

# Teen with a stoma



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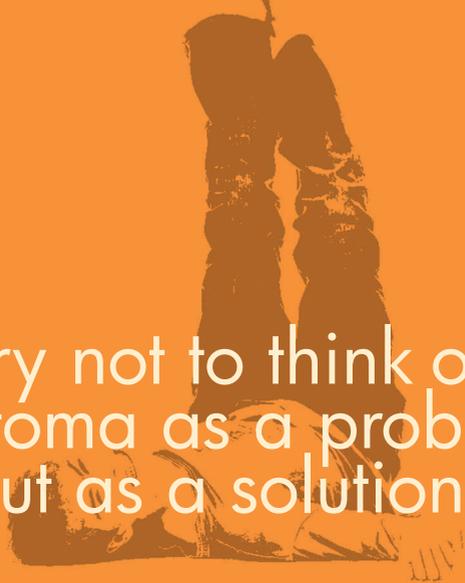
# We wish



We wish to thank Jamie, Zoe, Lauren, Károly and Helene for being open-minded and sharing their personal stories. They have done this to help others in similar situations.

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## Try not to think of your stoma as a problem, but as a solution

Dear friends

# Dear

I was asked to tell you a little bit about what it's like living with a stoma. In fact, I only need to tell you this: You can live a normal, active life with a stoma. To illustrate this, here is my story.

When I was 13 years old, I contracted an aggressive form of ulcerative colitis that came on rapidly. I fell ill in January. In March – just two months later – the situation was so bad that I had no choice but to have surgery done. A total colectomy, when the large bowel is removed, was performed, and I woke up after surgery with an ileostomy. My health before surgery had been pretty bad, so people around me (my parents, doctors and nurses) decided that it was best not to burden me with information about stomas, appliances, etc. So when I woke up and was confronted with the fact that I had a stoma, it came as quite a shock. Though I think it was the only choice for me then. I spent a month or two in hospital, I came home in April, and I didn't return to school until May. My stoma was a secret. The only person that knew about it was my very best friend – beyond that, nobody knew anything. And, in fact, nobody found out either. Looking back, I believe the most important reason why I wanted to keep it a secret was that among all those teenagers at school, several were potential girlfriends, and I felt that I'd prefer to tell them such things myself rather than they heard it from others. After the sixth form, when I became a medical student, things changed considerably. My stoma wasn't a secret as such anymore.

# friend

r

A few girlfriends crossed my path. I discovered that when sex was concerned, these girls were not as easily shocked or frightened as I feared they might be. Actually, I found it rather easy to explain everything to them. And besides, the stoma was never a handicap and never caused any problems when having sex.

Playing sports – football, tennis, swimming, skiing – was something that I really enjoyed before my surgery. It is still an important part of my life, something I couldn't live without. I've also participated in several expeditions in the South American Andes, such as the El Dorado Expedition in 1987.

This brings me to an advantage of having a stoma. When travelling in the tropics, many people suffer from diarrhoea, and you always see travellers running for the toilet. An ostomate is rarely one of those travellers: we can collect our waste in a pouch and thus have time to look for a toilet without running for it!

n o s

I'm now a pediatrician, a children's doctor. I've also got children of my own, and my eldest son is 13 years old. There's never a moment in my life when I feel that my stoma restricts me. And that's my main message to you: Don't let the stoma decide what you can and cannot do – in my opinion you can do almost anything!

Thank you,



Károly,  
Ileostomy since he was 13 years old.

# You know

You know, whether you're a boy or a girl, being a teenager – just being young – means dealing with all sorts of changes and challenges. I was right in the middle of that complex stage, between being a child and an adult, when I got ill and had to have major surgery. I was 13 years old when I had a stoma made. So, in addition to all the natural changes that my body was going through, I also had to deal with being ill and getting a stoma.

I assume that if you're reading this book, it's either because you've just had a stoma or are about to have one. Coping with all that was quite a handful for me. The three teenagers you'll meet in this book – Jamie, Zoe, and Lauren – also had to deal with some pretty big changes in their lives. In this book they tell us what it is like to have a stoma as a teenager.

Jamie, Zoe, Lauren and I have all had a difficult time in our own ways – but we've all coped. There's no one way of handling things! You have to find yourself again after your operation, find your own rhythm and work out how to take into account the changes caused to your daily life.

