

# The Day I Got My Stoma



Attention to Detail. Attention to Life.



When you were told you needed a stoma, you may have felt frightened, angry, and upset. This is a normal reaction; yet you may not know how to deal with your feelings.

This booklet aims to give you insight into other children's/teenager's experiences of having a stoma and how they cope.

Ask your Stoma Nurse any questions you may have, as they have cared for many children like you with a stoma and will be happy to help and support you through this time.

If you would like to speak to or meet someone else with a stoma, ask your Stoma Nurse and she/he will put you in touch.

I hope this booklet addresses any worries or concerns you have, and you find it useful reading other children's experiences of having a stoma and how they dealt with any situations or concerns you may have.

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Sheffield Children's **NHS**  
NHS Foundation Trust

I would like to give a big thank you to the parents and children who have given their stories to this booklet, because I know for some this has not been easy and brought back some memories for them. Without you, this booklet would not have been produced. I would also like to thank Jo Sica from Hollister for encouraging me to put this together, and Barbara Conti from Hollister for all her hard work in helping produce this booklet. Lastly, my thanks to Hollister Incorporated for putting this work in print.

Thank you all,  
Helen

## Life with a Stoma Bag

*By Connor Hook*

I have had ulcerative colitis for approximately three and a half years. I have tried five different types of medicines and with not much success. First of all, at the beginning, it started off at about 5 - 10 times a day that I was going to the toilet. It progressively got worse over time, and I went to the toilet more and more. Life at school was very hard because people kept asking questions, and I became more and more conscious and nervous about it.

One of my medications (the steroids) had awful side effects: puffed out cheeks, constantly hungry, always thirsty, headaches, sleepless nights, and getting angry for no reason (these were just the worst ones). These tablets did not help at all and, every time I tried to take less of them, my bleeding came back even worse than before.

The doctors said that they could try one other type of medicine, but it only had a 50% chance of working. The tablets unfortunately did not work, so I decided to have the operation to remove my colon. I will have three operations before I am as back to normal as possible.

Two weeks before my operation the Stoma Nurse, Leslie, came to see me and my mum. She explained everything that was going to happen — gave us some books to read, gave us a hug, wished us good luck, and left saying "See you after the operation." She was lovely and stopped my worrying. My mum, on the other hand, was shocked and scared for me.

I had the operation, and it was a lot more painful than I thought it was going to be. I had some sickness after the operation, but I got better as each day went by. I was allowed home after one week.

The Stoma Nurse came out to see me after the operation. She is great and really funny, and she phones all the time to see how I am and comes around whenever we need her.

Most of the time, I don't remember I have the bag on, and emptying it isn't too difficult. Changing it becomes easier as time goes by, especially now it has healed up. Mum is usually about to help, but I do it most of the time. The only difficult bit is cutting the hole to the right size which I'm not much good at that. I will be able to have pre-cut ones soon.

Going back to school is hard, especially as I missed so much time before the operation because of the illness. But it's good as I get to see my friends again. I have to be careful not to knock the stoma as that can really hurt.

I feel more confident in myself now, as I don't have to keep dashing off to the loo. My face is not swollen anymore and now people have stopped looking at me and asking questions—they just ask how I have been.



**Dear Readers,**

*My name is Karen Clift. I am 16 and I have a stoma.*

Before I had a stoma, I was very ill. I got rushed from hospital to hospital. I was on a drip and lots of different tablets, but I was not getting any better. So at one point I had a infliximab drug. I got told I may have to have a stoma and I was like No! No! No! I am not having a stoma, because I don't want a scar or to be a freak. I thought my boyfriend would finish with me and I would never get another boyfriend ever again, and my friends would not like me.

The time passed and I was still no better. The docs said I have to have a stoma or it may be life-threatening, so I had no choice.

After the operation, my lung gave way and the doctors rushed around and I was put on a breathing machine. A few days later, I was up and about the ward with help, but I would not look at the stoma. When it needed emptying, my mum had to do it for me because I would not look at it. I thought I was a freak, but I wasn't and you won't be either. I got used to it after some time, but when I or my mum would empty it I had to put tissue up my nose because it smelt so much. I would not change the back plate. My mum would do that.

I have had the stoma nearly a year now and I am fine with it. I still get upset from time to time.

