caring for a child with a stoma
Finding out that your child needs ostomy surgery can be an extremely traumatic time for a family. It will be difficult to watch your child undergo the surgical procedures, even though you recognise that this may be the only option for your child to survive. It will also be a huge learning curve for you and your family as you will have to learn new skills to treat your child’s medical condition whilst at the same time juggling your own busy lifestyle.

It is important to remember though that help is at hand. Besides your child’s doctors, you can consult with Stoma Care Nurses (also known as Enterostomal Therapy (ET) nurses or Wound, Ostomy & Continence (WOC) nurses) who are trained to deal with all aspects of ostomy care. The following guidance will also hopefully be of some help to you in understanding your child’s condition and the issues you may face in the near future.

**What is a stoma?**

A stoma is an opening that is created to allow stool or urine to pass out of the body. Although more common in adults, it is not unusual for a child to have ostomy surgery. For some the stoma is carried out as a temporary measure, to allow the gut a period of rest and recovery, whilst for others it may be permanent, having been carried out as a life-saving measure. Some of the most common conditions that might necessitate a stoma are:

- Imperforate anus: where there is no exit for the bowel or its contents.
- Hirschsprung’s disease: where nerves called the ganglion nerves are missing and waste matter cannot easily pass.
- Inflammatory bowel disease: this includes Crohn’s Disease and Ulcerative Colitis, both inflammatory diseases of the intestines.
- Neonatal necrotising enterocolitis: this occurs when a portion of the bowel is dead and cannot function and is most common in premature babies who weight less than 3 pounds at birth. In this case a stoma can mean life to a baby.
- Spina bifida: where part of the spine fails to develop properly and in more severe forms of the disease, the spinal nerves that control the muscles of the legs, bladder and bowels may be affected and a stoma needed.
• Accident, injury and other causes: these include cancer and also injuries to the bowel or bladder caused by car accidents, etc

After surgery, your child will pass stool/urine through the stoma instead and will not be able to control when this occurs. To help with this a pouch is worn to collect the waste.

**What does the stoma look like?**

• Stomas will be a pinkish red in colour, similar to the inside of your mouth, and will be soft and moist.

• Do not be alarmed if your child’s stoma looks different from other pictures you may have seen as the appearance of the stoma will be unique.

• It is also common for the stoma and the area around it to be slightly swollen for around 6-8 weeks after surgery, after which the swelling will subside.

• Sometimes the stoma may bleed a little, for instance if brushed by a towel or dressing. This is entirely normal as stomas have a lot of blood vessels and the bleeding usually stops very quickly.

• Stomas have no nerve endings and therefore no feeling so it will not hurt when touched.

• Dependent on the type of stoma, it can be located on different parts of the body.

• Dependent on the type of stoma, the output will be different.

• The stoma may sit out above or be slightly below the skin level.

• The stoma may grow with your child, especially if it is permanent. It is important, therefore to re-measure the stoma from time to time to ensure that the pouch still fits correctly.

• At times when your child is crying you may notice a change in the colour of the stoma. However, the normal colour will return when the crying stops.
What types of stoma could my child have?
There are 3 types of stoma and the type of stoma your child has will be determined by the reason for the surgery.

1. **Colostomy**
   This is the most common stoma type for a baby or child. A colostomy is an opening made into the large intestine or colon. The stool can then pass from the stoma out of your child’s body which tends to be solid in consistency but can sometimes be liquid.

2. **Ileostomy**
   In an ileostomy the opening is made in the small intestine – the ileum. An end or loop of the small intestine is brought through the skin’s surface on your child’s abdomen and the output then passes out through the stoma. The ileostomy will resemble a ‘spout’ because the waste is more liquid. Due to the fact that ileostomy output contains digestive enzymes, this can be harmful to the skin and so requires extra care when pouching.

3. **Urostomy**
   A urostomy is an opening made to divert urine from the bladder and also resembles a ‘spout’ as the output is urine.