For me having a stoma has actually meant a serious improvement in my everyday life compared to how it was before I got the stoma. I now feel much more at ease, much stronger and healthier than I used to be. I'm not saying that you'll wake up the day after the surgery and think: Great! This is the best thing that's ever happened to me. Of course, it takes time to get used to new ways of doing things – you should never forget that.

**U** The years have flown by. I'm now 23 and I've had a stoma for many years already, and everything is now second nature. My stoma is just part of me, and sometimes I forget that I have one. Maybe that sounds strange. But that's how I feel at times. I live a good life with my stoma. My study is really interesting, I've got a wonderful boyfriend, I've got lots of friends, and my stoma doesn't limit me in any way. But it took time to reach the point where I am today.

If you ask me, you've got to be prepared to ask for help, for people's understanding, and for time – you need time to get used to your situation. Actually, it's the same for everyone around you – they might need some time to get used to it too. You can choose to tell people a little bit about your stoma, or a lot. It all depends on how open you want to be about it. But don't forget that in general, most people are caring and considerate.

**Q** In my experience, your stoma care specialist can be a magnificent support. They've had special training, and they've got many years' experience of helping other people who've been through the same things as you. So you can ask them for information and they can help you get in touch with organisations for people who have had stoma surgery or have the same illness as you. Enjoy reading the book. I hope it will help you find your own way of living with a stoma. Only you know what is best for you. And remember: Don't be afraid to ask for help and support if you feel you need it. I'm sure you'll find all the help you need.



Helene,  
Ileostomy since she was 13 years old.



If I can't do some-  
thing it's **definitely**  
not because of my  
stoma



# Jamie, 14

Colostomy since he was 11 years old

## **Permanent colostomy**

While I was waiting to have my colostomy, I browsed the Internet to try and find pictures of young people with stomas. I especially wanted to see what the actual stoma would look like. It wasn't easy to find an appropriate picture. They were all photos of elderly people or were worst case scenarios. I wanted to participate in this project so that other teenagers who are about to have this surgery can see a young person who already has a stoma. I held a photo shoot for this (the photographer herself had a stoma) and can assure you that all the pictures show me as I look – no airbrushing or altering was done! I chose to wear jeans and a t-shirt for daily wear and included swimming trunks to show everyone that you can wear any type of clothing you want because no one would know that you had a stoma. I have had my stoma for over 3 years now, and nobody has ever noticed that I have one – even when swimming or when fashions changed and tight jeans and t-shirts were the clothes to wear.

Lastly, I have included pictures showing my stoma. My stoma is a small part of me... An important part that has changed my life for the better, but still a small part!

## **I couldn't control my bowel movements**

Before I had a stoma, life was a bit of a challenge. I just couldn't control my bowel movements. I couldn't go anywhere without taking a change of clothes, some towels, and everything else you might need in case you had an 'accident'.

## **Stoma – I'd never heard the word before!**

When I was eleven years old, the doctors suggested that I should have a major surgery in order to form a stoma or in my specific case to undergo a colostomy surgery. I'd never heard anything like that before. The staff at the hospital told me what a stoma was and how it works. I realised that a stoma could mean that I would avoid the daily problems I'd been having throughout my life, as having a pouch on my stomach would allow me to control my bowel movements. I was immediately excited about this new idea because it sounded as though it would totally change my life - for the better! A stoma could also stop me from being teased and bullied. I could become a normal kid – I'd be able to go out and play, ride a bike, play football – and wear boxer shorts just like all my friends. I never had any doubt that having a colostomy was what I wanted. The doctors and nurses – and my parents – were more worried than I was. I was sure that it was what I wanted, and it was what I needed.

## **The toughest part before my surgery was the bullying**

Before I had my stoma, life was tough. One of the worst things was that I couldn't wear boxer shorts like my friends. If I wore boxer shorts, then I'd have big problems if I'd had an accident – boxer shorts don't hold poo. It was horrible. I was teased. It was very tough and I had a really difficult time. My years in primary school were the worst years of my life. I was teased to a point where I almost believed the bullying was justified. I seemed to have reached a point where I almost agreed with the kids who were bullying me – I felt it was okay to tease me because of the problems I was having and especially because of the smell. All that teasing and bullying made the final decision to have a stoma much easier for me.

