

Supporting 'young people' living with a colostomy at school - the negatives and the positives...

Among the numerous telephone calls we receive on the helpline, are many from anxious mothers or families with children of school age who have a colostomy. There seems to be a distinct lack of advice and support for the families of children attending school at any level.

We are hearing very sad stories of children with a stoma being side-lined at school. Some even placed in a classroom on their own because other children won't sit by them. Name calling is also an issue. No-one should be made to 'feel different' or to suffer just because they have a colostomy. School is after all, a place for learning, perhaps schools should recognise there is a need to teach understanding and compassion as well as the ABCs.

Schools also have a legal responsibility towards children with medical needs - we must try to educate the schools, their staff and pupils to accept children with colostomy's.

Some schools and parents need to be made aware of the Individual Education Plan (this plan is designed to set out strategies which can be used to meet each child's identified needs). It is important that all parties meet to discuss a child's needs - school staff, parents and if possible a health professional.

Parents - especially those who have already had difficulties within the school system - may find it difficult to approach the school again. This is when it is especially important to have support from 'outside'. We want to make all head teachers and other teaching staff aware that their attitude if negative towards any child with a medical problem can seriously impact on that child's school attendance and their home life.

For anyone, being made to 'feel different,' by those around you is an upsetting experience. Some children with a colostomy may find themselves excluded from school activities, such as sport. It is important for the school and staff to recognise there is no medical reason - why a child with a colostomy should not play sports or do anything else he or she feels comfortable with.

Children who have been through the trauma of needing a colostomy show great fortitude and courage. Teachers should be made aware of their experiences and the symptoms suffered, some of which are outlined below:-

- An urgent need to go to the toilet
- Diarrhoea
- Severe abdominal pain
- Extreme tiredness
- Nausea
- Passing blood with stools
- Lack/loss of appetite
- Weight loss and failure to grow.
- Suffering the embarrassment of having an accident and worrying about smell.

Although receiving a colostomy frees the child from these symptoms. It takes time to overcome and recover from a colostomy operation. Even some 'grown-ups' find it hard to come to terms with 'living with a colostomy' - how much harder must it be for a child to cope?

Psychologically, it is very difficult for children to deal with the embarrassment of having a colostomy and the need to wear an appliance. They may be very concerned with how they look, whether it will smell, or how they are going to cope with it - all perfectly normal questions - asked by all 'to be' colostomates. With the correct support from family, friends and school authorities these doubts can be overcome. What needs to be emphasised to schools, is simply this - 'having a colostomy gives people freedom to get on with their lives'.

A child with a colostomy needs to build confidence and knowing that their school supports them will help. Schools should provide designated toilet and disposal facilities for used pouches. Indeed, everything should be made easy for the child. Some children may want to keep the matter of their colostomy private and this should be respected.

Children who have any kind of medical condition need to be encouraged and supported by everyone around them. The children themselves are plucky individuals - let us all ensure that this is recognised.



Having a colostomy doesn't bother me at all...

I feel I'm a 'normal' person having lots of fun, in fact some times I forget I even have it.

I'm a little girl who loves dressing up and if it means my tummy is showing I just pull my skirt up a bit to cover my bag, it's no big problem. I prefer dresses as they're a little comfier but we never buy special clothes as there's no need. I'm just as fashionable as all my friends. The only time you might see a bump in my clothes is when I wear my leotard for ballet or gymnastics. I sometimes wear a ballet skirt or leggings with my leotard to help cover things but no one ever asks about my bump so it can't be that noticeable. One thing's for sure, you definitely can't see it when I'm skiing!!

"School is brilliant as all my teachers help and support me. I'm just like any other member of the class. Some of my friends know about my bag, others don't. That is the nice thing about a colostomy. You can choose who you tell. All my class know I've been in hospital and think I'm very brave, they are really understanding."

I don't like bullies and I won't stand for it. People can say nasty things but I'm prepared for that and I have some very special friends who stick up for me. Having a colostomy is nothing to be ashamed of. It's not my fault I have one. I can't change it, but that won't stop me living a fun and exciting life.