Selecting your child’s appliances
Before leaving hospital with your child, your Stoma Care Nurse will be able to answer any queries that you may have. Be sure to ask them any questions that might be concerning you and also ensure that you are prepared for the pouch changing regime. You should have the opportunity to help the nurse out with pouch changes to build your own confidence. Also ask for information about follow-up visits and medication if the subject hasn’t been raised. It is worth noting that certain medications may affect stomal output and its consistency. This is common but you might want to consult your medical team if it is something you are worried about.
Prior to discharge from hospital, your Stoma Care Nurse will be able to show you a selection of appliances that are available. The key characteristics of Pelican Paediatric Pouches (as supplied by Eakin) are as follows:

- A hypo-allergenic skin protector that is kind and gentle on young skin. This skin protector is also ultra-thin and moulds to create a secure fit.

- A soft, skin-tone fabric that is cool and comfortable against the skin. The Pelican Pouch range all have teddy bear printed fabric with a split backing to allow easy viewing of the stoma without removing the pouch and enables easier pouch fitting.

- A waterproof filter system to allow controlled deodorised airflow.

- Where the waste is fairly runny (e.g. with an ileostomy or some colostomies) a drainable pouch should be used. Our range of Pelican Pouches with their Clipless Closure System ensures the pouch is very quick and easy to empty and clean.

- With a urostomy, the pouch will be emptied frequently. In the Pelican Pouch Paediatric range, a Urostomy Pouch is available with a soft, flexible and secure tap, for added comfort. The flow can be controlled on emptying by simply squeezing the tap.

- The flexible tap also enables a secure connection to most commonly used night drainage systems.

- A fabric backing behind the tap provides extra comfort, while the plastic under the tap can be wiped clean.

- This pouch is specifically designed to ensure minimal pooling of urine at the base of the pouch to aid complete emptying. The non-return valve prevents back flow of urine.
A Convex Drainable Pouch can be used to provide extra protection against leakage, particularly where the stoma is flush or retracted.

In addition to the features shared with the other Pelican Pouches, the convex pouch offers some unique benefits:

• The Convex Skin Protector moulds to individual body contours and achieves a snug fit around the stoma. The soft shallow convexity has the effect of ensuring that the stoma empties into the pouch and therefore prevents leakage. This extra security is possible without any of the problems associated with traditional, rigid convex pouches.

• The skin protector is durable, offering long lasting protection. Like all Eakin products, it is extremely skin friendly and comfortable to wear. A flexible foam backing provides additional comfort next to the skin.

• The starter hole cuts from 5-30mm, allowing greater flexibility of use. The material is easy to cut, leaving a smooth edge for extra comfort.

The Neonatal Pelican Pouch has all of the same features as before but has no starter hole for care of loop ileostomies and mucus fistulae.

All convex pouches should only be used after prior assessment by a stoma care specialist.
A quick checklist for what you should be looking for in a pouch is:

- Comfortable
- A good, secure fit
- Adheres well to the skin
- Quiet (no ‘rustling’ under the clothing)
- Discreet – shape and colour
- Is easy to empty
- Won’t cause any damage to the skin

You will find more information on the above products and how they are used on our website www.eakin.eu and follow the link to your country.

### Accessories that are also available to help you:

**Cohesive SLIMS®**: Should be used where the skin is painful or excoriated.

The Cohesive® is placed snugly around the stoma to heal and protect the skin from leakage and harmful enzymes. Can be broken in half and remoulded for use on small babies.

**Cohesive® Paste**: Can be used to fill any dips or crevices in the skin to achieve a flat surface for optimum pouch adhesion.

**Perform**: This is a solidifying agent available from Eakin and can be used to thicken pouch output so that it is easier to manage and empty.

**Release**: A fragrant adhesive remover for pain free pouch removal.
Changing an appliance

Drainable pouches may be emptied several times before they need changing, however, closed pouches need changing more often. The following guidance may be of help in developing your own pouch changing procedure:

- Before you attempt to change an appliance make sure that you have the new pouch at hand as well as everything else that you might need. With a baby, this is just like changing a nappy, only you might need an extra pair of hands to hold the baby still!
- Empty the pouch before it gets too full, otherwise it may leak and always remember to empty it before the child goes to bed or goes for a nap. Older children can sit on the toilet to empty their pouch.