*My stoma is a small part of me*



**The stoma has become a natural part of my body!**

The stoma is part of my body now, a natural part of my body. Just like my nose! I don't go around all day thinking Oh my god – I have a nose. And the same goes for my stoma. After my stoma surgery, I could do many things I hadn't been able to do before. So, now the stoma has become a natural part of my body and my life!

**It was easy to learn how to change my stoma bags!**

It didn't take long to learn how to change the bags myself and to work out how to deal with my stoma. It took me only ten days. For many years I had to change my clothes and wash myself after an accident, so just being able to change and throw away my stoma bags is so neat and tidy. This meant I had a pretty serious motivation to work out how to change the stoma bags myself. It gave me the freedom to go and play outside with my friends – just being normal!

I'D BE ABLE TO  
PLAY, RIDE A BIKE



I wasn't quite sure who I could tell about my son and  
I've been very open about it to my family as well as my best friends

GO OUT AND  
PLAY FOOTBALL

and their families. But at the same time, I also think it's something very personal. I think it's very important that I can choose whether or not to tell anyone. I don't really want to tell people at school about it - they don't need to know! No one has realised that I have a stoma and no one could guess. To them I'm normal and actually now I feel normal. Now I've got a stoma and I don't smell so I'm not teased any more. My family is very supportive. I'm the one who decides who needs to know about my stoma.

My advice to other kids or teenagers who may find themselves in the same situation as me would be: look at the pictures and search for information on the Internet or in books. Try to find someone you can talk to – preferably someone with a stoma who can tell you about their experiences. It may give you a better sense of what a stoma is and how you can still have a good life with a stoma. And always remember – a stoma has never stopped me from doing anything. If I can't do something, it's definitely not because of my stoma!



I'M NORMAL, AND  
ACTUALLY NOW  
I FEEL NORMAL

*Lauren had a temporary stoma due to chronic inflammation of the colon. Now, she has a pouch, an artificial colon made from a section of the small intestine. Lauren had her stoma surgery in 2005.*

*It can be difficult to accept getting a stoma. Lauren had a difficult time and this is why she wants to be anonymous.*

# Lauren, 16

Ileostomy since she was 13 years old

## **I didn't want anyone to know about my stoma**

My brother has a stoma - so I had a rough idea of what it is. But I'd never really talked to him about it - and when I got one myself, I just broke down completely. I couldn't discuss it with anyone. I didn't want anyone to know. My mother had done it all before - having a child with a stoma, that is. For her, and for my sister, telling other people that I was about to have one too seemed perfectly natural. Only it wasn't natural for me. The fact that they told other people about it was really too much for me. I just couldn't stand it. I was hurt by the fact that they didn't understand how hard it was for me to talk to other people about it. I felt like they weren't respecting my wishes when I said I didn't want other people to know, and I'm sure that's influenced my relationship with my mum and my sister.

## **I was afraid of how my friends would react**

I was in hospital for quite a long time. Of course, some of my school

friends asked me why I wasn't going to school, but I never gave them a direct answer. When I look back on it, it was probably because I was afraid of how my friends would react. I remember a time when we talked about stomas at school, and the reaction in the class wasn't encouraging. I think that was one of the reasons why I chose to keep it to myself. I didn't want to be different - I wanted to be like everybody else. And with a stoma, I really felt different; it was pretty unpleasant and it was really, really difficult for me.

### **My body - I hated my body**

Before I had the stoma, I was taking a lot of medicine to try and get rid of, or at least calm the inflammation in my colon. I was a teenager, and suddenly I felt like my body was exploding. I was given steroids. One of the side effects of that kind of medicine is that the allocation of fat in the body changes. I felt like suddenly I just didn't look like myself any more. I was so unhappy. Extremely unhappy. From wearing smart clothes and looking good, I suddenly started wearing baggy clothes that hid my body. I still find it hard to look at my abdomen, which is heavily scarred from the operations. I often feel ugly when I compare myself with other people. I think I've had my fair share of stuff to deal with in my early teenage years: the side effects of the medicine, the stoma, and the scars on my body.





