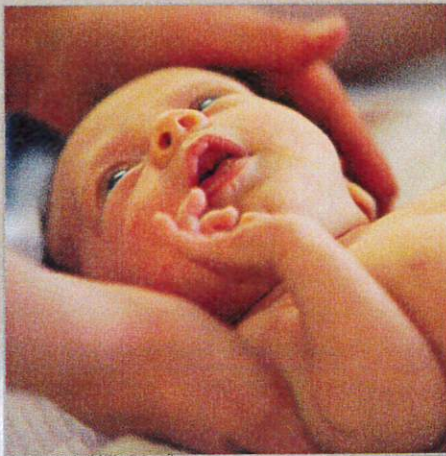


# Caring for Your Child with an Ostomy







Caring for a new baby or raising a young child is a wonderful, life-enhancing experience. It is also a challenge, even in the best of circumstances.



If your child needs stoma formation, your happiness will no doubt be mixed with concern over the special care that is needed. Besides learning to understand your child's medical condition, you will be called upon to learn new skills in managing the ostomy system and figuring out how to balance those needs with your busy lifestyle.

You do have sources for help. Besides your child's doctors, you can turn to specially trained stoma care nurses who specialise in ostomy care. The professional team at Hollister also has knowledge and experience with ostomies and is ready to help.

Hollister has created this book to support you. It is a source you can turn to anytime - as a ready reference and a supplement to the information you receive from your medical team.

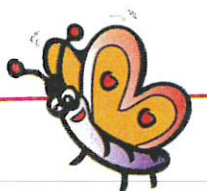
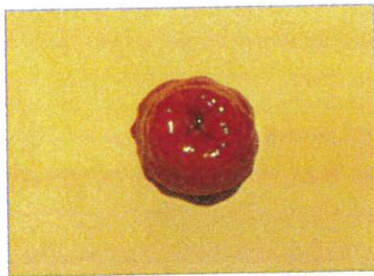


# Caring for Your Child with an Ostomy

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# The Ostomy (Stoma)



## Fact:

The stoma is normally red. However, sometimes when your child is crying you may notice that it changes colour. The normal colour should return when your child stops crying. A temporary colour change is not usually a reason for concern.

**“Ostomy”** is a general term to describe a procedure where an opening is created in the body. The opening, called a “stoma,” allows stool (bowel movement) 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 baby or child may need an ostomy. It is often a life-saving operation.

**Stomas** should be red like the inside of your mouth, and they should be moist and soft. Stomas might bleed a little when rubbed or touched. This is normal because stomas have a lot of blood vessels. They 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. Here are some things that are the same for all stomas and some things that make them different from each other.

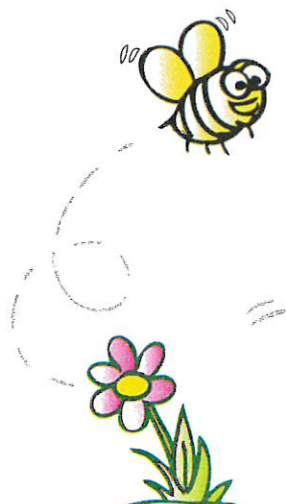
## What is the same about stomas?

- Stomas are red. They look a lot like the inside of your cheek.
- Sometimes they may bleed a little. This is normal.
- They are usually moist and soft.
- They have no feeling and will not hurt if touched.

## How do stomas differ from each other?

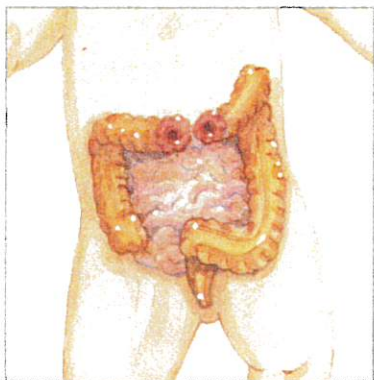
- They may be temporary or permanent.
- Some children have more than one stoma.
- They can be located on different parts of the body
- Stomas may be different shapes and sizes.
- They may stick out above or be slightly below the skin level.
- They are made for different reasons and the output is different.

Read more on page 3 about different types of ostomies.