I am hoping to have it removed this or next year. Good luck!

By the way my boyfriend did not break up with me, he was fine about it all. And my friends helped me in every way they could. I met some nice people like Helen Woodcock, little Helen as I call her; Matthew, a support worker, and my mum who was there all the way — and I just want to say thank you to everyone.

And don't worry, you will be fine.

From,

Karen Clift



## Martyn Glossop

### *Before I had my Stoma*

I was 14 years old when I first started to feel ill, and I experienced diarrhoea and stomach pains. It was about six months before I was diagnosed with Ulcerative Colitis. My quality of life was very poor; I was unable to attend school and missed a year of my GCSE work. The worst part was not being able to go out with friends for fear of not being able to find a toilet. I had numerous stays in hospital, trying different treatments to help me, but unfortunately nothing seemed to work. When I was 15 years old, I had to have a stoma.

### *Having a Stoma*

At first, when I was told I was having a stoma, I was really nervous and scared, but I knew I had to have it done. I spent about 10 days in hospital having the operation. In that time I was shown how to care for my stoma for when I got home. In the beginning, the stoma was quite swollen and changed shape over the next couple of months, so I spent a lot of time resizing the plates. At first, I didn't like to look at the stoma and would put off having a shower because of this; however, over time I became comfortable with my stoma. I used to experience the bag leaking at night, but to overcome this I used to place the bag horizontally before going to bed and this seemed to work. It was about three months after the operation when I returned to school.

### *Life after having a Stoma*

My quality of life after having a stoma couldn't be better. I experience none of the symptoms I had previously had, and I can finally get on with my life. Having the stoma meant I had to avoid certain foods such as nuts, popcorn, and marshmallows; which was only a minor drawback and didn't affect me much. I chose only to tell one of my friends that I had a stoma, and no one else suspected I had a stoma as its easily hidden under clothes.

I was told that I would be emptying my bag about four or five times a day, but in my case I only have to empty twice a day, which is a bonus. After a while, my family and I started to forget I even have a stoma, as it doesn't really affect my daily life.

The only problem I faced with my stoma was that it got blocked, and I had to have another operation to fix the problem, but this doesn't happen to everyone.

### Three Years On...

After having my stoma for three years, I started to think about having it reversed, and I am now going to have the operation to have this done sometime in May 2008. However, not everyone can have their stoma reversed as it all depends on the individual. If this operation isn't a success, I would just go about my normal life with my stoma.





## Ruby

*Age 12*

*Age 9 when had surgery*

My illness first started in late 2003, early 2004, when I started feeling sick and having headaches. By June 2004, I felt awful, always wanting to sleep and never wanting to do any sports or playing out with my friends — I just didn't have the energy.

I was really excited as a few weeks later when I found out I was going on holiday to Spain — but the worst was to come. We had been there for a week, had one more week to go, and it was back on the plane home. I felt really ill on the second day of the second week. Then, that night, I came down with sickness and diarrhoea. My parents knew something was really wrong with me. When we got home from the long two weeks, I still didn't feel well, in fact even worse than ever. We kept going to the doctors, and they said I just had a bad stomachache and it would go off. I was beginning to get really upset because I really loved school and because I was so ill, I was missing all my friends and teachers who I loved to bits.

Then, one day, my parents took me to the hospital and they said they would have to do an investigation to see what was wrong with me. A few months had passed and they found out that I had something called Crohn's Disease. It was not contagious and was something I would have to live with; all I had to do was take tablets and I would be able to be a child again, active and healthy. In November 2005, they found that with Crohn's Disease your bowel can be infected, and mine sadly was infected badly. So, after I had a chat with the doctor about having it removed, I said yes to the operation.

I was so scared and nervous about what was to happen. Now, three years on, I'm so healthy and fit. I still have my stoma. I told some of my close friends, so they know that if I ever need them for anything in life. Having a stoma is nothing to be scared of and having surgery done can do you the world of good. I'm so glad I had the operation, it has changed my life completely.



## Susie Rogers

Age 14-½

### End of April 2006

Toxic megacolon, had emergency subtotal colectomy, and formation of a terminal ileostomy. Making friends in hospital, to be honest where better to make a few new buddies. We've all got something in common, and we all need cheering up.



