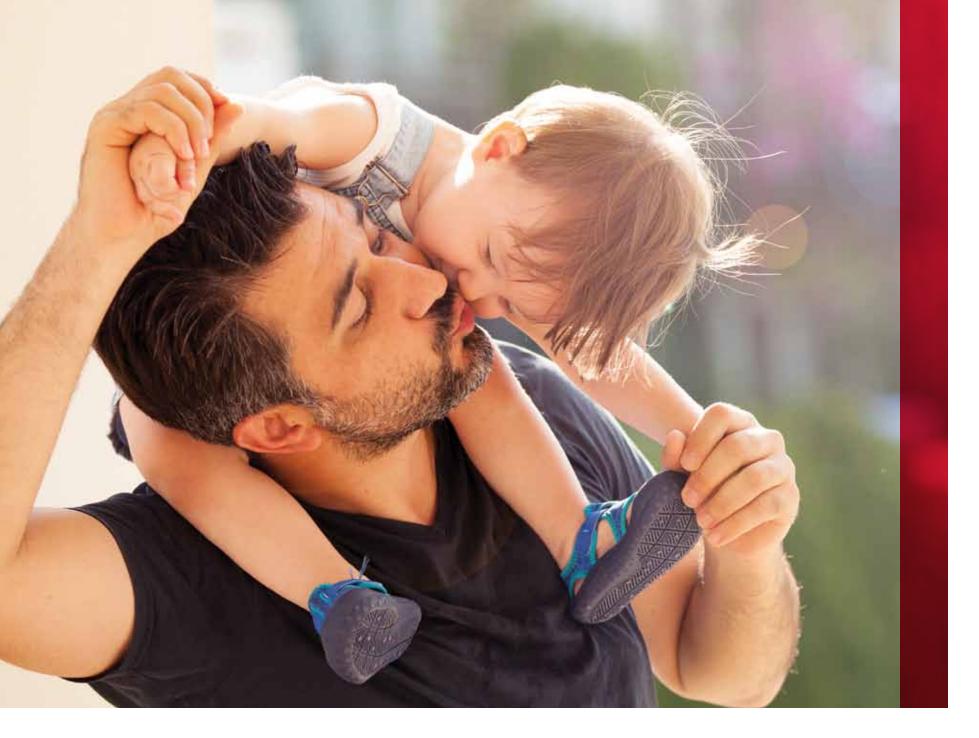
# Caring for Your Child

### with an Ostomy



Ostomy Care Healthy skin. Positive outcomes.



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A glossary is included at the back of this booklet to help with some terms with which you may not be familiar.

Caring for a new baby or raising a young child is a wonderful yet challenging experience, even in the best of circumstances. If your child needs ostomy surgery, you will not only need to understand your child's medical condition, but also the new skills required to manage the pouching system and how it all works with your busy lifestyle. In addition to your healthcare professional, specially trained Wound, Ostomy and Continence (WOC) or Enterostomal Therapist (ET) nurses who specialize in ostomy care can help. The professional team at Hollister Incorporated also has knowledge and experience with managing ostomies and is available to offer support. Use this book as a reference and supplement to the information you receive from your child's medical team.

## What is an ostomy (stoma)?

"Ostomy" is a general term to describe a procedure where an opening is created in the body. The surgically created opening in the abdomen, called a "stoma," allows output (stool or urine) to drain out of the body. An ostomy may be a new type of surgery for you, but it is not an unusual type of operation for infants and children, although it is more common in adults. There are many reasons why a newborn or child may need an ostomy. It is often a life-saving operation.

Stomas should be pink or red and slightly moist. Stomas might bleed a little when rubbed or bumped. This is normal because stomas have a lot of blood vessels. They also don't hurt when touched because there are no nerve endings. Your child's stoma may look different from pictures or from other children's stomas you may see.

#### All stomas typically:

- Are pink or red in color and slightly moist
- Bleed easily when rubbed or bumped (for example when washing), but should resolve quickly
- Are not painful

#### How stomas differ from each other:

- They may be temporary or permanent
- Some children have more than one stoma
- They can be located on different parts of the body
- Stomas may be different shapes and sizes
- They may stick out above or be slightly below the skin level
- They are made for different reasons and the output (stool or urine) is different

FACT

The stoma is normally pink or red. However, sometimes when your child is crying you may notice that it changes color. The normal color should return when your child stops crying. A temporary color change is not usually a reason for concern. However, if this color change persists, contact your child's healthcare professional.