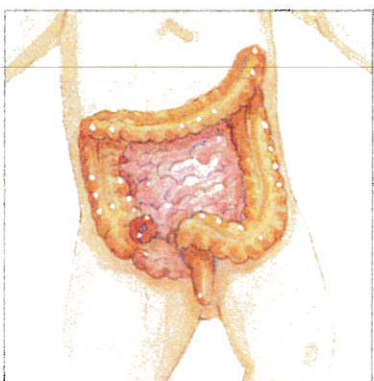




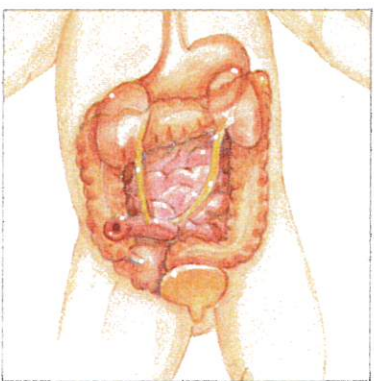
# Types of Ostomies



**A colostomy is an opening in the colon or large bowel.**



**An ileostomy opens into the ileum or small bowel.**



**A urostomy is an opening into the urinary system.**

The type of ostomy your child has will be determined by the reason for the surgery. 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 the most common type of stoma for an infant or child. It is an opening into the colon or large bowel. 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. Flatus (wind) is common.

An **ileostomy** is an opening into the ileum which is part of the small bowel. The small bowel 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 bowel, they can damage the skin. The stool is liquid in consistency. This will be discussed in more detail later in the booklet when we talk about pouching.

A **urostomy** is an opening into the urinary system. The urinary system is made up of the kidneys, ureters, bladder and urethra. The kidneys filter and produce urine. The urine travels from the kidneys down the ureters and into the bladder for storage before it is eliminated from the body.

Urine comes out of the urostomy stoma. The urine may also contain some mucus.

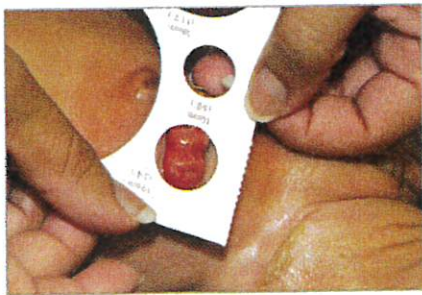


## Tip:

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 stoma care nurse, paediatric nurse or doctor.



# After the Surgery



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

It can be stressful to see your child for the first time after surgery. There may be lots of tubes and equipment in or around your child. Your presence can help calm your child. The hospital staff are 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 doctor 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.

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 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. Ostomy systems that fit well provide the best wear time.



## 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.

## Notes

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# Getting Ready to Go Home

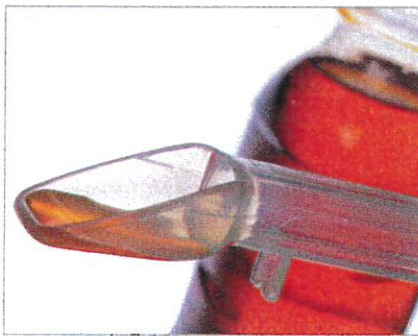


Taking your child home from the hospital after ostomy surgery is rewarding but it may be a little bit scary. Here are a few things to review prior to discharge that can make your transition to home a little easier.

- Be sure you watch the procedure for changing a pouch, more than once if possible. You should also have a chance to change it yourself before your child goes home. Take the opportunity to empty your child's pouch when your nurse is around. You may not feel like an expert yet, but your confidence will build with practice!
- Make a list of all the key phone numbers. This list might include: the nurse, doctor and company that provides your child's ostomy supplies.
- Be sure to have information about scheduling follow-up visits, medication and other care your child needs such as incision care.



## Medication



Before discharge from the hospital, make sure you understand any medication that your child needs to take. Know what they are for and how often they are needed. Only give medication to your child that has been prescribed by their doctor.

When starting a medication, you may notice a change in the stoma output. When collecting the 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.

Consult your child's doctor before giving any over-the-counter medication or home remedies. If your child is taking many different types of medication, it is helpful to bring them with you to the clinic or doctor's surgery for follow-up appointments.