Brooke Taylor - Age 7

Websites specifically for children and their families...

www.convatec.co.uk

Provides a link "just for kids" section. This site is designed to act only as a guide for parents and professionals.

www.smiliespeople.org.uk

Forum set up by Ollie, a teenager who has an ileostomy.

www.vicnet.net.au/youinc

YOU (young ostomates united) This is an Australian website but young ostomates may find the stories helpful as many are written by teenagers.

www.ostomates.org

Shaz is an ileostomate from Western Australia and had her surgery at the age of 10. Her website is designed to be an interactive support page for new and experienced ostomates. It is for ostomates by ostomates.

www.ostomylinks.co.uk

This website offers links specifically for children, teenagers and young adults. Links are available for parents. Includes discussion boards and ostomy chat rooms.

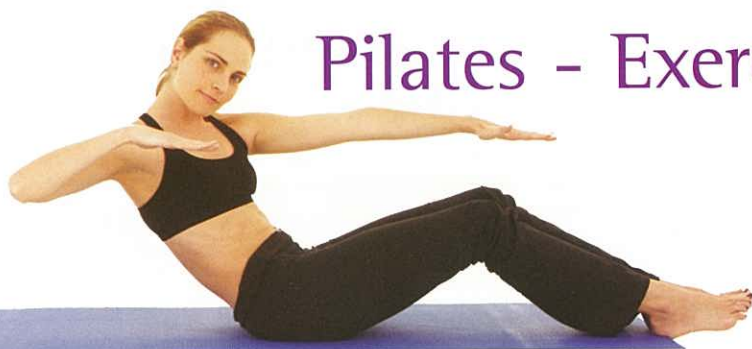
www.ostomy.support.info

This website offers interactive support, product information and lifestyle guide.

www.colostomyassociation.org.uk

The Colostomy Association is working hard to change people's attitudes to a colostomy. This is especially important for children - we are here to support families with children who have a colostomy and to help educate those who do not understand 'what it is like to live with a colostomy'.

Pilates - Exercise and Ostomates



"The attainment and maintenance of a uniformly developed body with a sound mind, fully capable of naturally performing our many daily tasks with spontaneous zest and pleasure."
Joseph Pilates

You may have heard of Pilates (pronounced pi-la-tiz) and the benefits this type of exercise has to offer. Having a colostomy has never stopped me from taking and teaching regular exercise and that includes the Pilates method.

The Pilates method of exercise, was developed in the early 20th century by a man called Joseph Pilates. There are many people who follow these exercises and many instructors teaching them in the United Kingdom.

The exercises focus on the core postural muscles which help keep the body balanced and help to provide support for the spine. In particular, Pilates exercises teach awareness of breathing and alignment of the spine, and aim to strengthen the deep torso muscles which keep your tummy and back stronger and can sometimes help in preventing an abdominal hernia.

As a colostomate of five years and a Pilates Instructor, I have found this type of exercise to be especially suitable for me, as the movements can be fairly easily adapted to suit the individual and can be very gentle and non-threatening. I was lucky to recover from the surgery within a short time frame and was teaching again after 12 weeks. It felt quite scary facing a room full of people who were all looking at me and I was concerned they would all be able to see my colostomy bag! In fact only a few people knew what operation I had undergone and other people had no idea as the bag could not be seen (even in skin tight Lycra)! My worst fear was the stoma making one of its unannounced loud sounds that remind me of an elephant. But most of the time I could sense when this was about to happen and put my hand over the stoma to muffle the sound. Obviously undergoing any major abdominal surgery is going to affect your ability to exercise, but my stoma has never stopped me doing all the things I did before I had it. I'm just very careful to exercise sensibly, cautiously and most of all within my capabilities.

The Pilates mat program follows a set pattern, with exercises following on from one another in a natural progression. Beginners start with basic movements and build up to include additional exercises and more advanced movements.

People who enjoy Pilates say they stay with the program because it's diverse and interesting. You can do fewer repetitions of a number of exercises rather than lots of repetitions of only a few. Joseph Pilates intended his exercises to be something people could do on their own once they've had proper instruction, cutting down the need to remain dependent on a trainer.