It is not necessary to clean out the inside of the pouch when the child is wearing it. In fact putting water into the pouch to rinse it may weaken the skin barrier seal, hence reducing weartime.

There is no fixed amount of time that indicates when a pouch requires changing as this will depend on a number of factors eg. level of stomal output, activity of your child, etc. As a general indication, a pouch could last from 1-3 days on a child. However, if the pouching system becomes loose or is starting to leak then you will know that it needs to be changed.

When removing a used appliance, this should be done gently to protect the skin around the stoma.
- Empty the appliance first, if it is drainable, then use one hand to remove the appliance while supporting the skin with the other hand. If you encounter any difficulty with pouch removal or your child is experiencing any discomfort then Release Adhesive Remover can be used. This is available in either an aerosol or wipe format. The aerosol is sprayed around the edge of the adhesive and after a few seconds the pouch can be gently peeled away. The Release Wipes can then be used to remove any additional residue that has been left on the skin.

The used appliance should be disposed of in a sealed bag but NEVER flushed down the toilet.
- The new appliance should then be applied to clean, dry skin.
- Instructions on how to apply the pouch will be available within the pouch packaging. For a step-by-step guide please refer to our online tutorial ‘Fitting a Bag’ at www.eakin.eu
Skin Care
Your skin is the base, on which all of your stoma products will be placed, so it is vital that it is kept in good condition. The skin around your stoma should be the same colour and condition as the skin on the rest of your body. If you have any queries regarding your child’s skin please consult our ‘Skin Care’ booklet.

Clothing
Although your child will not need to dress any differently, it is advisable to avoid clothes with a stiff waistband that will rub against the stoma or prevent the pouch from filling. But if it is too loose the waistband could slip down and catch in the appliance causing it to loosen.
Many parents find it helpful to use one-piece outfits or vests that button underneath to help keep curious hands from pulling off the stoma pouches.

Swimming
Swimming will not be restricted by having a stoma. A pouch should be worn as normal underneath your child’s swimming costume. An ostomy belt can be worn to make the pouching system feel more secure if necessary.

Travelling
Travelling does not need to be restricted because of your child’s stoma. It may just take a little more preparation before travel.

• Take plenty of ostomy supplies with you (around double what you would normally use - just in case!).
• Keep enough supplies in your hand luggage to last you for a week or so.
• Obtain a list of medical professionals and ostomy associations local to your destination just to be on the safe side.
• Check your travel insurance policy to make sure you are covered.

It is important to remember never to delay changing a leaking appliance for any reason. Within just a short while the skin can become sore and irritated.
Food

Unless your doctor or Stoma Care Nurse recommends a special formula or dietary guidelines, your child will most likely be able to eat a balanced diet. Your doctor may recommend introducing new foods slowly just in case it causes a problem. Some foods will change output colour and consistency slightly but this is generally nothing to worry about. It is important for your child to eat regularly, to chew foods thoroughly and to drink plenty of fluids. Some foods such as green vegetables, baked beans, onions, spicy foods and fizzy drinks will produce more gas/wind so it may be best to cut down on your child’s intake of these common offenders. The ‘Diet’ booklet in this series will offer more guidance on this subject.

Problems that you may encounter

1. **Surface bleeding:** Sometimes the stoma may bleed a little, for instance if brushed by a towel or dressing or if the child falls. This is entirely normal as stomas have a lot of blood vessels and the bleeding usually stops very quickly.

2. **Bleeding from inside the stoma:** This is not normal and should be reported to the doctor immediately.

3. **Wind and flatulence (Colostomates & Ileostomates):** Gas/wind can be a common problem causing the pouch to ‘balloon’. Although some pouches contain filters to remove gas, you may want to try to avoid it in the first instance. The following are considered common foods for causing gas:
   - Vegetables such as broccoli, cauliflower, cabbage, spinach and brussel sprouts
   - Baked beans
   - Onions and garlic
   - Fizzy drinks
   - Eggs
   - Fish
   - Spicy foods.