## Types of ostomies

The type of ostomy your child has will be determined by the reason for the surgery. As a parent, it is important to know the type of ostomy your child has. Each has its own qualities that you should know about for proper care. If you are not sure about your child's ostomy, ask your WOC/ET nurse, pediatric nurse, or healthcare professional. With a colostomy and ileostomy, the opening is made from a portion of the intestine. For a urostomy, the opening is made somewhere along the urinary tract.



A colostomy is a surgically created opening in the colon or large intestine.

#### Colostomy

A colostomy is the most common type of stoma for an infant or child. It is a surgically created opening into the colon or large intestine through the abdomen. When undigested food enters the colon, water is absorbed. The stool is stored in the colon until it is passed from the body. Stool (bowel movement) comes out of the colostomy. It may be liquid or solid in consistency. Gas is common.



An ileostomy is a surgically created opening in the ileum or small intestine.

A urostomy is a surgically created opening that allows urine to drain.

### lleostomy

An ileostomy is a surgically created opening into the ileum, which is part of the small intestine. The small intestine contains digestive enzymes which break down food to help with digestion and absorption of nutrients. The output from an ileostomy is stool — similar to the colostomy. One major difference is that the output from the ileostomy also has the digestive enzymes. Although normally present in the small intestine, they can damage the skin. This will be discussed in more detail later in the booklet when we talk about pouching.

#### Urostomy

A urostomy is a surgically created opening into the urinary system that allows urine to drain. A urostomy allows urine to flow out of the body after the bladder has been removed or bypassed. When a person has a urostomy, urine is no longer eliminated through the urethra. Instead, it is eliminated through the urostomy. The urine may also contain some mucus.

FACT

The skin around the stoma is also called peristomal skin. It should be intact without irritation, rashes, or redness. It should look similar to healthy skin elsewhere on your child's body. If you discover red, broken, or moist skin around the stoma, seek the assistance of a WOC/ET nurse.

### After the surgery



A stoma measuring guide will help you to cut the skin barrier to the correct size.

#### **Calming your fears**

It can be stressful to see your child for the first time after surgery. There may be several tubes and equipment in or around your child. Your presence can help calm your child. The hospital staff is there to help. Be sure to ask questions if you do not understand something.

When you look at the stoma for the first time, there is a good chance the healthcare professional or nurse will be with you. Remember, the stoma has no feeling. You may notice stitches around the stoma. These will dissolve on their own. Parents often wonder if the incision can become infected; this is possible but is rare.

#### What to expect

There is no way you or your child can control the output from the stoma. Initially, there may or may not be a pouch over the stoma. Depending on the reason and type of surgery, the stoma may work right away or it may take days. Eventually a pouch will be needed to collect the stool (bowel movement) or urine, and to protect your infant's skin.

After surgery, the stoma may be swollen. It is common for it to change size and get smaller. It may continue to shrink for up to eight weeks after surgery. The stoma may grow with your child, especially if it is needed for a long time or if it is permanent. Since changes are normal, it is important to re-measure the stoma periodically so you are sure you are cutting the skin barrier to the correct size. Measuring guides are provided in each box of your products. Pouching systems that fit well provide the best wear time.

### Getting ready to go home

You may feel both worried and excited when taking your child home from the hospital after ostomy surgery. Here are a few things to review prior to discharge that can make your transition to home a little easier:

- Observe the procedure for changing a pouch, and practice changing and emptying it yourself before your child goes home
- Leave with written step-by-step instructions on your child's pouch change procedure
- Ask your nurse to enroll your child in Hollister Secure Start services to receive a personalized introductory kit at home and help in finding a supplier that handles the products you need and accepts your child's insurance
- Find out whether you need to contact your supplier to reorder supplies or if they will contact you
- Take supply information with you when you meet with your child's healthcare team in case a new presctiption is needed
- Make a list of all the key phone numbers: WOC/ET nurse, healthcare professional, home care agency, company that provides your child's ostomy supplies, and social services contacts

TIP

Be sure to have information about scheduling followup visits, medications, and other care your child needs such as incision care.