If you decide to try out a session, get the most out of your Pilates workout by thinking about the following:-

- **Focus Your Mind** - Pilates is designed to combine breathing with your body's movements. Instructors teach ways to keep breathing and working together with the exercises. You will also be taught to concentrate on your muscles and what you are doing, aiming to unite your mind and body, which can also help to relieve stress and anxiety.

- **Be Comfortable** - Wear comfortable clothes (as you would for yoga - shorts or track suit bottoms and a T-shirt are good choices) and usually Pilates is done without shoes. If you start feeling uncomfortable, strained, or experience pain, you should stop (as with any exercise).

- **Flow** - When you perform your exercises, avoid quick, jerky movements. Every movement should be slow, but still strong and flexible. Joseph Pilates worked with dancers and designed his movements to flow.

- **Enjoy!** - The nice thing about Pilates is you don't have to break into a sweat if you don't want to. Pilates is primarily about strength and flexibility, so combining other types of exercise is just as important. As well as Pilates try to incorporate a form of aerobic exercise like swimming or brisk walking 2 or 3 times a week.

If you are interested in participating in a session, check with your local leisure centre (details can usually be found on your local council's website) as they will have a whole list of things you can try that include Pilates. Your local Primary Care Trust should have a list of Health Walks in your area - a great way to get fit and meet some new people.

If this article inspires you to try Pilates, start slowly and steadily, trying not to overdo anything, until you find a level you are comfortable with. Some gyms have specialist programmes for people recovering from surgery or with specific types of illness, disability or medical condition. You may wish to discuss this with your GP, Practice Nurse or Stoma Care Nurse, as they may be able to refer you onto one of these schemes.

On a positive note, the benefits of regular exercise are many, regardless of having a stoma or not! You should aim to do at least 30 minutes of moderate (non-intensive) physical activity five days a week. Moderate exercise can include going for a gentle walk, or doing some gardening. However, if you have been inactive for a long period of time, try to build up to 30 minutes a day over the course of several weeks. Also, avoid high-impact exercises, such as sports that involve hard jolts to your body, for example football or squash. Remember to always start an activity slowly and gently, always warming up before you start and cooling down at the end.

When you feel the time is right for you to start exercising, I am happy to talk to you in person via email or phone. I can be contacted via the Colostomy Association on: 0118 939 1537. I am also happy to talk to any fitness professional that wants to know more about exercise and stomas. Whatever you want to try, keep to a few simple rules, but most of all enjoy!

Bronwen Lowy

Check with your GP or SCN before you commence any exercise programme.

- Start slowly
- Go at your own pace and listen to your body
- Stop when you've had enough.
- Enjoy the experience!
- Don't feel intimidated.

Please remember to always ensure that you have checked with your medical practitioner before you commence any type of sport or physical activity.

'X marked the spot' and I was off to surgery...

Lisa shares her experiences of colostomy reversal and bowel resection



Lisa Tubbs - getting back on track

At twenty-six I didn't know what a colostomy was! I didn't even realise young people had colostomies as I associated them with older people. I quickly found out I was wrong...

I have suffered from severe Endometriosis for years and was having yet another Laparoscopy to laser off the adhesions attached around my ovaries, bowel, rectum, kidneys and other infected areas. Endometriosis is a condition in women where cells that usually line the womb are found elsewhere in the body, these cells behave in the same way as those that line the womb, so every month they grow during the menstrual cycle and then shed blood. This internal bleeding, unlike a period, has no way of leaving the body and leads to inflammation, pain, and the formation of scar tissue (adhesions). There is no cure and the only way these adhesions can be removed is by laser.

A week after my routine operation all was not well and I was rushed in for an emergency colostomy because a fistula had formed. The doctors formed a temporary stoma to allow time for my bowel to heal on it's own as they wanted to prevent having to perform a bowel resection. Although I was informed before the Laparoscopy that there might be a 2% chance I could end up with a colostomy bag (because there was so much endometriosis around my bowel and rectum) ever the optimist and being squeamish I didn't research into it.

Not knowing was probably better in hindsight. Even before the emergency operation I refused to look at any pictures of people with colostomy bags or read about how they worked as I knew I would find it easier to cope looking at it on my own body. They marked my tummy with an 'X marks the spot' and I was off to surgery.

