower the end of the pouch and drain the contents into a container, a diaper, or the toilet. You may also withdraw the stool into a syringe.

4. If the stool is thick and won’t drain, squirt a small amount of room temperature tap water into the pouch. Shake it gently. Slide your fingers down the outside of the pouch to push the stool out.

5. Clean the pouch by pouring water into the pouch, swishing the water around and then removing it using a container, diaper or syringe.

6. Uncuff the end of the pouch, then use a tissue to clean the last 2 to 3 inches of the inside and outside of the pouch.

7. Press air out of the pouch and close the pouch.

8. If there is stool on the closure, clean it off before closing it to avoid any odor.

Keep the end of the pouch clean to minimize odor.
Empty the pouch. Then take it off by lifting the wafer while pushing the skin down and away from the wafer.

Next, clean the skin around the stoma with warm water and a soft cloth. Dry the skin well.

Check the stoma for any redness or sores.
Changing the pouch

4. Measure the stoma using the guide that comes with the wafers.

5. Trace the opening of the stoma onto the paper backing of the wafer.

6. Using scissors, cut the wafer \( \frac{1}{8} \) inch larger than the stoma. Run your finger around the cut rim of the wafer to smooth any rough edges. Place the wafer over the stoma to test the size and trim to fit, if needed.

7. Warm the wafer to help it stick better by placing it between your hands or under your child’s body.

8. Remove the paper backing from the wafer. Avoid touching the sticky side of the wafer. Apply the stoma paste to fill in skin creases or gaps. Place the wafer around the stoma. Make sure the stoma is not trapped between the wafer and the skin.

9. Press the wafer onto the skin, starting at the stoma and moving outward. Smooth out any wrinkles and make sure the wafer is secure. Use a cotton swab to press the inner edge of the wafer around the stoma.

10. If you are using a two piece system, attach the pouch to the wafer.

11. Secure the end of the pouch.

12. Place a warm pack over the pouching system to help the wafer stick.
Wear time

Wear time is the length of time between pouch changes. Wear time is different for every child. Premature infants and children who have new ostomies will have limited wear time because of the large amount of liquid stool. Over time, the amount of stool decreases and may become thicker. Normal wear time for infants with an established stoma is 2 to 3 days. Older children can go 3 to 5 days between pouch changes. Wear time is affected by how active your child is, how watery the stool is, and how often the pouch is emptied. Remember to empty the pouch when it is ⅓ full, otherwise the pouch gets heavier as it fills and will pull away from the skin.

If the pouch needs to be changed more than once a day, it may be best to remove the pouch and double diaper your child. To do this, first apply a diaper cream to the skin around the stoma. Then place a smaller diaper or an absorbent sanitary pad over the stoma. Secure it with a larger diaper or abdominal binder.

Skin care

Good skin care around the stoma includes keeping the skin clean and dry. Pouches that don’t fit well allow stool to leak onto the skin and can cause skin problems. The skin around your child’s stoma should look the same as the rest of the skin on his abdomen. It should not be red or sore.

Here are some recommendations to help keep the skin around the stoma healthy:

- Avoid using cleansers or moisturizers that contain oils, deodorants, or perfumes. These may irritate the skin and keep the wafer from sticking.
- When cleaning the skin, you don’t need to use soap. If you choose to use soap, make sure it is very mild and is rinsed completely off the skin.
- Use the right pouching system, the one recommended by your child’s ostomy team. You can avoid many skin problems, such as irritation or sores, simply by using the right pouching system.
- Check the wafer every day. Make sure it’s secure and not leaking. Leaking under the wafer can irritate your child’s skin.
- Check the skin around the stoma for redness with each pouch change or with any sign of leaking.
Daily care tips

Activity
Children with ostomies are just like other children and should not be treated differently. Children with ostomies can participate in most activities. Ask your child’s doctor before participation in contact sports. You may bathe your child with the pouch on or off. Water will not go into the stoma. Your child may go swimming but should always wear a closed pouch. Special tapes and products help keep the pouch in place while swimming.