### Understanding medications

Before discharge from the hospital, make sure you understand any medications that your child needs to take. Only give medications to your child that have been prescribed by their healthcare professional.

When filling a new prescription, tell your pharmacist that your child has an ostomy. Be sure you tell them the specific type of ostomy — colostomy, ileostomy, or urostomy. Sometimes they may recommend a liquid form of the medication to improve absorption. When starting a medication, you may notice a change in the stoma output.

Consult your child's healthcare professional before giving any over-the-counter medications or home remedies. If your child is taking many different medications, it is helpful to bring them to the clinic or healthcare professional's office for follow-up appointments.

TIP

There is a lot to remember. Keep a journal of questions you have and information you have been given, or write them down in this booklet. Include key phone numbers you will need. Take pictures of your child and include them in your journal.

### Pouching systems explained

The pouching system consists of two main parts — the skin barrier and the pouch.

The **skin barrier** is the portion of the pouching system that fits immediately around the stoma. It protects the skin from contact with stool, urine, or enzymes and holds the pouching system in place.

The **pouch** is the bag that collects output (stool or urine) from the stoma. It is made of a material designed to contain the odor.

#### **Two-Piece System**

Skin barrier and the pouch are two separate pieces, connected by a plastic ring called a flange.

#### **One-Piece System**

Skin barrier and the pouch are a single unit. It is very flexible and easy to use.





Drainable pouching systems can be used to empty stool and gas



Urostomy pouching systems have a spout at the bottom to drain liquid or urine

#### **Skin Barrier**

The opening in the skin barrier should be the same size as the stoma. A cut-to-fit skin barrier allows you to customize the opening so that the skin is covered and protected. The skin barrier should also help the pouching system stick to the skin. It should hold the pouch on but not be too difficult to remove.

#### Pouch

The type of pouch you use will depend on the type of stoma. If your child has a colostomy or ileostomy, you will use a drainable pouch that opens at the bottom so you can empty it. For urine or very liquid stool, you will use a urostomy pouch that has a spout at the end which can be opened to empty the pouch.

There are also closed pouches, which do not drain at the bottom. These pouches work well when there is little discharge from the stoma (e.g., preterm infants) or with younger children for specific occasions (e.g., swimming).

TIP

If your child's stool is liquid, placing a couple cotton balls inside a drainable pouch can help absorb some of the fluid. Infants tend to suck on everything. When babies suck or cry, they swallow air that ends up in the pouch. Too much air in the pouch can break the seal. Some pouches include a filter which allows gas out of the pouch without causing odor. This is usually used with colostomies and some ileostomies — never with a urostomy.

Accessories are optional items. Each of these serves a specific function and is used only when indicated. Examples of accessories include barrier rings, barrier paste, odor eliminators, or ostomy belts. Use these products if directed by your WOC/ET or pediatric nurse.

### How to empty the pouch

One of the first skills you will learn is how to empty the pouch. This is not much different from changing a diaper. You do not need to wear gloves although you may see the nurses in the hospital do this.

- Empty the pouch when it is 1/3 to 1/2 full of discharge or gas.
  Do not let the pouch overfill. Empty your child's pouch before activities, a nap, bedtime, or trips in the car. A tissue or baby wipe works well for cleaning the bottom of the pouch
- If you use disposable diapers, you can simply empty the pouch contents into the diaper when you are changing your baby's diaper. Occasionally your child's healthcare professional may ask you to measure the output
- If you are using a two-piece pouching system, you may find it easier to snap off the pouch to empty it. Take off the full pouch and snap on an empty one

- If your child is an infant, it might be easier to empty the pouch if you angle the pouch to the side when you apply it. If your child is older and walking, angling it straight up and down is better for pouch filling
- If you have a toddler or young preschooler, they may be ready to sit on the toilet when you empty their pouch. A potty seat will help so they are comfortable. Placing some toilet tissue in the water of the toilet bowl prevents splashing as the contents are emptied
- You do not have to clean out the inside of the pouch when your child is wearing it. Putting water into the pouch and rinsing it out may actually weaken the skin barrier seal and reduce wear time. If the stool is difficult to get out of the pouch, you may consider using a lubricating deodorant. This product makes the inside of the pouch slippery so that the contents empty more easily. It also has the benefit of eliminating odor. Do not substitute other products such as cooking oil, baby oil, or soap as they can weaken the pouch seal

### Changing the pouch and skin barrier

#### Replacing at the right time

How often you change the pouching system depends on how long the skin barrier stays in contact with your child's skin. If the pouching system leaks or comes loose, it is time for a change. The pouch should also be replaced if your child tells you their skin burns, itches, or if they are pulling on their pouch or seem unhappy when there is no other explanation.