THE FACT  
THAT THEY  
TOLD OTHER  
PEOPLE ABOUT  
MY STOMA  
WAS REALLY  
TOO MUCH  
FOR ME

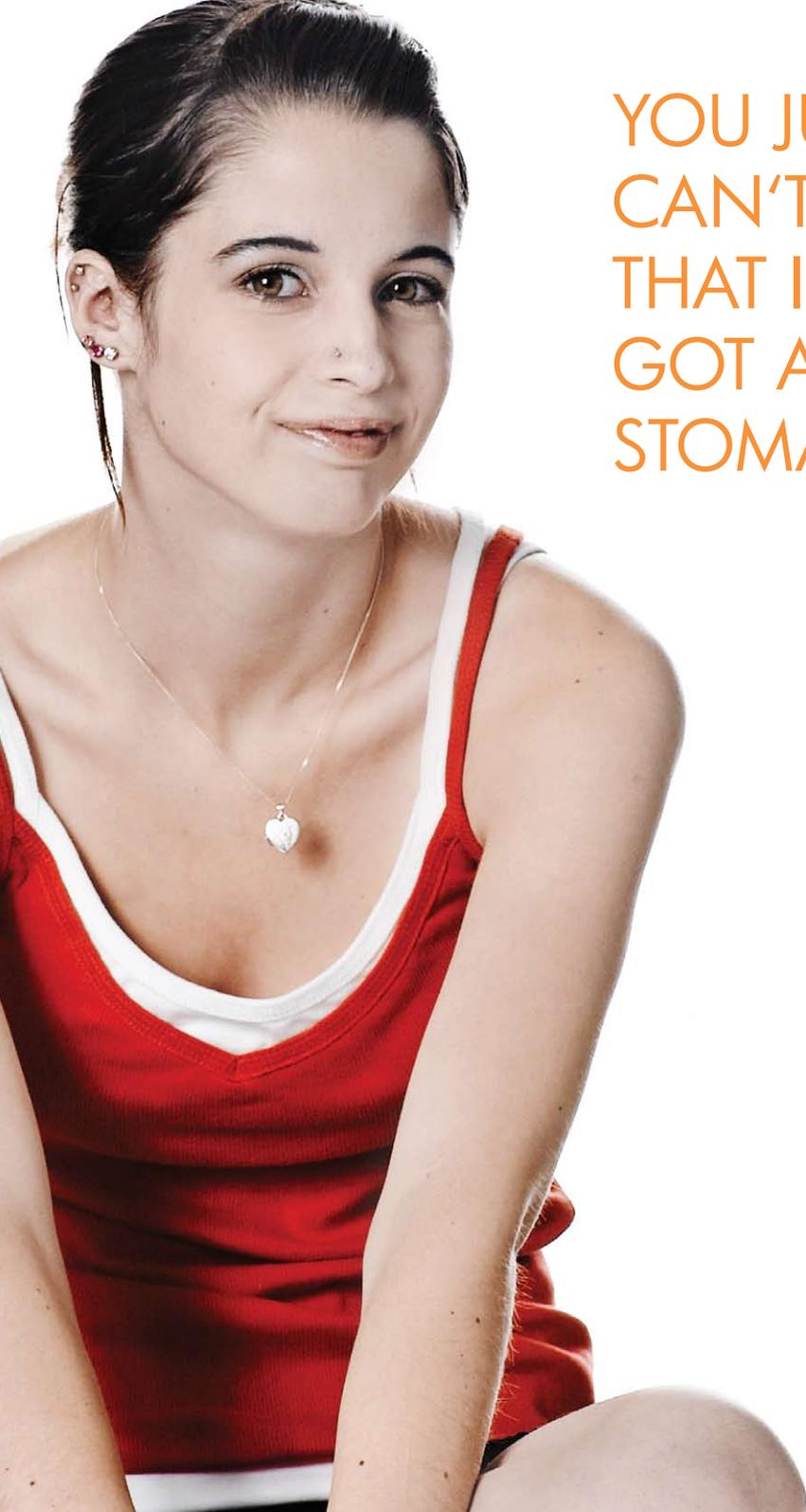
### **It helped when I met another girl who had a stoma**

My nurse introduced me to another girl, Zoe, who also has a stoma. That's really been a massive help. I met her after they had replaced my intestine and I didn't have a stoma anymore. Meeting Zoe has been really good for me. When I think back over the entire period, two of the main things that helped me get on with my life were my contact with the stoma care nurse and my friendship with the other girl, Zoe. I'm not sure I'd have been able to get on with things if I hadn't had these two to talk to. I don't know what or who else could have helped me. People are different, they react differently. I guess the most important thing is for you yourself and for other people to understand who you are and accept your reactions.