Medicine
Some medicines are absorbed in the bowel. Depending on where your child’s ostomy is, these medicines may not be absorbed and will pass through the stoma into your child’s pouch. Make sure your child’s doctor orders medicines that can be absorbed in the stomach or above your child’s ostomy.

Clothing
One-piece clothing is often best for infants and young children with an ostomy. This type of clothing hides the pouch and prevents your child from pulling it off. To avoid irritating the stoma, do not use clothing with elastic or belts that run across the stoma.
Eating to Stay Healthy

Children with ostomies do not need a special diet, but they may need a few precautions. Because food does not go all the way through the bowel, some of it does not get completely digested. Foods that may cause problems are those with casings, such as hot dogs and sausage, and those that are high in fiber, such as raw fruits and vegetables, dried fruits, nuts, popcorn, and beans. In an ileostomy, these types of foods can cause a blockage if not chewed well. Other foods can change the consistency of the stool.

Eventually, your child will probably be able to return to a normal diet that includes the vitamins and nutrients your child needs to stay healthy. At first, though, your child should follow the tips below.

- **Chew foods well.** This helps your child digest foods more easily.
- **Be sure to drink something with every meal.** This helps food pass through the intestines more easily. Encourage appropriate adequate fluid intake for your child’s age (e.g. 8 to 10 glasses a day for a school-aged child)
- **Eat 4 to 6 smaller meals per day.** Eat the largest meal at noon and a small meal in the evening. This will help reduce stool output at night.
Eating to prevent food-related problems

Before surgery, the foods your child ate affected the amount of gas and odor he produced. Foods also affected whether he had constipation or diarrhea. With an ostomy, it’s especially important to control these things. Learning the way different foods affect your child will improve his experience with an ostomy.

The table below has suggestions on how to help your child avoid specific digestive problems.

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>YOUR CHILD SHOULD:</th>
<th>YOUR CHILD SHOULD AVOID:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gas</td>
<td>• Eat slowly.</td>
<td>• Skipping meals.</td>
</tr>
<tr>
<td></td>
<td>• Chew with mouth closed.</td>
<td>• Drinking through straws.</td>
</tr>
<tr>
<td></td>
<td>• Talk with the ostomy nurse about ways to control gas and odors that occur after eating certain foods.</td>
<td>• Eating gas-producing foods <em>(See food list on next page).</em></td>
</tr>
<tr>
<td>Odor</td>
<td>• Include these odor-reducing foods in his diet: buttermilk, cranberry juice, orange juice, yogurt, parsley.</td>
<td>• Eating odor-producing foods <em>(See food list on next page).</em></td>
</tr>
<tr>
<td></td>
<td>• Empty the pouch often.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Use an odor-resistant pouch or put special deodorant tablets in the pouch.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ask your child’s doctor about odor-reducing medications such as bismuth.</td>
<td></td>
</tr>
<tr>
<td>Blockage</td>
<td>• Chew foods well to break down fiber into smaller pieces.</td>
<td>• Eating high fiber foods <em>(See food list on next page).</em></td>
</tr>
<tr>
<td></td>
<td>• Drink at least 8 to 10 glasses of fluids a day. Water or fruit juices may be the most helpful.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Eat small servings. Eat your largest meal at noon and a smaller meal in the evening. This will help reduce your child’s stool output at night.</td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td>• Try these foods to help relieve constipation: Coffee or other warm drinks, cooked or fresh fruits and vegetables, fruit juices.</td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td>• Drink at least 8 to 10 glasses of fluids a day.</td>
<td>• Eating foods that loosen stool <em>(See food list on next page).</em></td>
</tr>
<tr>
<td></td>
<td>• Eat your largest meal at noon and a smaller meal in the evening.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Eat foods that thicken stool. <em>(See food list on next page).</em></td>
<td></td>
</tr>
</tbody>
</table>
### Food Lists
Foods and their possible effects on the stool:

