



## Understanding the impact of stoma surgery on the child and family

Stoma surgery has a tremendous impact on both the child and family. The entire family experiences a change in their everyday life and the impact of this change cannot be underestimated.

This article is the first in a series of two, both of which are based on the recently published paediatric stoma care best practice guidelines.<sup>1</sup> This article focuses on children in the age groups from neonates to school age, identifying the key topics you need to consider in order to adjust your nursing approach to the needs of these different age groups.

### Neonates

#### *Characteristics of this developmental stage*

The neonatal stage is where the parents, especially the mother, bonds with the newborn. Contact is crucial, and under ordinary circumstances, the baby will spend a great deal of time with the mother.

#### *Emotional impact of stoma surgery*

Giving birth to a baby with a congenital defect, or a disease that requires formation of a faecal or urinary stoma, can be a difficult experience for new parents. The baby's condition may require that the mother and infant are separated, which might jeopardise their initial bonding. Parents may feel a variety of emotions, including guilt, blame, shock and self-doubt. They may

even question their ability to be good parents given the baby's medical condition.

#### **Check out *Paediatric stoma care: Global best practice guidelines for neonates, children and teenagers***

Paediatric stoma care is still a relatively undescribed field, and little literature and research are available. To provide more information about this area, an international group of paediatric stoma care experts – the Global Paediatric Stoma Nurses Advisory Board (GPSNAB) – has developed global guidelines for healthcare professionals. The guidelines cover the full spectrum of paediatric stoma care, from recognising stoma indications to addressing the emotional impact of stoma surgery. To get your copy of the guidelines, visit [Coloplast Professional](#)

### *Nursing approach*

It's a good idea to familiarise yourself with the five stages of grief, as defined in the Kübler-Ross model.<sup>2</sup> This model is relevant, as parents are actually mourning the loss of their 'perfect newborn'. They will go through these phases and it will be important for you to be able to identify which stage of grief they are experiencing. You can then adjust your approach based on where they are in the grieving process. Parents will also need reassurance. They need to feel that they are not alone,

<sup>1</sup> Paediatric stoma care: Global best practice guidelines for neonates, children and teenagers, published in December 2018

<sup>2</sup> See the Glossary of the Paediatric guidelines for more information about this model.

and that they will have professional support throughout the entire course of treatment.

#### *Useful tips:*

1. Make sure the parents understand the explanations they receive
2. Give them the time and space they need to express their feelings
3. Emphasise the baby's positive progress
4. Involve the parents in the baby's daily routine, (e.g. feeding, nappy changing, skin care, supportive holding and skin-to-skin contact)
5. Once the daily routine is established, teach the parents the basics of stoma care and pouch changing. It is important to remind them that touching the stoma does not hurt the baby
6. Make sure to involve both parents in the instruction and support good technique

### **The first two years of life**

#### *Characteristics of this developmental stage*

Children of this age are usually afraid of new faces. They mostly trust their parents, rather than other people. They are greatly influenced by their environment and the facial expressions of those around them.

### **Emotional impact of stoma surgery**

Parents may be sad and anxious when their child has to go through surgery. They may worry about the child's reaction, anticipating possible distress from the experience. Some toddlers may show anger towards their parents, seeing them as responsible for the confusion, frustration or pain they are experiencing as a result of their condition and the surgery they have to go through.



#### *Nursing approach*

Since children of this age primarily trust their parents, it's important that you establish a good relationship with them. If they see that their parents trust you, they will understand that they can trust you as well. You can use

play and physical contact to establish a rapport with the child, so your relationship is based on more than unpleasant procedures. As this age group is highly influenced by their environment, it's very important that both you and the parents use positive facial expressions and language throughout the care. This can help the child adjust to the stoma.

Young children live in the moment, so save explanations until right before you are ready to carry out a procedure (e.g. a pouch change). Explain stoma care in words the child can understand. Adapt to the child's world, rather than asking the child to adapt to yours.

#### *Useful tips*

1. Have everything you need to change the pouch ready before you begin
2. Use the parents to create a calming atmosphere. Distractions can be helpful to shift the child's focus away from the procedure
3. Involve the children and let them have a say. But they need to know that certain rules apply
4. As it's natural for children of this age to be curious about and want to explore the stoma, it's a good idea to dress them in a one-piece garment or a jumpsuit, to limit access to the stoma

### **Pre-school children**

#### *Characteristics of this developmental stage*

Pre-school children need independence and autonomy. This is the age for genitalia discovery and it is also around this time that children are potty trained. Pre-schoolers are very interested in their bodies and they are convinced that the part of the body that receives the most attention is the most important one.

#### *Emotional impact of stoma surgery*

Children may have conflicting emotions about the surgery and view the stoma as some sort of punishment. Some may feel ashamed and boys may have castration fantasies related to the surgery. Parents may feel guilty, which can lead to them being lenient when caring for the child. Others may have the opposite reaction and be overly protective. Whilst these reactions are natural, parents need to realise that they should raise their child in a normal manner. They should focus on helping their child to cope with the stoma.

### *Nursing approach*

For pre-schoolers, the digestive and urinary systems are a mystery. They can name their body parts but they have little knowledge of how their internal organs work. Your role is to demystify these systems by using simple, clear explanations. Pay attention to their fantasy world and use their imagination to your advantage. Some children won't express their feelings outright but you can get them to open up by using puppets and dolls to help them express their concerns and emotions.

#### *Useful tips*

1. Encourage the parents to let the child be involved in caring for the stoma. Help them resist the urge to be over-protective
2. Once the child is home, maintain contact with the family, so you can continue to offer support and advice

### **School-age children**

#### *Characteristics of this developmental stage*

This is the age where children acquire autonomy. They can care for their own personal needs. They begin to acquire competencies and abilities. In addition to being students, school-age children have activities and a social life. This is also an age where intimacy becomes important. Children may begin to feel shy about their genitalia.

#### *Emotional impact of stoma surgery*

Having a stoma created at this age may signify a loss of the control the child has struggled so hard to gain. Prior to surgery, the child was independent in his or her personal care. After surgery, all of this changes. Suddenly, the stoma gets all of the attention. Children can feel confused, uncertain and even ashamed. Parents are often more emotionally affected than children. They may worry about the child missing school, or about what will happen if the pouch leaks while the child is away from home. They may feel guilty about not being able to protect the child from bullying.

### *Nursing approach*

Your role is to advocate for the child's autonomy. Help the parents to see that by involving the child in stoma care, they can give the child back some control over their daily routine. When dealing with the child, you'll find that some of the same methods apply as when dealing with pre-schoolers. Your goal is to demystify the situation, explaining everything in clear and simple terms. Try to get them to open up about their fears, so you can promptly address any misconceptions they have.

#### *Useful tips*

1. School-age children should have access to at least two staff resources when at school
2. They should have extra clothes and stoma supplies available, either in their backpack or locker, in case of leakage

The second article in this series will look at the emotional impact of stoma surgery on adolescents and their families.

For more practical tips and guidelines related to paediatric stoma care and education, please go to the *Paediatric stoma care: Global best practice guidelines for neonates, children and teenagers*. You can download your own copy at [Coloplast Professional](#)