I DIDN'T WANT  
TO BE DIFFERENT  
- I WANTED TO BE  
LIKE EVERYBODY  
ELSE







YOU JUST  
CAN'T SEE  
THAT I'VE  
GOT A  
STOMA!

# Zoe, 17

## Ileostomy since she was 16 years old

*Zoe had a stoma made in her small intestine in 2006 due to chronic inflammation of the colon.*

### **Diarrhoea and pain**

When I was eleven years old, I had some problems that suggested that something was wrong. Diarrhoea and stomach pain. Things were pretty bad for a while - but then suddenly these problems disappeared. They were gone for almost two years. My problems then returned with renewed strength. Finally, the doctors found out what was causing my diarrhoea and stomach pain. It turned out to be chronic inflammation of the colon, colitis ulcerosa. I was treated with significant amounts of adrenal cortex hormone. For a while I had the medicine injected directly into my vein; after six weeks, the doctors started to talk about having a stoma as a possible solution. I remember hearing the word stoma for the first time 3-4 weeks before my operation.

### **I wish I had met the stoma care nurse earlier**

But strangely enough, I didn't meet her until the day after the operation. It was unfortunate that I hadn't had a chance to talk to her earlier. Until a week before surgery, I completely blocked what was going to happen out of my mind. But a week before surgery, I suddenly started to search for information about having a stoma. I was scared and confused. Everything I read seemed to be horror stories. But when I met my stoma care nurse, I started to relax. I just wish I'd met her in the weeks before the operation.

### **At first I felt insecure**

The first two weeks after my surgery, I felt pretty insecure. After two weeks, however, I started to relax more. I talked to the nurse several times while I was in hospital. She told me no one could see I had a stoma, and that more people than you think have one. You just can't see that I've got a stoma!

### **I'm quite open and relaxed about it**

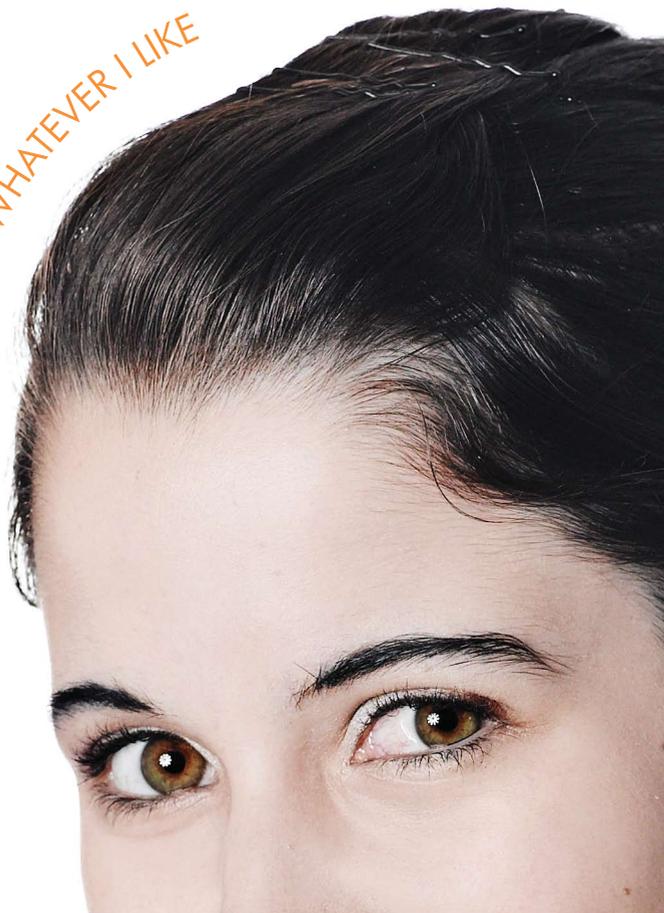
I told my closest friends I'd got a stoma. A lot of people asked me why I hadn't been to school for ages. When they asked me, I told them the truth. But I didn't go around telling everyone about it. My family and I went through everything together, and they've been very supportive. My mother was very concerned about food. Would I be able to eat the same stuff as before? They wanted to see my stoma. It was a bit difficult for them to understand what a stoma is and how it works. Actually, understanding it all was pretty difficult for me too. It would be a good idea if a stoma care nurse could sit down and talk to your family too.