I came round still in denial and not wanting to look under the covers. The nurses were amazing and very supportive which helped me get over the fear. I really felt their empathy which made me feel better and not ridiculous for overreacting. With the best support from my friends and family, I started to deal with it. It was scary to say the least, but you quickly adapt to things thrown your way and realise you can't always prevent things happening to you.

Crying every time I passed wind in front of people was a regular occurrence during the early days. The lack of control was very embarrassing especially being female and very prudish about flatulence. After years of being discrete and private, it was out there for all to hear!

But as time went on, surprisingly I grew quite attached to my stoma. Knowing that it was going to be temporary definitely made it easier to deal with. I wouldn't have been so strong if it was a permanent stoma.

It's very hard for anyone at any age but initially I definitely found it difficult to cope with being young, single and having an active social life. I got braver as time went on and started going out again. I quickly learnt the hard way that drinking too much had a bad reaction in the morning but I adapted by trying other drinks with less fizz.

Buying a new wardrobe to hide the bag was my treat to myself as it helped with my confidence and body image. No one ever guessed I had a colostomy bag as they are quite discreet and by adapting my clothing and wearing magic pants I helped hide it and hold it in.

After six months I had a barium enema to see if the fistula had healed on it's own. I was very anxious before the examination because everything hung on the results. If it had healed on it's own I would have a simple reconnection of my bowel and the colostomy removed. Unfortunately it hadn't, so I went in for a reversal operation of the colostomy bag and the removal of a large part of my bowel and rectum.

Having a bowel resection is a major operation and recovery is longer but emotionally it is easier to deal with. Coming round from the operation I was in such a daze as it was a lengthy operation. I was very weak and it took me a lot longer to regain my energy and bounce back from it. I was in hospital for a week after the operation as you have to be able to have a bowel movement to confirm that the operation has been successful. (I had a small colectomy at the end of the colon where it joins the rectum (part of the sigmoid colon). That first bowel movement was a massive relief and the entire four bed ward celebrated!

During the first few months you can experience going to the toilet up to fifteen times a day, sometimes with urgency and soreness. Unfortunately the frequency is very different to what you may have previously experienced and after about two years it evens out and your body settles down to what now feels normal. You spend a lot of time in the bathroom so taking up Sudoku or reading passes the time!

Initially after the reversal I missed my colostomy bag as I had become comfortable with using it and I was scared about going to the toilet in the normal way again. Because half of my rectum was removed it got confused, my brain had to re-educate the rectum when I needed go to the toilet because it wasn't compacting the stools. There is a continual sensation of urgency which you have to train your mind to ignore. It took time, and it never goes back completely to how it was before the operations but it's manageable. Going five or six times a day seems normal now.

From keeping my colostomy a tight secret whilst I had the bag I was more open about discussing it afterwards as I was proud of what I had gone through and felt stronger for it. Those that were aware of the bag whilst I had it were understanding and in many cases quite curious and wanted to know more out of genuine interest.

I work in a Design Agency in London and have done the whole way through my journey. Now, a year and a half on I am ready to start getting on with my career as it was on hold for quite some time as you have to put your health first and make yourself feel good.

There were many funny, embarrassing and cringing moments throughout the six months when I had my colostomy bag but you have to try to see the funny side of these things and laugh!

Lisa attended the recent Induction Days and is now a volunteer for CA...

For new readers to Tidings it is probably worth giving some background to the Department of Health (DoH) Consultations and how we have got to this current position.

The first Consultation impacting on the supply of stoma products was published back in October 2005 and was meant to review the way that products were delivered to patients and how much companies would be reimbursed for providing both the products and the services. At the same time one of the key aims of the consultation was 'to maintain and where applicable improve the current quality of care to patients'. It was evident, from reading the Consultation proposals, that quality of care to patients would be adversely impacted if reimbursement to companies was going to be reduced.