The typical wear time of a pouch on an infant can vary from one to two days. Sometimes small children may get up to three days wear time. Ideally, you will find a predictable wear time, but you will also need to be flexible. Wear time is influenced by how much is coming out of the stoma, your child's level of activity, and other factors.

#### Gentle removal and cleaning

When removing the skin barrier, gently push the skin away from the back of the adhesive with your finger, a moist cloth, paper towel, or cotton ball. Have a tissue or soft paper towel ready to handle any discharge that may happen after the pouch is off. Clean the skin around the stoma (peristomal skin) with water.

FACT

When removing the skin barrier, you may notice that the skin where the adhesive was has lightened up in color. This is temporary and will go away.

#### Applying the pouching system

- 1. Measure the stoma using the stoma measuring guide before every barrier application.
- 2. Make sure the skin around the stoma (called peristomal skin) is clean and dry before applying your skin barrier. Avoid moisturizers around the stoma.
- 3. Apply the skin barrier, making sure it fits where the skin and stoma meet. If your child is wearing a two-piece pouching system, try placing the skin barrier on their body in a diamond shape for a smoother fit.
- 4. Apply gentle pressure to the skin barrier for about a minute for best adhesion.
- 5. Verify that no skin is showing between the skin barrier and the stoma to help prevent leakage and skin irritation.

At first, pouch changes may seem uncomfortable for your baby or child. You may also feel clumsy as you learn what works best. Be assured, this process gets easier with time and practice. Step-by-step instructions are found with your pouching system.

TIP

If you are changing your child's pouch more than once a day because of leakage, tell your WOC/ET or pediatric nurse.



#### **Keeping skin healthy**

The skin around the stoma is called the peristomal skin and should look similar to the skin anywhere else on your child's body. It is not more or less sensitive. Although the stoma has no feeling, the skin around it does. A properly fitting skin barrier and the right barrier formulation helps protect the skin from being irritated by the stoma drainage.

One of your most important goals is to keep the skin healthy. Get into the habit of cleaning the peristomal skin each time you change the barrier. Less is better when caring for the skin around the stoma. For most people, water is sufficient for cleaning the skin. Do not use any baby wipes, oils, powders, ointments, or lotions on the skin around the stoma. These products contain ingredients that can prevent the pouching system from sticking. Just like ensuring the proper fit around the stoma, ensuring the pouching system sticks properly to the skin can help prevent leakage and skin irritation.

#### Gentle care for newborn skin

If you have a newborn infant, the baby's skin has not yet had the chance to develop and mature. For that reason, you will want to take extra care with all products used on the newborn's skin. Gentle products are designed to prevent tearing. Because substances can be absorbed through immature skin, use only products that have been recommended by your child's healthcare professional.

The skin should not be irritated as this can be uncomfortable for your child. Open areas, a persistent redness, or red bumps on the skin are not normal. It is essential to determine the cause and treat it appropriately. Be sure to seek the recommendations of your WOC/ET nurse or other knowledgeable healthcare professional.

### Planning ahead

extreme heat or cold.

#### **Be prepared**

TIP

Children tend to keep their own schedules but you can be ready by planning ahead.

Store ostomy supplies in a cool, dry place. Do not leave

them where they will be exposed to a wide variation

in temperature — such as in the sun, in your car, or in

If possible, change the pouch when the stoma is less active. This will depend on when your child has eaten. First thing in the morning or at least two hours after eating or drinking is a good time. Prepare the new pouching system before you remove the used pouch.

If there is a time during the day when the child is normally quiet, that is also a good time to change the pouch.

If the pouch needs to be changed and your baby is very upset and crying, just wait. Hold your baby until he or she is calmer. You will both feel better and the whole process will go more smoothly.