I've not been afraid to tell other people I have a stoma, and actually, I've not had any really bad experiences. I was teased at school to start with, but I put a stop to that myself by explaining to them what it was all about. That stopped the teasing.

### **I feel okay about my body**

I feel okay about the way I look. I'll even wear a bikini, even though I have a stoma. It's not so important to me anymore. The first time I saw my stoma, I wouldn't even touch it. The stoma care nurse had to help me with everything. The first time I changed the stoma pouch myself was after I came back home. The nurse visited me at home, and I had no problems changing the stoma appliances myself. After two weeks, I started wearing normal clothes and stopped wearing baggy clothes to hide my body. When you feel okay about having a stoma, other people will feel okay too.

I CAN DO WHATEVER I LIKE



## **Stoma and boyfriends – no problem!**

I had a boyfriend and I told him I had a stoma. I told him what it is and why I had it. It wasn't a problem at all. Nonetheless, sometimes having a stoma has felt a bit lonely. I didn't know anyone else who had one. So I hadn't met anyone who knew the thoughts and feelings I was having. People who haven't experienced it can't possibly know what it's like.

## **I met another girl with a stoma**

My stoma care nurse introduced me to Lau. It was a great help to talk to another girl who had been through something similar. It helped me to relax about things. We could talk about everything. We are very different people, and we reacted quite differently to having a stoma. Lau is very shy about it, while I've been more open. We're just two very different persons who reacted extremely differently to having a stoma.

## **The worst thing was falling behind with my homework**

I'd prefer to be totally healthy like most of my friends. But that's just not the way things are for me. I had chronic intestinal disease and now I've got a stoma. I've got used to the stoma, and living with it is fine. Throughout everything, the worst thing for me was being away from school a lot when I was ill and had my surgery. That still bugs me. I like going to school, and I want to get a good education. So getting behind with my school work was hard.

## **Now I'm in control of my life**

The best thing about having a stoma is that I'm in control of my life. I can do whatever I like. I couldn't do that before I had my stoma. I always had to be near a toilet. There were periods when I was in a lot of pain. As well as the diarrhoea, there were many times when the pain really took over. Now the pain is over. My colon's been removed, and that's where the disease was. No colon, no pain....!





Find someone you can talk to  
and if possible someone who also  
has or **used** to have a stoma

Try not to isolate  
**yourself**



# Hints and Tips

## Stoma

A stoma is an opening in the bowel that is led through the abdominal muscles and skin to be stitched to the skin. The word stoma is Greek and means mouth/opening. The stoma is the same colour as the inside of the mouth as it has the same kind of mucous membrane.



There are no nerve endings in the mucous membrane, so the stoma won't hurt when it's touched.

Naturally, the area will be sore right after surgery, but you won't feel any pain later on. The stoma may bleed, but it isn't dangerous in any way. There are many fine, small vessels in the mucous membrane, and therefore it doesn't take much for a bleeding to occur.

The most common stoma types in the bowels are ileostomy and colostomy. Stomas can also be made in the urinary passage (urostomy).

If you have a stoma of the large bowel, the stools will be firm and in most cases a bowel movement will occur once or twice a day. If you have a stoma of the small bowel, the stools are relatively loose. This is due to the fact that the colon (large bowel) isn't functioning any more. The colon extracts fluids and salts from the content of

the bowel, and if the colon is out of function, the stools become more liquid. The stools exit the bowel several times a day, usually in connection with meals.

Whether you have a stoma of the small or large bowel, you will not always be able to feel exactly when you are going to pass wind. However, most people learn how to recognise the sensation. There is a filter on the stoma pouch that ensures that most of the air is released from the pouch without any odour.