Working closely with other Patient Associations, including the Ileostomy Association and the Urostomy Association, we have provided responses to the initial Consultation and the further five that followed taking us up to the end of 2007. Consultation 6, which closed in December 2007, made proposals which would have meant a reduction in reimbursement to manufacturing companies of approx £25m. Our response flagged, yet again, that if companies were forced to make these savings then patients would be impacted by a reduced product range, reduced funding for research and development of new products, potential reduction in sponsorship for nursing positions etc.

During the early part of 2008 the DoH held a number of meetings with interested parties (companies, nursing groups, patient associations etc) in an attempt to fully understand everybody's concerns and to draw the Consultations to a close. Following these meetings a final Consultation was published in June with a closing date of 9th September. By the time you read this edition of Tidings our response will have been submitted along with those from the other Patient Associations.

In terms of the proposals within this latest Consultation, I can confirm that the DoH have listened to the concerns raised by patient groups and understand the implications for patients. The proposals will still mean a reduction in the reimbursement to companies (now £5m compared to £25m in the previous proposals) and we await with interest the steps that companies will take to make these savings. From my understanding the majority of companies are accepting of these proposals and can now move forward after spending 3 years reviewing the DoH Consultations.

A summary of responses to the Consultations will appear on the DoH website in due course and, hopefully, we should be able to report the end to these reviews in our Winter Tidings.

Scotland- As the DoH Consultations in England draw to an end we are gearing ourselves up for a Consultation in Scotland.

A number of changes are already in place in Scotland regarding the range of companies who are able to supply products to Hospitals and we would be

grateful to hear any feedback on this that any of our Scottish readers may like to provide to us. The process at present is somewhat confusing in that patients may only have access to the products of three or four companies whilst in hospital but then should be given a wider choice once they return to the community. These processes have been put in place without any consultation with patients and thought of the impact that they may have.

I was invited to attend a meeting with Shona Robinson MSP back in August along with Anne Demmick from the Ileostomy Association and Hazel Pixley from the Urostomy Association where we were able to express our concerns over the issues raised by the changes. We were pleased at being given this opportunity and happy with the assurances which Shona was able to give us.

We are now awaiting a draft report on the work of the Stoma Care Review Group following which a draft Consultation paper will be produced for us to comment on prior to publication. It is hopeful the Consultation will be published by the end of the year.

As always we will keep you updated on developments and if you have any specific concerns regarding the position in Scotland please let me know by writing to me at Head Office.

Ray Goddard
Office Manager, Trustee and Treasurer

What is a prolapsed stoma?



A prolapse of the stoma occurs when the bowel protrudes through the stomal opening in the skin to a greater extent than was anticipated. The severity of the prolapse can vary from a small 2-3 cms prolapse to a large 10cms plus prolapse. Any prolapse is frightening and distressing for the patient and should be handled sensitively by a trained Health Care Professional. The patient should be referred to the Consultant Surgeon or the Specialist Stoma Care Nurse for careful assessment to ensure successful management of the condition.

Contributing Factors

A prolapse can occur in any stoma type but is more common in loop stomas, especially loop transverse colostomies (McCahon; 1999). The causes of a prolapse are many but include an oversized hole made in the abdominal wall at surgery (McErlain et al; 2004), increased abdominal pressure due to tumour, pregnancy or chronic coughing (McErlain et al; 2004), excessive exertion, including heavy lifting (McCahon; 1999) and obesity (McErlain et al; 2004).

Management of the Prolapse

Management of the prolapse can be conservative or surgical but all patients must be given support and reassurance during this frightening time. The psychological effects of having a large piece of bowel protruding through the abdominal wall, often being visible under clothing, can be great and fear of further problems can be a considerable factor. For any degree of prolapse the main consideration is psychological support. The patient should be given a full explanation about what a prolapse is, what may have caused it and what to look out for with regard to change in the condition of the stoma. They should be advised to be careful when handling the stoma so as not to cause any degree of trauma to the bowel and to note any change in colour, size or activity, which needs to be reported to the Specialist Stoma Care Team. If the prolapse is small some degree of adjustment with regard to appliance type may be all that is necessary to successfully manage the problem.