# Ostomy Systems



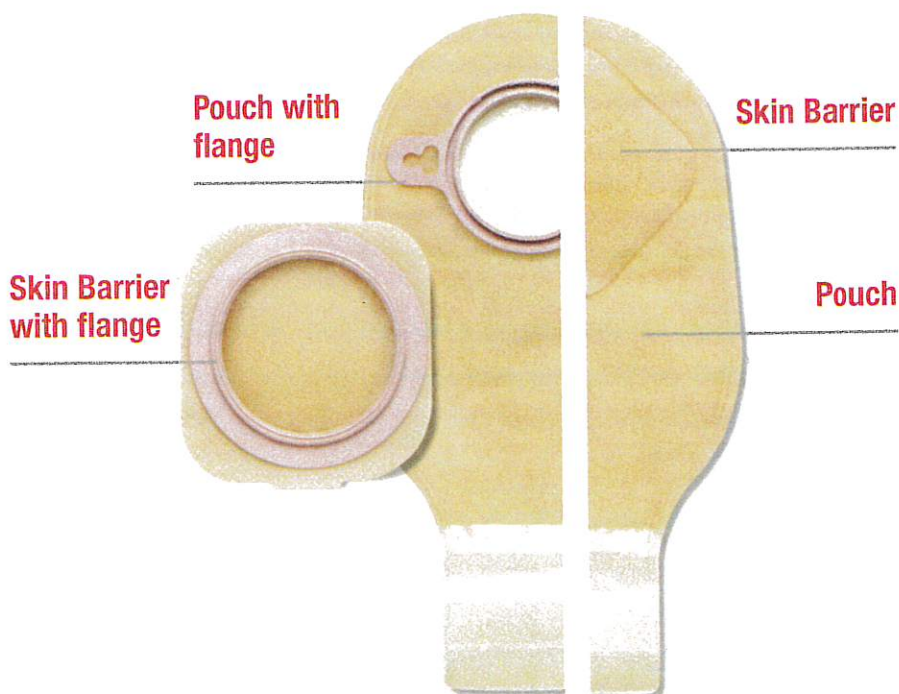
There are key parts to an ostomy system you should know about.

The **skin barrier** is the waxy part which sticks to the skin and fits around the stoma. It protects the skin from contact with stool, urine or enzymes. It is not a tape, but, like tape, it holds the ostomy system in place.

The **pouch** is the plastic bag that collects the stoma discharge. It is made of a material designed to contain the odour.

**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, odour eliminators or ostomy belts. Use these products if directed by your consultant or paediatric nurse.

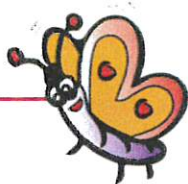
## Two-Piece System    One-Piece System



There are many options in an ostomy system. Let's review the different types so you know what is right for your child. At the end of this book, specific ostomy systems are illustrated and described.

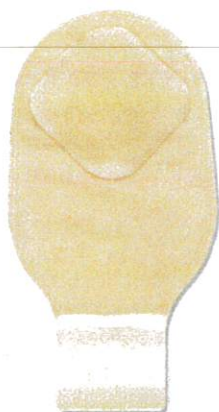






### Fact:

When you remove the skin barrier, you may notice a slight pink colour on the skin where the adhesive was. This is temporary and will go away.



**Drainable ostomy systems can be used to empty stool and flatus.**



**Urostomy ostomy 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 customise the opening so that the skin is covered and protected.

The skin barrier should also help the ostomy system stick to the skin. It should hold the pouch on but not be too difficult to remove. Hollister Pouchkins paediatric products use the gentle **SoftFlex** skin barrier.

## 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. premature infants) or with younger children for specific occasions (e.g. swimming).

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 wind out of the pouch without causing odour. This is usually used with colostomies and some ileostomies - never with a urostomy.

There are different pouch designs. In a **one-piece ostomy system**, the skin barrier is already attached to the pouch. It is very flexible and easy to use. Refer to Pouchkins One-Piece Ostomy System Care Tips for specific instructions on how to use the ostomy system.

With a **two-piece ostomy system**, the skin barrier is separate from the pouch. The pieces snap together with a flange (the piece that looks like a plastic ring) or attach with an adhesive. The Pouchkins ostomy system uses a **floating flange** so you can put your fingertips under the flange for support while you attach the pouch to the skin barrier. You can unsnap the pouch to change or empty it, or let the wind out. Refer to Pouchkins Two-Piece Ostomy System Care Tips for specific instruction on how to use.



### Tip:

As your child changes or becomes more active, the ostomy system that works best may change. As children grow, they may need a larger pouch or the addition of accessories. The stoma care nurse can help you decide when to make these changes and what changes to make.



# Emptying the Pouch

One of the first skills you will learn is how to empty the pouch. This is not much different from changing a nappy. 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 flatus, stool or urine. If it gets too full, it will leak or not last as long. It is always a good idea to empty the pouch before naptime and bedtime or trips in the car. After emptying, wipe the bottom of the pouch before closing. A tissue or baby wipe works well for cleaning the bottom of the pouch.
- If you use disposable nappies, you can simply empty the pouch contents into the nappy when you are changing your baby's nappy. Occasionally your child's healthcare provider may ask you to measure the output.
- If you are using a two-piece ostomy 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, 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 the 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 **Adapt** Lubricating Deodourant. This product makes the inside of the pouch slippery so that the contents empty more easily. It also has the benefit of eliminating odour. Do not substitute with other products such as cooking oil, baby oil or soap as they can weaken the pouch seal.