#### Foods That May Loosen Stool
<table>
<thead>
<tr>
<th>Foods</th>
<th>Leafy green vegetables (lettuce, broccoli, spinach)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chocolate</td>
<td></td>
</tr>
<tr>
<td>Dried or string beans</td>
<td></td>
</tr>
<tr>
<td>Fried foods</td>
<td>Prune or grape juice</td>
</tr>
<tr>
<td>Greasy foods</td>
<td>Raw fruits</td>
</tr>
<tr>
<td>Highly spiced foods</td>
<td>Raw vegetables</td>
</tr>
</tbody>
</table>

#### Foods That May Thicken Stool
<table>
<thead>
<tr>
<th>Foods</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Applesauce</td>
<td>Pasta</td>
</tr>
<tr>
<td>Bananas</td>
<td>Potatoes</td>
</tr>
<tr>
<td>Bread</td>
<td>Pretzels</td>
</tr>
<tr>
<td>Cheese</td>
<td>Rice</td>
</tr>
<tr>
<td>Creamy peanut butter</td>
<td>Tapioca</td>
</tr>
<tr>
<td>Marshmallows</td>
<td>Yogurt</td>
</tr>
</tbody>
</table>

#### Foods That May Cause Stool Odor
<table>
<thead>
<tr>
<th>Foods</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Asparagus</td>
<td>Eggs</td>
</tr>
<tr>
<td>Beans</td>
<td>Fish</td>
</tr>
<tr>
<td>Cabbage-family vegetables:</td>
<td>Garlic</td>
</tr>
<tr>
<td>(onions, cabbage, brussel sprouts,</td>
<td>Some spices</td>
</tr>
<tr>
<td>broccoli, cauliflower)</td>
<td>Turnips</td>
</tr>
</tbody>
</table>
FOODS THAT MAY **CAUSE GAS**

<table>
<thead>
<tr>
<th>Foods That May Cause Gas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cabbage-family vegetables: (onions, cabbage, brussel sprouts, broccoli, cauliflower)</td>
</tr>
<tr>
<td>Cucumbers</td>
</tr>
<tr>
<td>Dairy products</td>
</tr>
<tr>
<td>Dried and string beans</td>
</tr>
<tr>
<td>Sodas or other fizzy drinks</td>
</tr>
<tr>
<td>Radishes</td>
</tr>
<tr>
<td>Corn</td>
</tr>
<tr>
<td>Spinach</td>
</tr>
</tbody>
</table>

FOODS THAT MAY **COLOR STOOL**

<table>
<thead>
<tr>
<th>Foods That May Color Stool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beets</td>
</tr>
<tr>
<td>Red Jell-O*</td>
</tr>
<tr>
<td>Foods with artificial colors</td>
</tr>
<tr>
<td>Some medicines</td>
</tr>
</tbody>
</table>

Children with an ileostomy should be taught to chew their food well. This is especially true for **high-fiber foods** which can cause blockage in the stoma.

Encourage children to chew food well.

FOODS THAT HAVE **HIGH FIBER**

Remember, high-fiber foods need to be well-chewed to prevent a blockage.

<table>
<thead>
<tr>
<th>Foods That Have High Fiber</th>
</tr>
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<tbody>
<tr>
<td>Apples with peels</td>
</tr>
<tr>
<td>Meat with casings (bologna, sausage, hot dogs)</td>
</tr>
<tr>
<td>Chinese vegetables</td>
</tr>
<tr>
<td>Mushrooms</td>
</tr>
<tr>
<td>Coconut</td>
</tr>
<tr>
<td>Nuts</td>
</tr>
<tr>
<td>Corn</td>
</tr>
<tr>
<td>Popcorn</td>
</tr>
<tr>
<td>Dried fruit (raisins, figs, apricots)</td>
</tr>
<tr>
<td>Raw cabbage (coleslaw)</td>
</tr>
<tr>
<td>Grapes</td>
</tr>
<tr>
<td>Legumes (chickpeas, kidney beans, chili beans)</td>
</tr>
<tr>
<td>Raw celery</td>
</tr>
</tbody>
</table>
Complications

Stoma Complications

Stoma complications can be serious and may need to be monitored by your doctor. Contact your doctor or ostomy nurse right away if your child is experiencing any of the following complications.