This picture just goes to show you can do absolutely anything when in hospital. This is me shopping in River Island, with bag after an emergency operation to untwist my intestine - nose tube and cannula included.

### July 2006

On the beach at Norfolk helping with Girl Guides. I decided that I would do what I wanted to do, and no one could stop me. Sure people would look but just out of curiosity.



Me with my friends at Blackrocks on an adventurous trek. Having a bag hasn't stopped me...



**June 2008**

Had my stoma reversed



This is a few weeks after my reversal operation with my boyfriend. Nothing to hide—everything to be proud of!

**April 2009**

After my reversal, this is me on a school trip to China. I had a great time conquering The Great Wall, although I did not get round the whole thing.





# Pouchkins Pediatric Pouching Systems

## Premie Pouch



- 3777 (CUT-TO-FIT)**
- Use as a Premie Closed or Drainable Pouch
  - **SoftFlex** Skin Barrier - Flat
  - Without Tape Border
  - Without Starter Hole
  - Without Integrated Filter
  - Odour-Barrier Film
  - Without **ComfortWear** Panels

Ultra-Clear  
Code No **3777**

Cut-to-Fit Opening  
up to 15 mm



- 3797 (CUT-TO-FIT)**
- One-Piece Urostomy Pouch
  - SoftFlex Skin Barrier - Flat
  - Without Starter Hole
  - Without Tape Border
  - Odour-Barrier Rustle-Free Film
  - With ComfortWear Panels - Body Side Only

Transparent  
Code No **3797**

Cut-to-Fit Opening  
up to 38 mm

Pouch Length  
22 cm

## Newborn Pouch



- 3778 (CUT-TO-FIT)**
- Newborn Pouch; Use With or Without the Drain Valve
  - SoftFlex Skin Barrier - Flat
  - Without Tape Border
  - Without Integrated Filter
  - Odour-Barrier Film
  - Without ComfortWear Panels

Ultra-Clear  
Code No **3778**

Cut-to-Fit Opening  
up to 35 mm x 22 mm

## Two-Piece Skin Barrier



- 3761 (CUT-TO-FIT)**
- Two-Piece Skin Barrier
  - SoftFlex Skin Barrier - Flat
  - Low Profile Floating Flange
  - Without Starter Hole
  - Without Tape Border

Code No **3761**

Color Match  
•

Flange Size  
45 mm

Cut-to-Fit Opening  
up to 32 mm

## One-Piece Pouches



- 3796 (CUT-TO-FIT)**
- One-Piece Drainable Pouch
  - SoftFlex Skin Barrier - Flat
  - Without Starter Hole
  - Without Tape Border
  - Without Integrated Filter
  - **Lock 'n Roll** Closure
  - Odour-Barrier Rustle-Free Film
  - With ComfortWear Panels - Body Side Only

Transparent  
Code No **3796**

Cut-to-Fit Opening  
up to 38 mm

Pouch Length  
16 cm



- 3799**
- Two-Piece Drainable Pouch
  - Low Profile Floating Flange
  - Without Integrated Filter
  - Lock 'n Roll Closure
  - Odour-Barrier Rustle-Free Film
  - With Belt Tabs
  - With ComfortWear Panels - Body Side Only

Ultra-Clear  
Code No **3799**

Color Match  
•

Flange Size  
45 mm

Pouch Length  
16 cm



- 3795 (CUT-TO-FIT)**
- One-Piece Drainable Pouch
  - SoftFlex Skin Barrier - Flat
  - Without Starter Hole
  - Without Tape Border
  - With Integrated Filter
  - Lock 'n Roll Closure
  - Odour-Barrier Rustle-Free Film
  - With ComfortWear Panels - Body Side Only

Ultra-Clear  
Code No **3795**

Cut-to-Fit Opening  
up to 50 mm

Pouch Length  
18 cm

## Accessories



- 3774**
- Pediatric Ostomy Belt

Code No **3774**

Length  
24-43 cm



- 3779**
- Drain Tube
  - For use with Newborn Ostomy Pouch Code No 3778

Ultra Clear

Code No **3779**

Length  
155 cm

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Caring for a baby, young child, or teenager is a life-changing and challenging experience for any parent (most of us). If it is your child, and you are faced with dealing with a stoma, this can give added worry and concern. Sometimes the surgery is not always planned, so it does not allow much time for discussion and preparation.