### **Food**

If you have a stoma of the large bowel, you can eat the way you're used to. Remember to drink plenty of fluids. If you have a stoma of the small bowel, you have to be more careful in the beginning. It is important that you listen to your body and that you eat a balanced diet. Your stoma care specialist will probably have some brochures informing you about the effect of various kinds of foods on the consistency of the stools.

### **How to change your stoma pouch/wafer**

The first few times, it will probably be the stoma care specialist who changes your appliance/pouch. The two of you will agree on when you can take over. It isn't difficult at all, but it may take some time getting used to it. It also takes some time getting used to how the stoma looks on your stomach, but remember that if you are comfortable with your body, no one can tell you have a stoma.

### **Clothes**

Before surgery, you and your stoma care specialist will discuss the correct siting of the stoma. Therefore, it's important that you are wearing the clothes you normally wear, or have them with you, so that your point of view on where to place the stoma is taken into account. For example, while you can't hide the stoma under a very low-cut pair of pants, you can easily wear tight clothes over the top of the stoma.

## **Self-esteem**

When you are a teenager, lots of things are happening with your body. Sometimes it changes so fast that it may be difficult to keep up with all of it. For a period of time, you are both an adult and a child, and it may be difficult to know who you really are. Having a stoma may be difficult for most people, no matter what age they are, but in your teenage years when you are trying to find your identity, it may be even more shocking to see yourself with a stoma. Many people think that others are looking at them the same way that they may look at themselves. Most people are very critical about their appearance. They find it difficult to start an intimate relationship because they feel insecure about their partner's reaction to their stoma. Often it isn't like that at all, as it's the individual person that someone falls in love with and not the stoma. Many partners say that it's irrelevant and often they don't even think about the stoma at all. It's very important that you don't isolate yourself because you have a stoma. Find someone you can talk to about it, and if possible, someone who also has or used to have a stoma. Your stoma care specialist will be happy to help you get in contact with someone, as it can be a big help. She or he can also give you the addresses of stoma associations, and many of these have websites with chat rooms especially for young people.

# DID YOU KNOW -

# THERE ARE PROFESSIONAL ATHLETES WHO HAVE A STOMA

## **Sex**

Many people discover sex for the first time in their teenage years. While you might not be having sex, you may start to discover the more intimate parts of your body.

The teenage years are also when most of us get a boyfriend or a girlfriend and you may worry about how to talk about the stoma. It's up to you to find the best way and right time, but in general, it's best to say it early in a relationship. It usually makes things easier and can help you relax more.

Here is some practical information that may be of help to you:

- Empty the stoma bag or replace it before you start being intimate.
- You can fold the pouch and fasten it with tape, or replace the pouch with a very small pouch (mini cap), wear a sexy belt around the stomach, or wrap the stoma bag in a patterned fabric pouch.
- Pressure will not damage the stoma.
- The pouch cannot burst or break.
- When you are sexually aroused, the bowels are relaxed. This means that, in general, no stools or sounds of flatulence will enter the stoma while you are having sex.

## **Socialising**

Often, when a person gets a stoma, it really improves their quality of life, and they can do everything their friends do. Physically, nothing stops you. Try not to think of your stoma as a problem, but as a solution.

In relation to your circle of friends, it's your decision, and yours only, whom you want to tell about the stoma. Some prefer to talk openly about it with many others, some only tell one or two. The most important thing is that you do what you feel most comfortable with.

As stated earlier, when you are a teenager, you will try many things out, and at some point most teenagers will drink alcohol. What you need to know, is that for most people the stools are looser when they drink alcohol, so it might be a good idea to put on a new stoma bag/wafer before you go out so that you don't risk the wafer coming loose because of loose stools.

## **School**

Most people have a number of sick days when they have a stoma. Maybe there is a long spell of sickness before surgery, and afterwards there might be a period of time before you are well enough to go back to school again. It's difficult for many young people to accept that they might fall behind with their school work, but most hospitals offer tuition - so always accept such an offer.

## **Sports**

As mentioned in the section Socialising, there is by and large nothing you can't do, even with a stoma. Did you know that there are professional athletes who have a stoma?

Right after surgery there will, of course, be a period when you will not have the strength to do much. Also, you can't start any kind of physical training until 6-8 weeks after surgery as your abdominal muscles need time to heal. However, you can discuss all this with your doctor.