**Be sure to wash your hands after emptying or changing the pouch.**



## Tip:

If your child's stool is liquid, placing a couple of cotton balls inside a *drainable* pouch can help absorb some of the fluid.



# Changing the Pouch and Skin Barrier



## Tip:

If you are routinely changing your child's pouch more than once a day, tell your stoma care nurse.



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 or in your car on a hot day.

How often you change the ostomy system depends on how long the skin barrier stays in contact with your child's skin. If the ostomy 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.
- 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.
- Always apply the skin barrier to clean, dry skin. The adhesive will not hold well on wet skin. After you apply the skin barrier and pouch, hold your hand against the barrier and gently press against the skin until the entire barrier adheres. The warmth and gentle pressure will help create the initial adhesion to the skin.
- 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.

## Pouch Application

Step-by-step instructions are found in the Pouchkins Ostomy System Care Tips (see resources page 22). Additionally, you should carefully review the instructions for use accompanying the product. They help you understand the basics of ostomy systems. You can also get help from your stoma care nurse. Specific instructions are included with your products.

Call our Customer Service Department on:

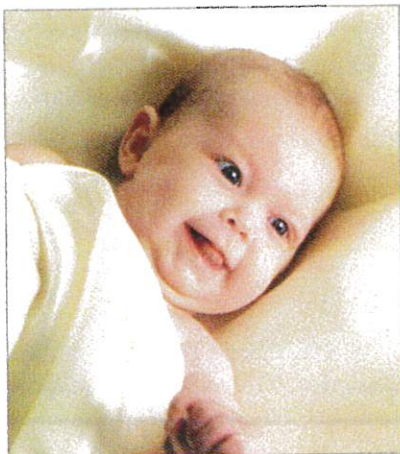
**UK: 0800 521377**

**Ireland: 1800 503400**





# Care of the Skin



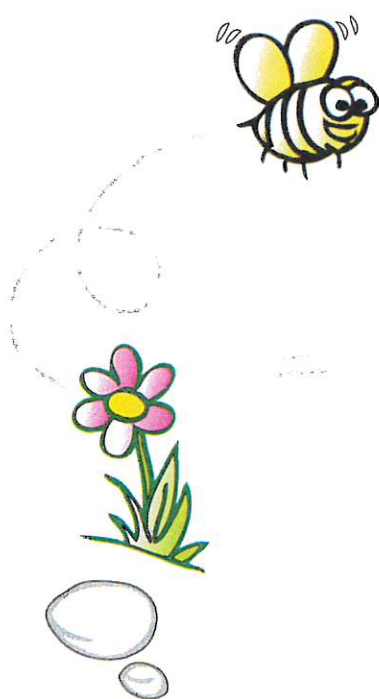
The skin around the stoma is called the peristomal skin and it is just the same as other skin on your child's body. It is not more or less sensitive. Although the stoma has no feeling, the skin does.

One of your most important goals is to keep the skin healthy. If the skin does not stay healthy, problems with pouch leaking may occur. To clean the skin around the ostomy, use just water. Or you can use a mild soap that does not leave a film or residue on the skin, then rinse with plain water. Always rinse off any soap. Soap or water will not hurt the stoma.

Do not use any baby wipes, oils, powders, ointments, lotions on the skin around the stoma. These products contain ingredients that can prevent the ostomy system from sticking.

If you have a premature 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, such as SoftFlex skin barriers from Hollister, 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 provider.

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 advice of your stoma care nurse or other knowledgeable healthcare provider.





# Plan Ahead



Children tend to keep their own schedules but you can be ready by planning ahead. There are many ways to make a pouch change stress-free. Being prepared can make all the difference ... especially for those unscheduled changes!

- 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 is a good time.
- Knowing your child's routine is helpful. If there is a time during the day when the child is normally quiet, that is the best time to change the pouch. For example, in the morning or after the evening bath might be good times in your household.
- 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!
- A toy or mobile can help to distract a wriggly 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 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 nappy bag, and at a grandparent's house.