This booklet aims to give you insight into other parents' experiences of caring for a child with a stoma, and how they learnt to cope and deal with the situation as you will. Don't be afraid to ask for help and advice from your Stoma Nurse or any other professionals involved in your child's care. Everyone will be more than willing to help and support you and your child to manage the stoma, and carry on with day-to-day activities.

I hope you find this booklet useful and informative, and that it gives you comfort knowing you are not alone and that others before you have learnt the skills to manage a stoma.

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Sheffield Children's **NHS**  
NHS Foundation Trust

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Thank you all,  
Helen



## Prem Baby

*Bev and Dave Walton - parents of Liam*

Following a very rocky start to life, we were told that our son, who was only 10 days old, would need surgery to have a stoma. We didn't really know what this meant, and the explanations the doctors gave us before the operation didn't really sink in or mean much. My grandma had had a stoma, so I thought I knew what to expect. However, following surgery, we were surprised to see our son's stoma - seeing his bowel uncovered wasn't what we expected - We expected a stoma bag to be in place. It also was upsetting to see him not perfect, not knowing how long he'd have his stoma and how we would cope.

After a few days of getting used to the idea and speaking to the Stoma Nurse, things started to become clearer. Nothing happened for a while and, eventually, (after a lot of assistance /encouragement) the stoma started working. This was when the bag was first fitted, and we were told we'd be doing that in the future. Until that moment, I don't think we'd given it any consideration as to who would be changing the stoma and what it entailed. This in itself was very daunting. Cutting the stoma bags to size was an experience - as they say, practice makes perfect (well almost)!

Emptying our son's stoma soon became the norm and was easier than changing nappies. The fun began when the bag leaked, became loose or needed changing. We dreaded this job and initially it was a two-man job (three-man if you count our 2-year-old who was always eager to help change his brother's "poo bag"). We seemed to be all fingers and thumbs and dreaded the bag leaking when out. Would we remember to take everything we needed with us? Where would we change it (people would often look and stare in baby changing rooms)?

There were times when I doubted my ability to fit the stoma bag, as each one I fitted came loose within 24 hours. It was upsetting when bags kept coming loose as I felt a failure. I felt like I was letting my son down, especially when the stoma site got sore. Help was always at hand, and with extra intuition, things started to get easier. When we were told we could have the stoma reversed, we were over the moon. It was a relief, and so we booked him for the operation as soon as we could. The reversal was a success, and within hours we had our first dirty nappy to change (at 7 months old). These came thick and fast, and it was at this time that we realized we actually missed the stoma bag!



## Chris and Kathryn

We were filled with pride and joy when Lucy was born. A beautiful baby daughter and sister to our four-year-old.

After an overnight stay at the birth centre, we were discharged the following day once the paediatrician had completed the relevant checks, and came home to show off our new bundle of joy.

Our world fell apart when the doctor visited to complete her 10-day check.


I was at home with my four-year-old and expected everything to be straightforward after the other checks seemed to be fine. When the doctor said that she thought that Lucy's anus didn't look to be in the correct place, I felt numb and sick. What did that mean? How serious was her condition? She went back to the surgeon to seek further advice, leaving me feeling alone and anxious. In the space of half an hour after her departure, I received a phone call from the doctor to say that we needed to go to Sheffield Children's Hospital with an overnight bag as soon as possible to see the Consultant there. My head was spinning!!! I immediately rang my husband to come home.

We arrived at the hospital and went straight to the Neonatal Surgical Unit where there was a bed waiting for Lucy. The Consultant verified that the doctor was indeed right to refer us. Lucy had an Anovestibular Fistula.

It was explained to us that with abnormalities like Lucy's, there could be other problems relating to this, mainly down the trunk of her body, i.e., hole in the heart, spinal problems, or kidney problems - to name just a few. Human nature makes you fear the worst, especially in these kind of circumstances. We spent a sleepless night at the hospital wondering if anything else was going to be found. X-rays and scans were done the following day which ruled out any other problems. We were so relieved! We were not prepared for what happened next.