Blockage

A child with an ileostomy may develop a blockage. This happens when food clumps together in the small bowel and clogs it.

The first signs of a blockage:
- A continuous spurt of very watery stool
- Feeling bloated or crampy near the stoma
- Swelling around the stoma
- Stool with a very strong odor

Signs of continued blockage:
- The flow of stool eventually stops
- Increased pain
- Nausea and vomiting

If you think your child has a blockage:
- DO NOT let your child eat any solid foods
- DO NOT give your child any laxatives or stool softeners

Try these things to clear a blockage:
- Gently massage the abdomen
- Have him rest in a warm bath for 15 to 20 minutes
- Tuck his knees to his chest and move his legs from side to side
- Give him a warm beverage
- Put on a pouch with a larger stoma opening

A blockage can become an emergency. If the blockage lasts more than 2 or 3 hours, or if your child starts to vomit, call his doctor or go to the nearest hospital emergency room. Prolonged blockage could cause the bowel to rupture.
Stenosis

Stenosis is an abnormal narrowing of the bowel or stoma which prevents stool from flowing freely out of the stoma. This results in thin or ribbon-shaped stool. If your child has ribbon-shaped stool or goes longer than normal without passing stool, call your child’s ostomy nurse or doctor.

Peristomal hernia

Occasionally part of the bowel pushes through the muscle and causes a bulging of the skin around the stoma. This is called a peristomal hernia and may be seen around the whole stoma or just part of it. This bulging may come and go depending on the pressure inside your child’s abdomen. If your child has a peristomal hernia, it is helpful to have him lie flat on his back when changing the pouch. A pouching system with a very soft wafer is needed around stomas with a peristomal hernia. The pouch may need to be changed more often.

Necrosis

Sometimes the blood supply to the stoma can get blocked. If this happens, the tissue will die, causing the stoma to become dark purple in color and then black. This is called necrosis and is a medical emergency. Call the doctor immediately if the stoma becomes very dark in color.
Retraction
The stoma may retract (draw back) into the body and look like a hole or pucker in the abdomen. If this happens the stoma, will not protrude (stick out) from the abdomen. Retraction makes it very difficult to keep a pouch in place. A special type of pouch is needed for these types of stomas and good skin care is especially important. Contact the ostomy nurse or doctor for possible treatment options.

Prolapse
Sometimes more of the bowel comes to the outside of the abdomen, making the stoma longer. This is called a prolapsed stoma. It happens more often in children because of their weak abdomen muscles. Call your child’s doctor if your child’s stoma prolapses. Many prolapsed stomas can be pushed gently back into the body, but will prolapse again when the child cries or coughs. It is best to use a one-piece pouch to prevent pinching a prolapsed stoma. Sometimes another surgery is needed to fix this problem.

Laceration
A laceration is a cut on the stoma that looks like a thin white line. When the wafer opening is too small, it can cause a laceration. Cutting the wafer opening a little larger will help the stoma to heal. Your child should feel no pain, but there may be some bleeding from a laceration on the stoma.
Skin Complications

Allergic Dermatitis

Allergic dermatitis occurs if your child is allergic to one of the products used in the pouching system. You will notice redness and damaged skin where the product touches the skin. It can be caused by the wafer, tape, stoma paste, stoma powder, or the pouch. Once you know what is causing the allergy, change to a different product. Your child’s ostomy nurse can help you determine which product is causing the allergy and what treatment to use.

Irritant dermatitis

Irritant dermatitis is usually caused from stool leaking under the pouching system. The leaking is often due to a pouch hole that is too large or a pouch that has not been changed often enough. The stool then leaks under the wafer and causes skin breakdown. Irritant dermatitis can also be caused by soap that is not completely rinsed off the skin. Irritant dermatitis will make the skin look red and damaged.