#### **Get started**

A toy or mobile can help to distract a wiggly child and keep them occupied during the pouch change.

Before you start, make sure you have all your supplies ready to use. At first, it might be easier to change the pouch when someone else is near by to lend an extra pair of hands. Perhaps you can plan a time when your spouse/significant other or another family member is around.

Older siblings can help by entertaining and distracting your child during the pouch change. An older child can also help with getting supplies ready or holding and handing them to you.

Have equipment in several places besides home - at day care, in the diaper bag, and at any caregiver's house.



Your child won't need special clothes because of a stoma, but there are ways to select clothing that will make life easier for both of you.

- Avoid clothes where the waistband rubs against the stoma or are so snug that it prevents the pouch from filling
- When diapering, some parents find it better to put the pouch on the outside of the diaper and others find it easier to put it inside the diaper
- When your child becomes more active, they might pull their pouch off and their activity may put some additional strain on the pouch seal

One-piece outfits that snap at the crotch hold the pouch more securely. Two-piece outfits make it easier to empty the pouch but they may also slide down and pull off the pouch before you are ready.

### Staying active

As a parent, you know that babies and young children are busy and on the go most of the time. Infants, toddlers, and young children are meant to be active and generally their ostomy will not prevent them from moving around. Here are a few helpful points.

#### **Bathing**

You can bathe your child with the pouching system on or off. Water will not go into or harm the stoma. If your child has a urostomy, check with your child's healthcare professional before allowing the water to cover the stoma. If you decide to leave the pouching system off while bathing, don't be surprised if the stoma functions when in the tub. Avoid using oily soaps or lotions around the stoma because they can interfere with the barrier adhering to the skin. If your child wears a pouching system when bathing, dry it off afterwards and check the seal for security.

#### Swimming

It is absolutely fine. The pouch should be worn while swimming. Larger swimsuits or a t-shirt can help cover up the pouch. Sometimes an ostomy belt or waterproof tape around the edge of the skin barrier can help make the pouching system more secure. The waterproof tape should be removed after swimming as it can irritate the skin.

#### Sleeping

It is a good idea to empty the pouch prior to naptime or bedtime. Sleeping on their tummy will not hurt the stoma, although it is recommended that infants should sleep on their backs for other medical reasons.

TIP

#### Travel

When traveling on a plane with your child, be sure to pack your supplies in your carry-on luggage. In a car, your child should always be in a car seat. Avoid placing the seat belt over the stoma.

#### **Crawling/Walking**

The rate and timing of physical and development growth can vary greatly from child to child — even when they don't have a stoma. When your child is ready, the stoma will not prevent him or her from normal movement. Once they become more active, there will be more stress on the pouching system. You may need to make some adjustments in products, but the child's natural curiosity and activity should not be discouraged.

TIP

When traveling, carry moist paper towels in a zip lock bag for easy clean up away from home. Do not use commercially available baby wipes on the skin as they may leave a film on the skin and prevent a good seal.

### Guidelines for healthy eating

A well-balanced diet is important for everyone. Many parents wonder if their child will have dietary restrictions because of the ostomy. In general, a "special" diet may be necessary due to other medical conditions but not because of the stoma. Here are a few guidelines that may be helpful.

#### Advantages of breastfeeding

Breastfeeding offers many advantages for both baby and mom. It is your choice. If your baby is in the Neonatal Intensive Care Unit (NICU), you may need to use a breast pump and save your milk until your infant can be fed. A person who specializes in helping breastfeeding moms is called a Lactation Consultant (LC). You may want to ask the nurses in the NICU if there is an LC available.

#### Introducing new foods

New foods can be added to your baby's diet as recommended by their healthcare professional. When a new food is added, it may change the color or consistency of your child's stool or may result in more gas. This is normal. Watch how they react to any new food. If it causes a problem with their output, consult your child's healthcare professional.

Gas is a common concern — especially with colostomies. Gas in the pouch can be due to swallowed air when the infant sucks. In an older child, gas can come from food, carbonated beverages, using a straw or chewing gum. The WOC/ET or pediatric nurse can provide suggestions for you.