**Our Travel Checklist**

- ☒ Skin Barrier
- ☒ Pouch
- ☒ Cotton Balls
- ☒ Pouch Closure
- ☒ Scissors
- ☒ Disposal Bag
- ☐ Other Supplies

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# Activity



**Activity in an older child, even sports, need not be limited just because of the stoma. Consult your child's doctor about any weight limits for lifting or activity in the early time after surgery.**

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 pouch on or off. Water will not go into or harm the stoma. If your child has a urinary stoma, check with your child's physician before allowing the water to cover the stoma. If you decide to leave the pouch off while bathing, don't be surprised if the stoma functions when in the bath. 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 pouch when bathing, dry it off afterwards and check the seal for security.

## Swimming

As you might guess from what you just read above, it is absolutely fine to swim with an ostomy. You are advised to use a pouch when 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 ostomy 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.

## Travelling

When travelling on a plane with your child, be sure to pack your supplies in your hand 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. However, once they become more active, there will be more stress on the ostomy system. You may need to make some adjustments in products, but the child's natural curiosity and activity should not be discouraged.



## Tip:

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



# Clothing



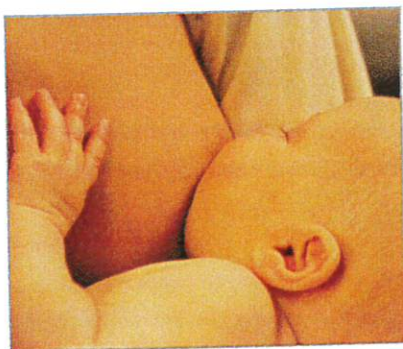
Your child won't need special clothes because of a stoma, but there are ways to select clothing that will make life easier for both of you.

- When selecting outfits, avoid clothes where the waistband rubs against the stoma or is so snug that it prevents the pouch from filling. One-piece outfits generally work better. Some two-piece outfits could slide down and pull the pouch off before you're ready. On the other hand, a two piece outfit can make it easier to empty the pouch.
- With nappies, you may have to try different options. Some parents find it better to put the pouch on the outside of the nappy and others find it easier to put it inside the nappy. Try different methods to see what works best.
- 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 T-shirts that snap in the crotch hold the pouch more securely near the body and can discourage their curious fingers.





# Diet and Nutrition



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. However, here are a few guidelines that may be helpful.

- Breastfeeding offers many advantages for both baby and Mum. 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.
- New foods can be added to your baby's diet as recommended by their physician. When a new food is added, it may change the colour or consistency of your child's stool or may result in more flatus. This is normal. Watch how they react to any new food. If it causes a problem with their output, consult your child's doctor.
- Flatus is a common concern - especially with colostomies. Flatus in the pouch can be due to swallowed air when the infant sucks. In an older child, flatus can come from food, carbonated beverages, using a straw or chewing gum. The stoma care or paediatric nurse can provide suggestions for you.
- 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 stoma care or paediatric 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.
- If there is no output from the stoma for a prolonged period and your child experiences cramping, diarrhoea or bloating, call your child's doctor.
- Fluid intake is important for all children. Infants and children with ileostomies can quickly become dehydrated. Refer to page 15 for discussion of dehydration.

## Notes



### Tip:

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

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# What to Watch For

**Be sure to ask your stoma care nurse or paediatric nurse and your child's doctor what they want you to inform them of after discharge from the hospital. You can make a note of these items in your journal or on this page of this booklet. 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.**

Because your child has an ostomy, there may be some situations that you need to be aware of. Report them to your healthcare provider if they occur.

## 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 will lead to further skin irritation. Contact your child's stoma care nurse or paediatric 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 physician and/or stoma care nurse.

## Retracted stoma

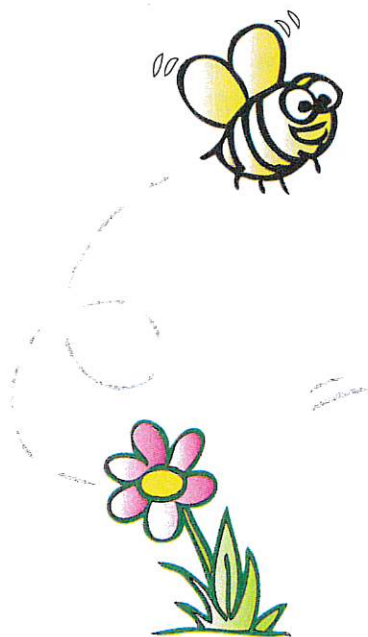
This happens when the stoma sinks below skin level. It may occur when the stoma swelling goes down or your child gains weight. Both are normal. If the stoma retracts, it may decrease wear time on your child's ostomy system. Your stoma care nurse may have suggestions on how to help.