Caring for allergic or irritant dermatitis:
1. Clean the skin, rinse it, and pat dry.
2. Apply a very small amount of Stoma-hesive® powder on the irritated red areas.
3. Lightly brush off excess powder. The powder will stick to the damaged skin.
4. Place pouch as usual.
5. Change the pouch as often as needed to keep stool off the skin.
6. Do this procedure with each pouch change until the skin is healed. If the skin still looks irritated after five days, call the ostomy nurse.
**Yeast infections**

A **yeast infection** or rash is caused by moisture on the skin from stool leaking under the wafer or from sweating. It is usually itchy and very red with small white bumps or peeling skin. It can also occur if your child takes antibiotics. If your child has a yeast infection, the doctor may prescribe an antifungal powder.

Ask your child’s doctor for a prescription of antifungal powder, not cream. Pouches will not stick if antifungal cream is used.

**Caring for a yeast infection:**

1. Clean the skin, rinse it, and pat it dry.
2. Apply a very small amount of the prescribed antifungal powder on the red areas. Lightly rub in the antifungal powder and then brush off.
3. Place pouch as usual.
4. Change the pouch every day until there is no more rash.

**Folliculitis**

**Folliculitis** is an infection at the base of the hair shaft (the follicle) that causes itching or pain. There are usually several small red or white bumps that look like pimples. It is caused by hair being pulled out when the wafer is removed. Folliculitis can be prevented by clipping the hair around the stoma very short. Folliculitis will usually heal on its own.

**Recommendations for Skin Breakdown**

If you have a hard time keeping a pouch on because of sore, weepy skin, your child may need to go without a pouch for a few days until the skin heals. Place a thick diaper cream over the damaged skin and double diaper your infant. For an older child, cover the damaged skin with a thick diaper cream and tape a sanitary napkin over the stoma to collect the stool. Change the diaper or sanitary napkin as often as needed to keep stool off the skin.
Dehydration

Dehydration means your child’s body does not have enough water or fluids to function properly. Children with an ostomy can become dehydrated more quickly than other children. This is especially a concern for children with ileostomies. Dehydration can be serious for children of any age. You need to pay careful attention to the amount of stool your child produces. You will become familiar with the amount of stool your child normally puts out each day. When this amount increases, you need to be alert for dehydration. Your child can also lose fluids with a high fever or with diarrhea, vomiting and excessive sweating. Contact the doctor if you think your child is dehydrated.

To avoid dehydration:

• Drink at least 8 glasses of fluids every day.

• Avoid drinking a lot of drinks that are sweet or sugary. These can speed up the movement of stool.

• Drink extra fluids during exercise, in warm weather, or if your child has diarrhea.

• Balance electrolytes. Electrolytes are chemicals such as salt and potassium that help the body absorb and use water. Ask your child’s doctor about a diet with foods high in salt and potassium. Salty foods taste good, but be careful that your child doesn’t overdo it.

These foods help prevent dehydration:

<table>
<thead>
<tr>
<th>High Salt Foods</th>
<th>High Potassium Foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>• broths/bouillon</td>
<td>• bananas</td>
</tr>
<tr>
<td>• buttermilk</td>
<td>• orange juice</td>
</tr>
<tr>
<td>• bacon</td>
<td>• grapefruit juice</td>
</tr>
<tr>
<td>• crackers</td>
<td>• squash</td>
</tr>
<tr>
<td>• ham</td>
<td>• Gatorade</td>
</tr>
<tr>
<td>• pretzels</td>
<td>• tomato or vegetable soups</td>
</tr>
<tr>
<td>• soups</td>
<td>• potatoes</td>
</tr>
<tr>
<td>• soy sauce</td>
<td>• smooth peanut butter</td>
</tr>
</tbody>
</table>

Signs and symptoms of dehydration

• The soft spot on your baby’s head sinks in when he is held up or sits up

• Fewer wet diapers

• Urine is darker in color and has a stronger smell

• Child may be fussy, sleepy, not hungry, or difficult to wake up.