Many ostomy product manufacturers now make specialist pouches to help in the management of both herniated and prolapsed stomas. Referral to the Specialist Stoma Care Team will provide the patient with advice regarding the use of an appropriate appliance, which needs to be large enough to contain the prolapsed bowel and the output easily. The template should also be checked to ensure that it fits correctly around the stoma without causing undue pressure leading to trauma (McCahon; 1999).



Courtesy of Salt's Healthcare

The use of a light weight abdominal support can also be beneficial as long as it is assessed prior to use by a Health Care Professional to prevent trauma to the prolapsed bowel (Myers; 1996).

For prolapses which are too large to manage conservatively, or for a prolapse which becomes discoloured surgical review is necessary for assessment regarding refashioning or even reversal if this is appropriate (McErlain et al; 2004). Surgical intervention is undertaken following review by the Consultant Surgeon and will involve removal of the prolapsed section of bowel and refashioning of another stoma, possibly being sited in another area of the abdomen.

References

McCahon, S. (1999) Faecal stomas. In Porrett T, Daniel N, (eds) Essential Coloproctology for Nurses London, Whurr Publishing

McErlain D, Kane M, McGrogan M, Haughey S. (2004) Prolapsed Stoma Nursing Standard 18, 18 41-42

Myers C. (1996) Appliance leakage. In Myers C (Ed) Stoma Care Nursing: A Patient-Centred Approach London, Arnold

Dear Nurse...

district nurses. It finally healed last November but has left me with an incisional hernia.

Now over a year later the subject of a reversal operation has been discussed. I have agreed to have my hernia repaired but I'm putting on hold any plans to go ahead with a reversal, owing to a very short rectal stump and IBS. I am taking the view that a reversal operation would probably lead to the problem of urgency and at worst incontinence. If that happened it might be necessary for further operations to return me back to where I am now.

Yes of course there are exercises that can improve control but after careful thought I've considered I'm marginally better off avoiding any more open surgery at the present time. I don't like having colostomy bags but that is surely better than incontinence pads.

Yes I have the option of changing my mind on future surgery but I live alone and at the moment my decision is no. I would very much like your opinion and to hear from other IBS sufferers who may have their own experiences to tell especially on the rather daunting decision regarding reversal operations.


A: I am unsure how much bowel was removed during your first surgical operations and therefore am unable to comment on the chances of frequency, urgency and the need to wear pads following this. Many patients have reversal of their stomas and do not suffer these problems but obviously everyone is an individual and many factors need to be considered. I would suggest you talk in detail to your surgeon and your Stoma Care Nurse both of whom can explain the potential risks for bowel problems afterwards and can give you more individualised information regarding your previous surgery and the implications for a reversal for you. They may also be able to arrange for you to speak to a patient who has undergone a reversal of their stoma previously and you can get the patients view on the procedure.

To get more information regarding IBS you could ask if your local hospital has a

Specialist Inflammatory Bowel Nurse who could help or ask your GP for any relevant information leaflets on this condition.

Q: I have just had a Colostomy one month ago. I am a vegetarian and I am suffering badly with trapped wind. It sometimes gets so bad that I start vomiting. I have asked my stoma nurse but all I get is 'your diet' which does not help me at all. I wonder if anybody has some useful tips to help me out. I am getting scared that I will not want to eat due to this and I know I cannot think like this so please help me!!

A: I am sorry to hear you are having problems with your diet and 'wind' following your surgery. You say you had your surgery a month ago so it is still very early days yet and you may find that as time passes the problems settle. However certain foods can increase the potential for 'wind' especially as you are a vegetarian. Some patients find that using things such as peppermint (tea, mints or cordial), fennel (tea, mints, tablets or the vegetable) or charcoal (tablets or biscuits) can help to reduce the amount and severity of the wind. Otherwise it is correct that you need to assess your diet and see if there are any particular foods which cause the wind to increase. You can then avoid these foods in the short term and gradually re-introduce them as time passes. I hope this helps.



Dear Nurse...

Please send your medical questions or any queries about stoma management to

Colostomy Association,
2 London Court
East Street
Reading
RG1 4QL

or e-mail
cass@colostomyassociation.org.uk

We will forward them to Julie Rust and publish her answers in the next issue of Tidings.