## Dehydration

Any child can develop diarrhoea 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 listlessness, less urine output and/or dark urine, dry mouth, sunken eyes, no tears. Babies and children with ileostomies can become dehydrated very quickly. You should become familiar with what is normal stoma output for your child - be able to recognise the usual consistency and how often you normally empty the pouch. Do not use over-the-counter medications to treat diarrhoea or vomiting without talking to your child's doctor. If the output from the stoma increases and you note signs of dehydration, call your child's doctor immediately. If you cannot reach them, go to the Accident and Emergency Department.

## Bleeding

The stoma may bleed and this is normal. However, if the bleeding does not stop, contact your doctor immediately.



## Notes

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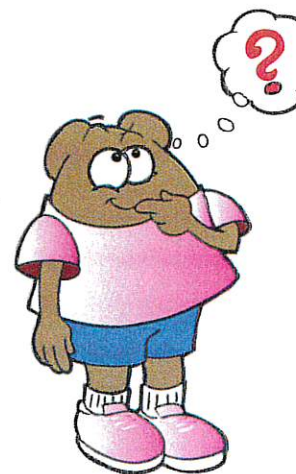


# Frequently Asked Questions

## Can my baby take a bath?

Yes. You can bathe your baby with the pouch on or off. Water will not go into the stoma. If your child has a urinary stoma, check with your child's physician before allowing the water to cover the stoma.

If you decide to leave the pouch off while bathing, don't be surprised if the stoma functions when your baby is in the bath. After the bath, do not use any oily soaps or lotions around the stoma that may interfere with the barrier adhering to the skin.



## 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, 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 I take my child swimming?

Yes. You are advised to use a pouch when swimming in a pool or lake. Larger swimsuits or a T-shirt will cover the pouch.

## Can my older child sleep on their tummy?

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

## Do I have to feed my baby 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 physician. When a new food is added, it may change the colour or consistency of your baby's stool or result in more flatus. This is normal. Watch how they react to any new food. If it causes a problem with their output, consult your child's physician.

## Can I breastfeed my baby?

Yes. Breastfeeding offers many advantages for both baby and mother. 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 odour?

There should not be an odour when the pouch is on securely. If there is an odour, it usually means there is a leak in the ostomy system or the spout of the pouch is not clean. Odour eliminators, like Adapt Lubricating Deodourant from Hollister, can help when the pouch is emptied or changed.

## Can my baby take medication?

Only give medication to your baby that has been prescribed by their physician. 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 colour. Does that mean something is wrong?**

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

### **My child has grown 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 cot 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 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 stoma care nurse may have some tips to help improve the seal.

### **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 stoma care 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.

### **What about day care?**

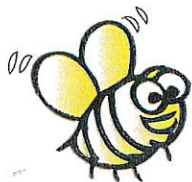
If you are planning to return to work, talk with your day care provider about your baby's ostomy and make sure they have plenty of supplies. You should teach several people how and when to empty the pouch. Plan how a pouch leak will be handled when you are not there.

Preparing for these situations in advance can alleviate anxiety and ensure that your child gets the best possible care when you are not around.





# Glossary



## Accessories

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

## Anus

The opening of the colon located on your baby's bottom.

## Bladder

A hollow organ where urine is stored before it is passed from the body.

## Colon

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

## Colostomy

An opening in the large intestine or colon. Stool from a colostomy can vary from liquid to formed. Flatus is also passed through a colostomy.

## Discharge

What comes out of the stoma. Also called output, it may be urine, stool and/or flatus.

## Ileostomy

An opening into the end of the small intestine called the ileum. Stool from an ileostomy is usually liquid or mushy and contains digestive enzymes. If the enzymes come in contact with the skin it can cause irritation.

## Intestine

A tube-like structure that begins at the mouth and ends at the anus. As food goes through the intestine, nutrients are taken in by the body and waste is passed out of the body as a bowel movement.

## One-Piece Ostomy System

An ostomy system which has the skin barrier attached to the pouch.

## Ostomy

A general term to describe an operation where an opening is 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.

## Output

What comes out of the stoma. It is also called discharge and may be urine, stool and/or flatus.

## Peristomal Skin

The area around the stoma and usually covered by the skin barrier and/or tape.

## Pouch

The bag that collects the discharge or output from the stoma.

- **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.
- **Closed pouch:** A pouch that does not open at the bottom. To empty, it must be removed. Usually used for stomas with little output.
- **Urostomy pouch:** A pouch with a spout at the bottom. Used for urine or very liquid stool.