• No tears, dry mouth

• Dry or wrinkled skin

• Dark circles around his eyes
Helpful tips by age

Babies (1 to 12 months)
In the first year, babies grow very quickly. It may be necessary to measure the stoma size frequently. You may also need to try different pouches as your child grows.

Babies are active. They roll, explore their bodies, and discover their world. To protect the pouch, keep it hidden in the diaper. Dress your baby in one-piece outfits or overalls.

Toddlers (12 to 36 months)
Toddlers are even more active. They crawl, walk, and run. Before you change the pouch, have all supplies ready. You can begin teaching older toddlers how to help by having them hand you supplies. To help protect the pouch, dress your toddler in overalls or pants without tight waistbands that ride over the stoma.

Preschoolers (3 to 5 years)
Preschoolers are intensely curious and want to be independent. They can help with certain parts of ostomy care, such as removing the pouch, emptying the pouch, and cleaning the skin. Keep lessons short, because your child’s attention span is probably short. Help your preschooler choose clothes without tight-fitting waistbands.
School-age children (6 to 11 years)

Children at this age can learn more about changing and emptying the pouch. By age 7 or 8, they should be able to take care of changing the pouch and emptying it on their own but may need assistance from time to time. However, parents still need to look at the skin occasionally to make sure there are no problems.

Children at this age may be self-conscious about being different from their peers. Let your child decide who he wants to tell. When your child starts school, he will need to take an extra pouch and changing supplies with him. Teachers will need written step-by-step instructions which can be found on page 13 to 15 of this booklet. Review these instructions with the teacher and school nurse. This will give your child a support person at school. At some point in this age group, it may be necessary to change to an adult-size pouch.

Adolescents (12 to 18 years)

By age 12 your child is generally able to assume self-care, make appointments, and order ostomy equipment. Your role as parent is to offer support. Teenagers do not need to tell everyone about their ostomy. They should only tell the people they want to know. To participate in active sports such as wrestling or football, your child should have approval from the doctor. Ostomy equipment for teens is the same as for adults.
Glossary

**Allergic dermatitis:** Red or tender skin caused by an allergy to a substance placed on the skin.

**Anus:** Opening where stool passes out of the body.

**Appliance:** The system of pouch and wafer used to collect stool from the stoma.

**Ascending colostomy:** A surgically created opening into the ascending section of the large bowel, which is located on the right side of the abdomen.

**Atresia:** Absence or closure of a body opening or passage.

**Blockage:** Something stuck in the bowel that keeps stool from passing from the body. This can be caused by a buildup of food particles.

**Colostomy:** A surgically created opening of the large bowel onto the abdomen where stool can be expelled.

**Colon:** The entire large bowel.

**Dehydration:** Extreme loss of water from the body.

**Descending colostomy:** A surgically created opening into the descending section of the large bowel, which is located on the left side of the abdomen.

**Folliculitis:** Redness or tenderness at the base of a strand of hair.

**Hirschsprung’s disease:** A disease where nerve cells in part of the bowel are not formed before birth. The lack of nerve cells affects the bowel’s ability to move stool through the small or large bowel.

**Ileostomy:** A surgically created opening of the small bowel onto the abdomen where stool can be expelled.

**Imperforate anus:** A condition that develops before birth where there is no outlet in the body where stool can come out.

**Irritant dermatitis:** Skin redness or tenderness caused by a substance that irritates the skin over a long time.

**Laceration:** A cut or tear on the stoma.

**Meconium ileus:** A blockage of the newborn bowel with thick meconium. Meconium is the first body waste produced by a newborn baby.

**Mucus fistula:** The far end of a double barrel stoma that does not produce stool; it often produces mucus.

**Necrotic tissue (necrosis):** Dead tissue.

**Necrotizing enterocolitis (NEC):** A condition when the blood supply to the bowel slows or is cut off. The bowel becomes infected and dies.