Only contact sports such as boxing and karate impose limitations for you. You can use a stoma shield which is a good way to protect the stoma.

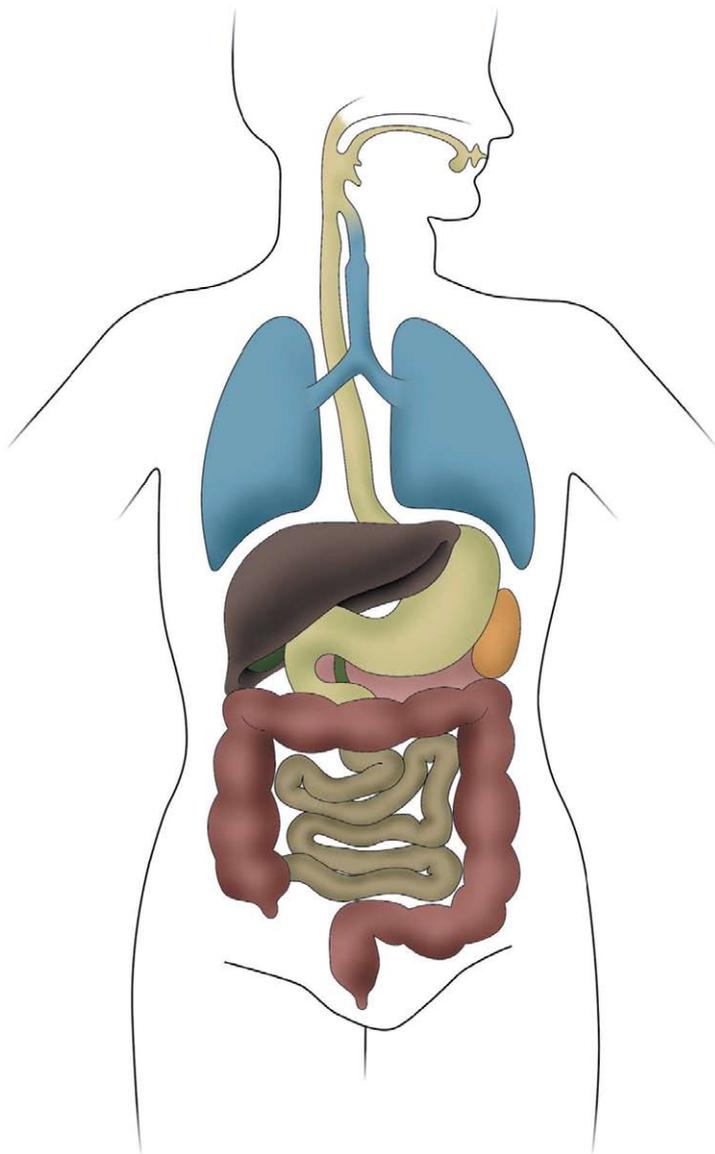
## **Travelling**

The only restrictions are those you make for yourself, if any. Of course, there are a few practical details that are good to know before you travel:

- Always take an ample supply of stoma products, and always pack it in your hand luggage if you are travelling by plane.
- If it's very hot, you will need to replace the wafer more often.
- If you have an ileostomy, you need to be careful so that you don't get diarrhoea. Talk to your stoma care specialist about any necessary precautions that you may need to take.

# Digestive system

Ask your stoma care specialist to mark the position of your stoma on the anatomical chart.







# Links

[www.dansac.com](http://www.dansac.com)

Here you can find more Dansac educational materials, product information and links to your local Dansac sales office.

[www.ostomyland.com](http://www.ostomyland.com)

[www.crohns4youngadults.co.uk](http://www.crohns4youngadults.co.uk)

[www.ostomylinks.co.uk](http://www.ostomylinks.co.uk)





[www.c3life.com](http://www.c3life.com)

Where people with stomas, families, friends and clinicians can come together to meet, learn and share real-life experiences and advice.

[www.nacc.org.uk](http://www.nacc.org.uk)

[www.smiliespeople.org.uk](http://www.smiliespeople.org.uk)

[www.breakaway-visit.co.uk](http://www.breakaway-visit.co.uk)

If you are comfortable with your body, no one can tell you have a stoma





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