



## Understanding the impact of stoma surgery on the adolescent 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 is the second article 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 examines how surgery impacts adolescents and their families and what you, as care-giver, can do to adjust your nursing approach to meet the needs of this particular group of children.

### 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](#)

### Adolescence

#### *Characteristics of this developmental stage*

The adolescent years are characterised by teenagers' quest for autonomy and independence. Adolescents are highly concerned with their appearance and they are beginning to understand their own sexuality.

#### *Emotional impact of stoma surgery*

Having a stoma during adolescence can be devastating to a teenager's self-esteem, especially in a society that focuses on body image, hygiene and appearance. In addition to coping with the practical aspects of life with a stoma, adolescents must tackle the physical, sexual, psychological and social effects as well.

The following sections unfold each of these areas and how adolescents may respond to them.

- **Physical concerns**

The most common reason that adolescents have stomas is inflammatory bowel disease (IBD). After surgery, teenagers may experience accelerated growth and sexual maturation. Teenagers who are already sexually mature may experience a regression during acute periods of their illness. Adolescent girls may lose their breast development and boys' muscle strength may diminish.

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

- **Sexual concerns**

Adolescents with a stoma put a great deal of emphasis on the acceptance or rejection of their body. They may have difficulty accepting their new body image and feel that they are no longer sexually attractive. They may also fear that their ability to perform sexually has changed. Some will react to these concerns by denial, avoiding the subject of sex and refusing to view themselves as sexual beings. Others will seek out sexual contact and interaction, just to prove to themselves that they are still sexually desirable.

- **Psychological concerns**

The psychological impact will vary based on the circumstances surrounding the adolescent's stoma surgery. If the stoma is temporary, adolescents tend to adjust more easily than if it is permanent. Emotional reactions can range from anger to sadness, from desperation to denial. Some teenagers develop defence mechanisms to cope with the loss of control of their eliminatory function. Some may refuse to recognise their limits, trying to do more than they should or acting as if they don't have a pouch at all. This can be a means of reasserting their independence and defying authority, all of which are a part of the adolescent experience.

- **Social concerns**

Stoma surgery impacts adolescents' social interactions both within and outside the family. Within the family circle, adolescents may feel they are different from everyone else and fear being rejected. They may feel they are a burden for their family, and that they have no value. Outside of the family, adolescents with a stoma may worry about how their peers will react. They struggle with whether or not to tell others about their condition, fearing betrayal and subsequent ostracism. Their illness and surgery mean they have to miss a lot of school, which can further contribute to feelings of isolation and abandonment.

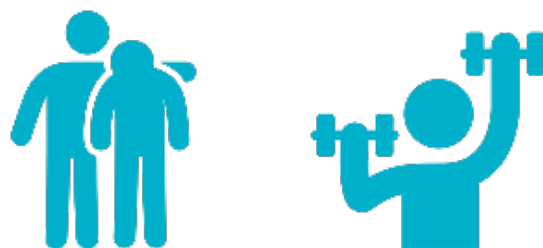
- **Impact on the parents**

Some parents will react by overprotecting their child. Often parents of teens with Crohn's disease and ulcerative colitis have spent so much time with a sick child that, once they have a stoma, the parents have difficulty letting their son or daughter become independent. Other parents will excessively promote the adolescent's autonomy.

- **Nursing approach**

Knowledge-sharing and communication are your two most important tools when working with adolescents. Pre-surgery, you can help by providing step-by-step information regarding the procedure, the tests and the stoma. Share what the adjustment process will be like post-surgery. Use visual aids, along with abstract and theoretical explanations to help them understand their condition more fully.

Adolescents with a stoma need to have someone they can rely on, someone who will not judge them, and someone who will give them the time they need to process what is going on. You might become that person. While providing emotional support is a critical part of your role, you must also be able to recognise your limits and refer to a psychologist when the adolescent shows signs of anxiety or depression.



Caring for adolescents with a stoma requires patience, availability and respect for their adaptability. It involves accepting who they are, without judgement and, at times, despite their attitude and behaviour. Above all else, it is about helping them adjust to their new condition, and recommending a pouching system that is reliable, comfortable, discreet and secure.

*“Adolescence is generally a time of turmoil. Many consider it a war zone – a time and place in life marked by open rebellion and negativism. In fact, the teenagers in question may be demonstrating nothing more than reasonable physical and psychological growing pains.”*  
– Katherine Jeter, 1982

## Working with adolescents with a stoma

What to do?	How to do it?
Try to understand, without being judgemental	Before meeting with an adolescent, familiarise yourself with the teenager's age and maturity level. Remember that adolescents can react with a wide range of emotions. Let them know that you understand their feelings and encourage them to express themselves.
Respect their intimacy and address sexuality issues	It's important to discuss the subjects of contraception and protection with them. The better you are at establishing an open, trusting relationship with the adolescent, the easier it will be to discuss these delicate topics with them and help them maintain a positive body image.
Help them interpret and deal with the reactions of others	Adolescents might not always understand why their parents react the way they do. You can help them to decode their parents' behaviour by explaining why they might be over-protective or stand-offish. Some adolescents will feel the need to share what they're going through with their peers. Work with them to help them find the right level of openness and prepare them for the wide range of reactions they might receive. Try suggesting that the adolescent carefully select a trusted friend to confide in.
Recognise their need for support	Adolescents with a stoma may feel that they are the only ones in that situation. That's why it's so important to introduce them to other adolescents with a stoma. This gives them a network with whom they can share their concerns and exchange ideas. Meeting other adolescents who are successfully coping with their stoma will give your patient hope, which is crucial to adjusting optimally.
Be alert to signs of depression or anxiety	You may become the adolescent's confidant, so it's crucial to be on the lookout for any signs of anxiety or depression, and to be ready to ask for a psychological consultation, if necessary.
Help them plan for life with a stoma	Adolescence is normally a time where children begin to plan for the future. Here your role is to help adolescents set realistic goals, which reflect their capabilities and limitations. Help them to avoid pitfalls such as denying or exaggerating their limitations. Career guidance can also help adolescents to be realistic about their future.

To find out more about the emotional impact of stoma surgery in younger children, please see the first article in this series.

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](#)