There was talk about a colostomy and a couple of operations to follow. For the immediate future, we had to stretch Lucy's anus to assist her with passing waste (poo). Emotions were running high at this point and tears started to run down my face. I started to blame myself for not noticing it myself and felt physically sick. For us to insert a dilator on a daily basis didn't seem natural or fair. Lucy was only 10 days old.

*continued on page 5*



The support we received from the hospital was tremendous. The stoma nurse visited us on the unit before we were let home, to show us what we needed to do. She then visited us at home on a regular basis, and we were always able to get hold of her if ever we needed her in between visits. Just knowing that we could talk to her anytime gave us great comfort. We gathered strength from each other and became used to the dilation until the date came through for her first operation.

When we were originally told that a colostomy needed to be carried out, our hearts sank. Neither of us knew much about the subject, but it sounded horrible. What were we going to have to put Lucy through? The colostomy was due to be performed. Although the operation had been explained to us in great detail and leaflets had been handed to us to read, nothing prepared us for how we felt when we saw it on our baby.

Lucy came through the operation like a real trooper, and we were able to come home after three days. Now, all we had to do was to get used to emptying and changing the bag. The stoma nurse changed the bag with us before leaving the hospital and arranged to visit us at home three days later. We had been told that the bag would need changing every four to five days, so we took comfort in the fact that we could change it with her when she visited. This proved not to be the case! The day after, it leaked. Panic struck. We had to change the bag on our own! Eventually through a lot of uncertainty and anguish, we did it. Lucy screamed the whole time, which made us more anxious. From then on, I dreaded changing her nappy just in case the bag was leaking again. Lo and behold, the following day the same thing happened.

By the fifth day of having to change it, I was becoming emotional. Why oh why was it leaking all the time? That morning, I sent my husband off to work without having changed the leaking bag and just sat and cried. There had to be a simple reason why it was leaking. I felt like we were failing Lucy. Each time we had to change the bag she seemed in distress. Through my tears, I looked at the template of the bag which we had cut. The problem was staring me in the face. We had cut it too close to the edge. A simple mistake but why had we not looked at it logically before now to save all the upset?

From then on, things started to get a little easier. We were able to order pre-cut bags once we had a good template. The visits from the nurse started to drop off as she was pleased with how we were coping. We were now changing the bag every four days. Result! It's true, you have to just get on with it for the sake of your baby, and that's what we did. We made an appointment with the Consultant to check that things were running to plan, and they gave us the next

surgery date. This was to undertake the reconstruction of her anus. This time, I wanted to take Lucy down to the anaesthetic room. At 16 weeks old, Lucy was now aware of my presence in the room and recognized my voice. I wanted to be with her as much of the way as possible. As they placed the mask over her face and her eyes started to slowly close, I gently stroked her face and held her hand, she managed a little smile before closing her eyes as if to say "It'll be ok mum." After a three-hour operation, we collected her from the recovery room. Lucy was drugged up with morphine and looked spaced out. It was such a relief to be able to cuddle her and hold her tight.

The surgery was raw, but very tidy. A catheter had also been fitted. Lucy was the ideal patient and, again, we were home in three days. Apart from applying a cream to her new bottom, we were relieved of duties for a week or two.

We are now at the point where we have re-commenced the dilation. This time, it seems a little harder. Mainly because Lucy is now older and is more aware of what is happening. Also, the fact that she is more mobile makes it harder to hold her still. The dilators are also much bigger in size. The date for the third and final operation to reverse the colostomy has now been set, and we can see that there is light at the end of the tunnel.

We had never heard of Lucy's condition before, but please take comfort that it is not uncommon and the surgeons are specialised in this area. We have definitely been in the best hands throughout our journey so far. The support of everyone has been incredible. The staff on S1 Ward, Intensive Care Unit and Neonatal Surgical Unit have all been friendly and supportive. The Stoma Nurse (Helen) has been incredibly patient and supportive to us and answered all of our questions, no matter how trivial they might have seemed. At such an emotional time, all kinds of things enter your head. Don't be afraid to ask. Finally we have continued continuity from our Consultant. He has always seen us in clinic after the surgery to discuss the next course of action and has carried out each operation himself. Everything has been explained in detail, and we have always been well informed at every stage.

We are now looking forward to a better new year when Lucy will have her final operation. She will still be under the Consultant for regular, twice-yearly check ups until she reaches puberty. Nothing can come close to the emotions and pressures we have had during Lucy's first six months of her life.  
Bring on the dirty nappies!!!!