#### Being aware of digestion issues

Children who have ileostomies may have a few additional guidelines. Some foods do not digest well and therefore may not pass through the ileostomy stoma. Your WOC/ET or pediatric nurse or a dietician in the hospital can help you identify these foods. To avoid problems, they may recommend limiting or omitting specific foods. Older children may be allowed these foods if they chew thoroughly before swallowing.

Fluid intake is important for all children. Infants and children with ileostomies can quickly become dehydrated. Refer to the next page for information on dehydration.

If there is no output from the stoma for a prolonged period and your child experiences cramping, diarrhea, vomiting, or bloating, call your child's healthcare professional.

TIP

Ask the healthcare professional or nurse about any dietary modifications that are important for your child. Write down foods that should be restricted or avoided.

### Issues of concern

When your child has an ostomy, there are issues that you need to be aware of at all times. Be sure to report what you have observed to your healthcare professional immediately.

#### **Skin irritation**

The skin around the stoma can become irritated. Some of these skin breakdowns are minor and improve quickly. If the skin becomes open and moist, it can interfere with a good seal. If there are frequent unscheduled pouch changes (twice daily or more often), it can lead to further skin irritation. Contact your child's WOC/ET or pediatric nurse for assistance.

#### **Prolapsed stoma**

This occurs when the stoma changes and becomes longer or larger than it had been. If this happens, it can be of concern. It is important to report this to your child's healthcare professional and/or WOC/ET nurse.

#### **Retracted stoma**

This happens when the stoma sinks below skin level. It may occur when the stoma swelling goes down or your child gains weight. Both are normal. If the stoma retracts, it may decrease wear time on your child's pouching system. Your WOC/ET nurse may have suggestions on how to help.

#### **Dehydration**

Any child can develop diarrhea, which may also be accompanied by vomiting. This can cause dehydration. Dehydration occurs when they lose too much fluid and are not able to replace it by drinking. Signs of dehydration include weakness, less urine output and/or dark urine, dry mouth, sunken eyes, and no tears. Children with ileostomies can become dehydrated very quickly.

You should become familiar with what is normal stoma output for your child — be able to recognize the usual consistency and how often you normally empty the pouch. Do not use over-the-counter medications to treat diarrhea or vomiting without talking to your child's healthcare professional. If you note signs of dehydration, call your child's healthcare professional immediately. If you cannot reach them, go to the emergency room.

#### **Bleeding**

The stoma may bleed easily when rubbed or bumped (for example, when washing) but should resolve quickly. If the bleeding does not stop, contact your healthcare professional immediately. If you cannot reach them, go to the emergency room.

Be sure to ask your WOC/ET or pediatric nurse and your child's healthcare professional what they want you to inform them of after discharge from the hospital. As a parent, you know your child, and if you suspect there is something not right, even if you are not sure what it is, you should seek medical attention.

### Frequently asked questions

#### What should I use to clean the skin and stoma?

Gently clean the skin using something soft like a cotton ball, washcloth, or paper towel moistened with water. It does not need to be sterile. If you use soap without oils or moisturizers, be sure to rinse completely. Most baby wipes add moisture to the skin which interferes with the barrier sticking well, so they are not recommended.

#### Can my child sleep on their tummy?

If that is the way they prefer to sleep and it is okay with your child's healthcare professional, it will not hurt the stoma. Empty your baby's pouch before a nap or bedtime.

#### Do I have to feed my child a special diet?

A special diet may be required by other medical conditions, but not because of the stoma. New foods can be added to your baby's diet as recommended by their healthcare professional. When a new food is added, it may change the color or consistency of your baby's stool or result in more gas. This is normal. Watch how they react to any new food. If it causes a problem with their output, consult your child's healthcare professional.

#### Can I breastfeed my baby?

Yes. Breastfeeding offers many advantages for both baby and mom. It is your choice.

#### Do I have to get certain clothes for my baby?

You don't need special clothes, but make sure waistbands don't rub against the stoma. Some two-piece outfits may slide down and pull the pouch off, but they do make it easier to empty the pouch.

#### What if I smell an odor?

There should not be an odor when the pouch is on securely. If there is an odor, it usually means there is a leak in the pouching system or the spout of the pouch is not clean. Odor eliminators can help when the pouch is emptied or changed.

#### Can my baby take medications?

Only give medications to your baby that have been prescribed by their healthcare professional. When starting a new medication, you may notice a change in his or her output. When filling a new prescription, tell your pharmacist that your child has an ostomy.