## Premature Pouch with SoftFlex Skin Barrier



**3777 (CUT-TO-FIT)** Box of 15

- Use as a Premature Closed or Drainable Pouch
- No Starter Hole
- No Integrated Filter
- Odour-Barrier Film
- Soft Wire Closure

| Ultra-Clear Stock No | Barrier Opening |
|----------------------|-----------------|
| 3777                 | up to 15mm      |

## Infant One-Piece Drainable Pouch with Lock 'n Roll and SoftFlex Skin Barrier

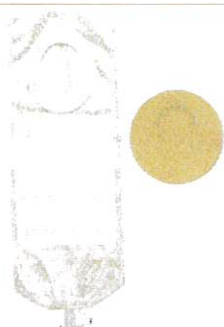


**3796 (CUT-TO-FIT)** Box of 10

- No Starter Hole
- No Integrated Filter
- Lock 'n Roll Closure
- Odour-Barrier Rustle-Free Film

| Transparent Stock No | Barrier Opening | Pouch Length |
|----------------------|-----------------|--------------|
| 3796                 | up to 38mm      | 16cm         |

## Newborn Pouch with SoftFlex Skin Barrier



**3778 (CUT-TO-FIT)** Box of 15

- Newborn Pouch; use with or without the Drain Valve
- No Integrated Filter
- Odour-Barrier Film
- Soft Wire Closure

| Ultra-Clear Stock No | Barrier Opening   |
|----------------------|-------------------|
| 3778                 | up to 35mm x 22mm |

## Child One-Piece Drainable Pouch with Lock 'n Roll and SoftFlex Skin Barrier



**3795 (CUT-TO-FIT)** Box of 10

- With Integrated Filter
- No Starter Hole
- Lock 'n Roll Closure
- Odour-Barrier Rustle-Free Film

| Ultra-Clear Stock No | Barrier Opening | Pouch Length |
|----------------------|-----------------|--------------|
| 3795                 | 50mm            | 18cm         |

## Infant One-Piece Urostomy Pouch with SoftFlex Skin Barrier



**3797** Box of 10

- No Starter Hole
- Odour-Barrier Rustle-Free Film

| Transparent Stock No | Barrier Opening | Pouch Length |
|----------------------|-----------------|--------------|
| 3797                 | up to 38mm      | 22cm         |





## Infant Two-Piece Floating Flange with SoftFlex Skin Barrier



**3761**

Box of 5

- No Starter Hole

| Transparent Stock No | Colour Match | Flange Size | Barrier Opening |
|----------------------|--------------|-------------|-----------------|
| 3761                 | •            | 44mm        | up to 32mm      |

## Infant Two-Piece Drainable Pouch with Lock 'n Roll



**3799**

Box of 10

- No Integrated Filter
- Lock 'n Roll Closure
- Odour-Barrier Rustle-Free Film
- With Belt Tabs

| Ultra-Clear Stock No | Colour Match | Flange Size | Pouch Length |
|----------------------|--------------|-------------|--------------|
| 3799                 | •            | 45mm        | 16cm         |

## Mini Two-Piece Drainable Pouch with Lock 'n Roll



**24743**

Box of 30

- Lock 'n Roll Closure
- Odour-Barrier Rustle-Free Film
- With Belt Tabs

| Stock No | Colour Match | Flange Size | Pouch Length |
|----------|--------------|-------------|--------------|
| 24743    | •            | 45mm        | 18cm         |

## Two-Piece Urostomy Pouch



**24830**

Box of 10

- Odour-Barrier Rustle-Free Film
- With Belt Tabs

| Stock No | Colour Match | Flange Size | Pouch Length |
|----------|--------------|-------------|--------------|
| 24830    | •            | 45mm        | 23cm         |

## Accessories (Use if recommended by your healthcare professional)



**7805**

Box of 10

- Adapt Barrier Rings (Flat)

| Stock No | Outer Diameter |
|----------|----------------|
| 7805     | 48mm           |



**79300/79301**

- Adapt Paste

| Stock No | Description | Quantity  |
|----------|-------------|-----------|
| 79300    | 57gm tube   | Box of 1  |
| 79301    | 14gm tube   | Box of 20 |



**7906**

Box of 1

- Adapt Stoma Powder

| Stock No | Description     |
|----------|-----------------|
| 7906     | 28g puff bottle |



**7917**

- Skin Gel Protective Dressing Wipes

| Stock No | Description                 |
|----------|-----------------------------|
| 7917     | 12 Cartons of 50 Wipes Each |