Chris & Kathryn



## Our Story

Our baby boy, Lewis, arrived into the world on 6 March 2008.

The day after he was born, we were told he had an imperforate anus (the lower part of his bowel had not formed properly).

He was taken to Sheffield Children's Hospital for emergency surgery for a stoma to be formed and was fitted with a colostomy bag. We were told with Lewis being so young, he had a 50/50 chance of getting through the operation.

I felt numb, helpless, and worried for what life was going to bring for my beautiful fragile little boy. Lewis came through the surgery okay. It was obvious he was going to fight his way through this. We were shown how to look after Lewis' stoma and how to put the colostomy bags on. We came home with the general equipment we needed.

At first I thought "Gosh, oh no, have I got to do that?" It felt like a huge responsibility to keep my Lewis' bowel movements alright. I soon got into the swing of things and it became an everyday job. I accepted that I had to help Lewis.

Twelve weeks later, Lewis had the bottom part of his bowel formed, and we had to do dilations to keep his anus opened.

His final operation was on 6 August 2008 to close the stoma and connect his lower bowel. Each operation was worrying, wondering how things would turn out for Lewis.

When Lewis went to the toilet for his first bowel action two days later on 8 August 2008, I got quite emotional and tears filled up in my eyes. Something I realized was having normal bowel actions I took for granted before my experience with my son Lewis. Having a stoma saved Lewis' life and led the way to progressive surgery for him to have normal bowel actions.

The nurses and doctors at Sheffield Children's Hospital, and also our community nurse, were very supportive and caring with their expertise and hands-on experience. I shall be eternally grateful to them.

Lewis' mum



## Parents of 15-year-old - Ian and Angela Clift

Dear Helen,

Our experience of what happened before our daughter's stoma was formed was nothing less than a tragic case of ulcerative colitis being left undiagnosed for 14 months and then being discharged with inappropriate medication in November 2006.

Karen was re-admitted January 2007, because she was bleeding heavily (1.75 Ltrs) in one day. It was a difficult time for us. We asked repeatedly if it could be ulcerative colitis, only to be told we were not doctors and he was. To be asked to trust doctors again for them to do a major operation on Karen, and that it was the only thing that could be done, made us ask a lot of questions and do a lot of research into this condition before we could accept the inevitable.

Happily, we met Karen's new doctor who, despite having Karen introduced to him in January with his words "the worse case of ulcerative colitis he had ever seen," took over, and he did the very best he could.

To see Karen go through this at 15 years old was heart-breaking. She struggled at school anyway, but this put paid to all her chances in her G.C.S.E. exams. They removed Karen's colon, because of the blood loss and to stop the bleeding. Karen is still bleeding and looking at further operations. This event has altered our lives for good, especially Karen's.

We have supported Karen through all her troubles, never making negative of things and only pointing out the positive. We now are at the stage where Karen is coping, and we are supporting her until the next decision is made as to what should happen.

We are hoping that a reversal surgery is what Karen wants, but it will have to be what Karen needs.

We would like to thank everyone who cared for Karen and got us all through this difficult time and is still ongoing, since she was admitted January 2007.

THANK YOU!

Sincerely,

Ian and Angela



## Baby - Jack

When our son, Jack was born, it was a wonderful experience, the midwife informed us he was a perfect little boy with 10 fingers and 10 toes. We were overjoyed. She ran her fingers down his spine — everything was well. She just happened to mention that Jack had a lovely little bum, then stopped. With a closer look at Jack's bottom she noticed that there was no anus.

We didn't really understand, a doctor came to check Jack, and within minutes we were told that he had a condition called "Imperforate Anus", and that he would need an operation to create a stoma. You can imagine our joy quickly turned to worry. On first hearing that your child requires a stoma it can be a very daunting experience for all of the family due to the fact that your child needs to have surgery. However, take comfort in the fact that it is more common than you think.

The medical staff at the hospital were very supportive. The next day, Jack was transferred to the Children's Hospital for some investigations to be done before he had surgery that night. You feel that you are on an emotional roller-coaster.