# They told us the stoma would be red. Sometimes it changes color. Does that mean something is wrong?

Occasionally, the color of the stoma will change. Sometimes, when a baby cries, the stoma becomes almost white. If the color change is temporary — less than a few minutes — it is usually nothing to be concerned about.

# My child has gotten older, and has now started pulling their pouch off. What can I do?

Children are naturally curious about their bodies and things around them. The pouch is no exception. It helps to dress your child in a one-piece outfit — even for naps. This can deter their exploration. A few toys in their crib can also help satisfy their curiosity.

# My baby's pouch used to stay on longer. Is there anything I can do?

As your baby becomes more active, there will be additional stresses placed on the pouch seal. This is frustrating, but normal. When they start to scoot, crawl, pull themselves up on furniture and walk, the pouch may come off more often. You don't want to limit this healthy activity. Your child's WOC/ET nurse may have some tips to help improve the seal. The stoma can get larger as your child grows, so be sure to continue to reasses the stoma to assure a correct barrier fit.

# The skin barrier we are using doesn't seem to be working as well. Is there something I can do?

There are a number of things that can affect the skin barrier. In warmer weather, the skin barrier may not last as long. Changes in diet or a new medication may impact its effectiveness. Often, as babies start teething, parents notice a change in the stool. This can cause the skin barrier to wash away and not last as long as before. Most of these are temporary situations. If the problem persists, check with your child's WOC/ET nurse. They may be able to recommend a skin barrier that is more durable.

#### Can we travel?

Yes. Planning ahead is important for any trip, but it takes on new meaning with a baby. Be sure you have plenty of supplies. If you are flying, take your baby's ostomy supplies in your carry-on luggage. Changes in environment or routine may reduce the wear time of the pouch seal, so be sure to pack more than you think you will need. When in a car, your infant should always be in a car seat.

#### What about day care?

If you are planning to return to work, talk with your day care provider about your baby's ostomy and make sure they have plenty of supplies. You should teach several people how and when to empty the pouch. Plan how a pouch leak will be handled when you are not there. Preparing for these situations in advance can alleviate anxiety and ensure that your child gets the best possible care when you are not around.

#### Where do I buy ostomy supplies?

Ostomy supplies are available from many sources, but they are a specialty item. You can't just pick them up at any drug store. If there is not a retailer in your area, you can get your products by mail. Contact your child's WOC/ET nurse for suggested locations to purchase your child's supplies.

#### Will my insurance pay for the ostomy pouches?

That depends upon your type of insurance coverage. Talk to your child's WOC/ET nurse, insurance provider, or physician. Even though these products do not require a prescription, an order from your healthcare professional may assist with reimbursement.

### Ostomy product supplies

Once you have established a product fit that is right for you, it is time to find a supplier that can provide you with an ongoing supply of ostomy products. There are several considerations when choosing a supplier:

- Do you want to work with a national or regional durable medical equipment (DME) supplier who can mail your supplies, or do you prefer to pick up supplies at a local pharmacy or DME supplier?
- Can the supplier bill your insurance in-network to minimize your out-of-pocket expense?
- Do you already have a DME supplier that serves your other medical device needs?

Ostomy products are specialized supplies that are not available through all pharmacies. You may choose to use mail order supply companies or purchase through a local retailer.

Many ostomy supplies are covered by private insurance plans, military benefits, Medicare, and Medicaid. Check with your carrier to find out your level of coverage and if you must use a specific supplier.

If you would like help finding supplier options, Hollister Secure Start services can help. Please call us at **1.888.808.7456.** 

### Hollister Secure Start Services

You may have questions about your child's ostomy and how to care for the stoma — but you don't have to figure it out on your own. Hollister Secure Start services offers FREE dedicated ostomy support for as long as you need it, regardless of the brand of products you use for your child.