   Yoghurt and yoghurt drinks may be beneficial in preventing wind.

4. **Constipation (Colostomates):** Constipation may occur as a result of medication or perhaps not drinking enough fluids. If your child is suffering from constipation it may be advisable to try the following:
   - Drink plenty of fluids - water is best
   - Eat more fruit and vegetables
   - Increase the amount of wholegrain and/or bran in your child’s diet
   - Try drinking fruit juice or more fruit purees.
5. **Diarrhoea (Ileostomates & Colostomates):** Diarrhoea can be an indication that your child is having trouble digesting food. If this is the case you should try to remove fibre from their diet and instead eat foods that thicken the stool.

Foods that may lead to diarrhoea include:
- Cabbage and other green vegetables
- Spicy foods
- Fruit (except bananas)

Foods that might help to alleviate this problem:
- Very ripe bananas
- Marshmallows
- Cheese
- Rice/ Noodles/ Pasta

Foods that may cause blockages include:
- Prunes or prune juice
- Citrus fruit juices.

Foods such as radishes, fish, beetroot, spinach and spices may cause your child’s urine to have an unusual odour and colour but this isn’t anything to worry about. Some medications may also affect the urine colour and odour.

6. **Discoloured urine (Urostomates)**

Foods that can help reduce urinary odours include yoghurt and buttermilk.

Generally if the urine is dark, this is an indication that your child is dehydrated and needs to drink more fluids.

7. **Blockages (Ileostomates):** As the ileum is quite narrow, foods which are high in fibre can cause blockages after surgery. As a result the output will lessen or even stop and your child may experience pain and nausea. If your child chews their food well and drinks lots of fluids this should help to avoid this risk.

Foods that may cause blockages include:
- Celery
- Popcorn
- Coconut
- Nuts
- Coleslaw
- Dried fruits
- Peas
- Vegetable skins.
8. **Skin soreness:** Skin soreness can be caused by a number of factors including an ill-fitting appliance where leakage may occur, a change in body size, a change in output, too frequent pouch changes or skin allergies. Eakin Cohesive® is the ideal treatment for sore skin as it absorbs moisture and blocks irritants from reaching the skin. You can find more information on skin care and the benefits of using Eakin Cohesive® in our ‘Skin Care’ booklet.

9. **Odour:** If your child’s stoma pouch is applied correctly then you should not experience any odour until you come to empty the pouch. Certain foods can cause increased odour:
   - Eggs
   - Baked beans
   - Spicy foods
   - Onions and garlic
   - Fish
   - Asparagus
   - Broccoli & brussel sprouts
   - Some cheeses.

Foods such as yoghurt and buttermilk might help to solve this problem.

If you do experience odour when you are not changing the pouch, then this could indicate pouch leakage. If this is the case then change the pouch immediately.

10. **Change in stoma colour:** Your child’s stoma may change colour slightly from time to time. However, if the colour change is quite sudden eg. becoming dark or blue in colour, check to see that it is not being restricted in any way. Consult with your doctor if you are worried.

11. **Prolapse:** When the muscles holding the stoma weaken and allow the bowel to slide out, therefore increasing the length of the stoma, this is known as a prolapse. This can be frightening for the child as some can be quite large but it does not usually cause any pain or affect the way the stoma functions.

    Prolapsed stomas can cause the pouch to leak and the hole of the pouch should be checked for the correct fit. If you are at all worried you should seek advice from your Stoma Care Nurse.
Help is at hand

Although it is alot to cope with at first, when you and your child develop a routine it will become easier. A stoma will not prevent a child from being healthy and active and fulfilling his or her potential in life. All children develop at a different pace and having a stoma will not affect this development in any way.

For help and guidance, your Stoma Care Nurse as well as other medical advisers will be on hand. There are also a number of Ostomy Associations & Groups available to provide information, encouragement and emotional support – your Stoma Care Nurse will be able to give you details of groups in your area. There are also numerous support groups and online discussion forums where you can find a wealth of information from other people in exactly the same situation as you who are only too willing to answer your queries.