The hospital staff were fantastic, everything was explained to us. They had to explain certain things three or four times, as I was still in shock that our newborn son needed surgery to create a stoma and that to correct his condition it would take three stages of surgery. Our son Jack was 24 hours old when he had the first stage of surgery to create a stoma. He was in surgery for a few hours, which seemed like a lifetime to us. As parents you want to protect your child, and we couldn't control what was happening. I kept crying and breaking down thinking that it was all my fault somehow.

After ether surgery, every detail was explained to us again. Everything had gone well. When you see the stoma for the first time, it can be quite frightening. It looks very painful and sore (but looks are very deceiving). Jack didn't have a colostomy bag fitted for a couple of days. We are relieved that all had gone well. It was a very emotionally draining time. Twenty-four hours earlier we were full of joy at his birth. Now we were looking at his tiny body after surgery with feeding tubes and wires everywhere.

The hospital staff was amazing. They explained exactly what all of the wires and monitors were doing. They really put us at ease. After a few days, Jack had his first colostomy bag fitted. Just watching the nurse fit the bag was a nerve-racking experience, knowing that soon we would be the ones that would have to do it. Within a couple of nappy changes, I felt confident enough to have a go at emptying the bag. It was always at the back of my mind that if I accidentally pulled on the bag or fastened his nappy too tight it would hurt Jack.

Once again, the nursing staff were excellent when it came to showing me how to take care and clean his stoma. The first few times, the nurse changed Jack's bag and talked me through it. Don't be afraid to ask any questions.

Then came the day for me to change Jack's bag — I was so nervous. What if I hurt him or didn't place the bag on correctly? The nurse was there to talk me through every step and reassure me that I was doing it correctly. After I had done it, I felt like I could take on the world.

Jack was in hospital for the first 16 days of his life. Before he was discharged from the hospital, we met with this Stoma Nurse Specialist and arranged home visits within the first week of him coming home.

After a couple of days, we needed to change Jack's colostomy bag. I was at home alone as my husband had gone back to work. Jack's Stoma Nurse had advised me not to change his bag on my own just yet. So, I cut a nappy into two pieces and placed half of a nappy over his cleaned stoma, then a nappy as usual until my husband came home. Then, together we changed Jack's bag for the first time. It's good to have each other's support while you change the bag. My husband would hold Jack's leg and arm down and comfort him while I fitted his bag.

Within a few changes, we had the confidence to change Jack's bag on our own. Jack's Stoma Nurse is very supportive and understanding. If I have any concerns, all I have to do is phone her up and she reassures me that all is well.

We now know from Jack's body language when to change his bag. He gets uncomfortable and moans, he will kick out with the left leg a lot. Now we are facing his second surgery to create an anus. He will still have his stoma until the third stage of surgery to close the stoma.

With the second stage surgery, he will be in hospital for approximately two or three days. After day 10, we will have to return to the hospital to start to dilate his anus with a special probe. He will have this done until it reaches the correct size for his age.

I am feeling very apprehensive about this procedure, I keep telling myself that I am doing this for Jack and not to Jack.





## Andrea Glossop (aka Martyn's mum) Before Martyn was diagnosed

Initially, when Martyn first started to become ill, we just assumed that he'd got a bit of diarrhoea/tummy bug. I took him to see the doctor and he didn't think it was anything serious, but said that he'd take some stool samples just to make sure. The results came back clear, so the doctor reassured us that there was nothing to be worried about and told us to keep using the Imodium® until the diarrhoea cleared up. A couple of weeks went by and Martyn's condition wasn't getting any better, so I took him to see the doctor again and insisted that he have further tests. We were then referred to Rotherham Hospital to see a doctor that dealt with children with similar symptoms. By this point, Martyn was becoming very ill, soiling himself most days on the way home from school when the Imodium had worn off. I felt very scared and isolated because no one seemed to have any answers as to what was wrong with Martyn. I was so terrified that Martyn had bowel cancer. Eventually, after numerous tests at Rotherham Hospital, Martyn was referred to Sheffield Children's Hospital.