Enrolling is simple and provides lifetime access to Hollister Secure Start services. Ask your clinician for help enrolling, or you can speak to a member of our team by calling **1.888.808.7456.** 

#### Here's how it works:

After you enroll, you will receive an introductory kit that includes a travel bag, stoma measuring guide, mirror, scissors, and educational booklets. You and your child will be matched with a dedicated Consumer Service Advisor who can walk you through the introductory kit and work with you to ensure you get the care you need, including help with:

- Finding the right products
- Helping you sort out your insurance coverage
- Identifying product supplier options
- Accessing an ostomy nurse over the phone to find answers to your clinical product questions
- Providing product information and condition-specific education
- Finding local resources

Your Consumer Service Advisor will check in periodically to see how you are doing and to answer any questions. You should expect your first phone call within 72 hours of enrolling.

To learn more about taking care of your ostomy or how Hollister Secure Start services can support you, please call us at **1.888.808.7456** or visit **www.securestartservices.com.** 

### Resources

Your child's healthcare professional and WOC/ET nurse will be providing very important resources for you in the days ahead. You will also have ongoing access to online information, or printed educational materials, at **www.hollister.com/ ostomycareresources**, such as:

#### **Hollister Secure Start Services**

1.888.808.7456 | www.securestartservices.com

#### **WOC Nurse**

These nurses specialize in the care of children and adults with ostomies and other related conditions. You can call us at Hollister Incorporated and we will be happy to help you find one in your area. You can also check out the WOCN web site at **www.wocn.org.** 

#### Your Physician(s)

Depending on your child's situation, they may have many different healthcare providers. Each plays an important role in your child's care. Be sure you have their phone number and medical specialty written down.

#### United Ostomy Associations of America, Inc. (UOAA)

If your child is going to have their ostomy for some time, you may find it helpful to check out the UOAA. In addition to offering support relative to ostomies, they have links to many other useful organizations such as the Pull-thru Network, Spina Bifida Association of America, and About Kids GI Health. You can visit their web site at **www.uoaa.org.** 

#### **Pouching System Care Tips**

These full-color care tip sheets use step-by-step photographs to help you understand exactly how pouching systems are used. They are available for one-piece, two-piece, and premie/neonatal pouching systems.

#### "Can They Still Wiggle and Giggle?"

This coloring book answers questions real kids want to know about living with an ostomy. It is helpful for the young child with an ostomy or for a sibling who might have questions.

#### **Ostomy Shadow Buddy**

These special buddies are for children who have had or will have ostomy surgery. A mom, whose son needed a stoma, designed Shadow Buddies. The huggable dolls have heart shaped eyes for love and a smile that never fails no matter what the situation. Learn more about Shadow Buddies by visiting **www.shadowbuddies.org.** 



### Glossary

#### Accessories

Optional ostomy supplies that may be recommended by your nurse. Examples include barrier rings, odor eliminators, or ostomy belts.

#### Bladder

A hollow organ where urine is stored prior to voiding (urination). It is removed or bypassed in urostomy surgery.

#### **Closed pouch**

A pouch without a spout or a clamp. Quick and easy to discard. It must be removed to be emptied.

#### Colon

Another term for the large intestine or last portion of the gastrointestinal tract.

#### Colostomy

An ostomy (surgical opening) created in the colon; part of the large intestine or colon.

#### **Drainable pouch**

A pouch that opens at the bottom so you can empty it. Uses some type of fastener at the bottom to close it. Used for ileostomies and colostomies.

#### lleostomy

A surgically created opening into the small intestine through the abdomen.

**One-Piece Pouching System** The skin barrier and pouch are a single unit.

#### Ostomy

A surgically created opening made in the body for elimination of

waste (stool or urine). It is red and moist and has no feeling. It is also called a stoma.

#### **Peristomal Skin**

The area around the stoma starting at the skin/stoma junction and extending outward to the area covered by the pouching system.

#### Pouch

The bag that collects output from the stoma.

#### **Skin Barrier**

The portion of the pouching system that fits immediately around the stoma. It protects the skin and holds the pouching system in place. Sometimes called a wafer.

#### Stool

Waste material from the bowel. Also known as feces or bowel movement.

#### Stoma

A surgically created opening in the gastrointestinal or urinary tract. Also known as an ostomy.

#### **Two-Piece Pouching System**

The skin barrier and pouch are two separate pieces.

#### **Urethra**

The narrow tube from the bladder through which urine drains from the body.

#### Urostomy

An ostomy (surgical opening) created to drain urine.

#### **Urostomy pouch**

Pouch with a spout at the bottom so urine can be emptied quickly.

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