**Ostomy:** A surgically created opening which is made through the abdominal wall to divert body wastes.

**Peristalsis:** The normal motion of the bowel that moves stool forward through the bowel.

**Peristomal:** The area surrounding the stoma.

**Prolapsed stoma:** When the stoma becomes elongated (longer) and more of the bowel comes to the outside of the abdomen.

**Pseudo-membranous enterocolitis:** Inflammation of the lining of the bowel which can involve both the small and large bowel.

**Rectum:** The very end of the large bowel where stool is stored in the body.

**Retracted stoma:** Stoma that does not protrude (stick out) from the abdomen. Instead, the stoma looks like a hole or pucker in the abdomen. The moist tissue lining of the bowel may not be visible.

**Sigmoid colostomy:** A surgically created opening of the bowel onto the abdomen where the descending colon and the rectum connect.

**Stenosis:** An abnormal narrowing of the bowel or stoma which prevents stool from flowing freely from the stoma.

**Stoma:** The visible part of the bowel that is surgically brought out to the skin on the abdomen wall.

**Stool:** Body waste (poop).

**Transverse colostomy:** A surgically created opening into the transverse section of the large bowel between the ascending and descending colon. It may be located anywhere in the middle section of the abdomen.

**Ulcerative colitis:** An inflammation of the interior wall of the bowel usually affecting the lower large bowel.

**Wafer:** The part of the pouching system that attaches to the body and connects to the pouch.

**Wear time:** How long the pouching system is worn between changes.

**Yeast infection:** A pink or red raised rash caused by too much moisture on the skin.
There are many people who can help you learn how to care for your child’s ostomy. Your child’s ostomy nurse can help you find other resources as well.

**National support website**
United Ostomy Associations of America, www.uoaa.org, 1-800-826-0826.

Many of the companies that make ostomy supplies also have useful information on their websites. Your child’s ostomy nurse can show them to you.

**Intermountain ostomy support groups**
- Salt Lake City, 801-408-5663 or 801-662-3693
- St. George, 435-688-4123
- Ogden, 801-387-5146
- Utah Valley, 801-357-8156

**Intermountain ostomy and wound clinics**
- LDS Hospital Wound Clinic, Salt Lake City, 801-408-3638
- Dixie Regional Medical Center Wound Clinic, St. George, 435-688-4293
- McKay-Dee Hospital Wound Clinic, Ogden, 801-387-5146
- Logan Regional Hospital Wound Clinic, Logan, 435-716-2850
- Utah Valley Regional Medical Center Wound Clinic, Provo, 801-357-8156
- Primary Children’s Hospital, (children only) Salt Lake City, 801-662-3691

**Supply companies**
Ask your child’s ostomy nurse for a list of national and local supply companies. If you have problems finding the right product to fit your child, the ostomy nurse can usually help.

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**Resources Special Instructions**

1. Prepare an ostomy kit for use when your child is away from home. The kit should contain the following:
   - pre-cut wafer
   - pouch
   - clamp
   - tissues

   Make sure your child always has the kit when he leaves the house.

2. Purchase additional ostomy supplies two weeks before you run out of them. Most medical supply stores do not stock ostomy supplies, and mail orders usually take 2 to 5 working days to be filled. Work with your child’s doctor and insurance company to ensure you have adequate coverage and supplies.

3. If you have questions or concerns about your child’s ostomy, call the ostomy nurse. Remember, it is best to work through a concern about your child’s ostomy before it becomes a bigger problem.

4. Keep supplies in a cool, dry place away from heat. Storing ostomy supplies in a hot car may damage them and cause the wafer to melt.

**Notes:**

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OSTOMY: CARE AT HOME
Special care for my child’s ostomy

<table>
<thead>
<tr>
<th>My Child’s Information</th>
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<tbody>
<tr>
<td>Type of ostomy:</td>
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<tr>
<td>Type and date of operation:</td>
</tr>
<tr>
<td>Surgeon:</td>
</tr>
<tr>
<td>Ostomy nurse:</td>
</tr>
<tr>
<td>Type of ostomy supplies:</td>
</tr>
</tbody>
</table>

To find these and other resources, go to: intermountainhealthcare.org