Now five months later, Martyn couldn't even leave the house without wearing incontinent pants. I felt very down and that no one understood what we were going through. I just wanted someone to tell us what was wrong with Martyn — not knowing was terrifying. It was a very scary and emotional time for the family. The doctors and nurses at Sheffield were excellent; this made a big difference to our morale. After yet more tests, Martyn was finally diagnosed with ulcerative colitis, which was quite aggressive by this stage. Martyn had to have quite a lot of medication, which was very upsetting for him and he found it quite stressful. I felt very guilty, and sometimes angry, having to watch my son go through this ordeal. Several months later, and lots of time in and out of the hospital, Martyn wasn't getting any better and his quality of life wasn't as it should be for a 14-year-old. The doctors decided that the best option was to remove Martyn's large bowel and leave him with a stoma. We were mortified. I couldn't bear the thought of him having this done, it seemed so unfair. I knew deep down that we had no other choice, but it didn't make it any easier. I really did feel that it was the end of the world and that Martyn wouldn't be able to lead a normal life. I was so terrified what the stoma was going to look like and how people would treat Martyn.

### Before the operation

Before the operation, we met the surgeon and he talked us through what was going to happen. This was very important to us as a family, and we were very grateful for this opportunity. We were then introduced to Helen, Martyn's Stoma Nurse. She was fantastic and reassured us that we were making the right decision. Helen's support was what kept us going and feeling positive. I constantly questioned myself whether we were making the right decision.

### After the operation

After the operation, we couldn't believe how quickly Martyn recovered. His health improved dramatically, and this made us all feel that we'd made the right decision. He'd finally got his life back and was able to go out! I feel having the stoma was the best thing that the doctors could have done for Martyn. The continued support from Martyn's Stoma Nurse afterwards and for the following months was imperative. We've never looked back since the operation and we often forget that he's got a stoma!

Martyn is now 18 and hoping to have his stoma reversed in May. I can't believe it's been nearly three years since having his stoma!



## Parent of 9-year-old at time of surgery

Before her illness was diagnosed, Ruby had been unwell on and off for some time. She lacked energy, had diarrhoea, stomach pains, and was just feeling unwell.

Her appetite was always very good, but then she started being sick. Every time she was going to be ill, she found it hard to get motivated. She'd just lay on the sofa, often with a temperature and sometimes a rash. She had a lot of swollen glands and her mouth was always sore. Trip after trip to the doctors, to be told it was a virus and more antibiotics were given.

Things started to get worse, and she started missing a lot of school. She'd force herself to get to school, then later I would get a phone call to fetch her home, she was not well!

Daily routines became interrupted, we had to be close to a toilet at all times. She had a lot of accidents. Having to use public transport was the worst thing. We'd be on the bus then she'd need the loo, so we get off and rush to find the nearest loo. We can laugh about it now, but at the time it wasn't funny.

She had to stop her swimming lessons and missed out on a lot of other activities.

Seeing her every day, I didn't realize how ill she had gotten. She never complained. Her weight began to drop, and she got really unwell. I couldn't get her in at the doctors, so her dad who at the time was working away said to change doctors. I did, and got in with a new G.P. the next day. He referred her to the hospital.

Within a week, we had an appointment. She was admitted for tests. She was diagnosed with Crohn's. Things just didn't seem to sink in. For the next few months she was still up and down. Steroids seemed to help for awhile. Other medication was introduced, and special diets were tried. Her weight began to get better as soon as the steroids were reduced, so did her appetite.

She still had to go to the loo a lot, and the pain was still bad. After trying various treatments, she was admitted again for another investigation. We were told that the best thing was to remove part of the bowel.

A date was arranged for the operation. Even though you are told things at the time they don't seem real - everything seems a blur. She came back from theatre, and we were told the operation had changed she had to have a stoma. The next few days were traumatic for us all. How is she going to cope with that? I felt nervous, how would I cope? Getting over the operation was the first hurdle. She just got better and stronger everyday.

I felt nervous at changing the bag. I also felt angry and asked "WHY?". Her dad was great, he just took control, and helped with changing and emptying, just him being there made a big difference. Things got better, and I felt more confident once we were at home. I knew that we had to be strong, although at times it was hard. Ruby felt better and became stronger. We had to change our routines, but it soon all falls into place.

I can't say it's easy sailing — it's not. We still have accidents, always when you don't want them; at school, shopping, parties, cinema and at the time they are upsetting. But at the end of the day, Ruby is a lot healthier, active, and has a more "normal" daily life. She missed out on a lot of her first years at school and with friends. Having the stoma has given this back to her. She has a better quality of life.