**78500/78501**

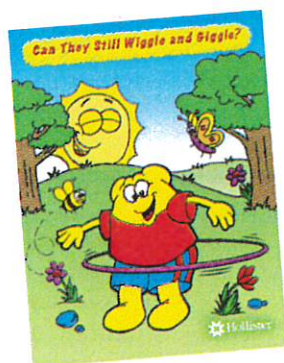
- Adapt Lubricating Deodorant

| Stock No | Description  | Quantity         |
|----------|--------------|------------------|
| 78500    | 236mL bottle | Box of 1         |
| 78501    | 8mL sachet   | Box of 50 sachet |



# Resources

**If you have questions about your child's care, be sure to ask! You are not alone. Here are just a few resources available to help you with information and support.**



## Stoma Care Nurse

These nurses specialise in the care of children and adults with ostomies and other related conditions. You can call us at Hollister UK and we will be happy to help you find one in your area.

## Your Physician(s)

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

## Hollister UK

Our mission is based on service and a commitment to make a difference. Nowhere is our dedication to world-class performance better demonstrated than by our reputation for consistently producing the finest quality ostomy products. Hollister's knowledgeable Customer Service representatives and clinicians can assist you.

Call us at **UK: 0800 521377 Ireland: 1800 503400** and check out our web site at **[www.hollister.com](http://www.hollister.com)**

## Pouchkins Ostomy System Care Tips

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

## Can I Still Wiggle and Giggle?

This colouring book answers questions real children 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 mum, whose son needed a stoma, designed Shadow Buddies. Marty and Miles Postlethwait have shared their story and helped children all over the world. The huggable muslin dolls have heart shaped eyes for love and a smile that never fails no matter what the situation. For each child, the Ostomy Buddy becomes a friend "just like me." Hollister Incorporated and Shadow Buddies have teamed up to provide these "special buddies for special children". You can learn more about Shadow Buddies by visiting **[www.shadowbuddies.com](http://www.shadowbuddies.com)**.



# Acknowledgements

**Hollister gratefully acknowledges the assistance and caring of the following nurses.**

**Bev J. Biller**, BSN, RN, CWOCN  
Tufts-New England Medical Center  
Boston, MA

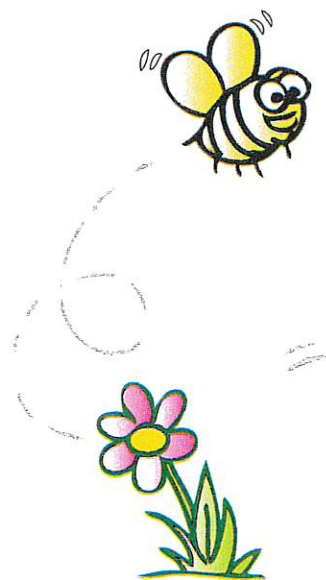
**Teri Coha**, RN, APN, CWOCN  
Pediatric Surgery  
Children's Memorial Hospital  
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**Beth Harrison**, RN, MSN, CWOCN  
Children's Hospital Los Angeles  
Los Angeles, CA

**Joan Lerner Selekof**, BSN, RN, CWOCN  
University of Maryland Medical Center  
Baltimore, MD

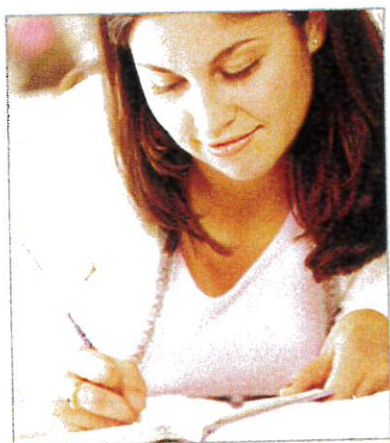
**Teri Robinson**, RN, BSN, CWON  
Arnold Palmer Medical Center  
Orlando, FL

**Bonita Yarjau**, RN, BN, ET  
Health Sciences Centre  
Winnipeg, Manitoba, Canada





## Your Own Story



Most likely, you did not expect your child to need ostomy surgery. No doubt, you have experienced a range of emotions such as surprise, worry, frustration. Knowledge and the correct products can help you remember this time for the right reasons - your child and not the stoma.

Keep in mind that the stoma does not delay your child's physical or cognitive development.

This is truly a special time in your life and in the life of your child. You want to capture these moments - the joys and the challenges - to share with your child when they are old enough to ask questions. Write your questions, instructions, thoughts, feelings and specific anecdotes in a diary or in this booklet. You can also preserve memories by taking pictures, saving a pouch, their Shadow Buddy or the colouring book to show your child when he or she is older.

This is a story about a special child ... yours!



## Notes

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