

So you've been told you need a stoma



What is a stoma?



What do I tell
my friends?



Inspired by
teenagers

What can I eat?

Hello

This information booklet has been designed for young people with IBD (*Inflammatory Bowel Disease*) specifically and covers all aspects of your life after stoma formation e.g. what you can eat, activities you can do, what happens on holidays – but there are other resources available to you, so please discuss this with your stoma/specialist nurse.

After you were told you needed to have a stoma, you may have felt confused, angry and you may have not really known what it meant.

You will probably have heard some people saying that you needed to wear a *bag*.

You may have thought:

"Does that mean I am going to have a shopping bag to poo into?"

"What will the bag look like?"

"Do I get to choose the bag?"

"Where will the bag be?"

As a teenager, you may think that the adults around you do not understand what your issues are about having a stoma. The healthcare professionals managing your care will have seen many young people who required a stoma and will be able to help you and your parents. You must ask them questions.

If you wish to meet or speak to a person your age who has had a stoma, please discuss this with your stoma/specialist nurse and they will try to arrange this for you. You may initially find it easier by using messaging options.

There are also support groups available for you to join, to help you cope with your stoma. You can either attend meetings that are arranged locally or use the internet to

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join discussions via chat rooms or forums. *(You will probably be able to navigate this better than most adults, but please use caution and if there is anything on a site that concerns you, discuss it with an adult.)*

Let's start

So you've been told you need a stoma

There will be a team of people involved in your care pre-operatively (*before your operation*) and post-operatively (*after your operation*), if you require a stoma. Many of these you will know since you were diagnosed with IBD, including:

- paediatric gastroenterologists
- IBD/gastroenterology nurse (*depending on local services*)
- surgeon
- stoma care nurse
- child counsellors/psychotherapists/psychiatrist
- ward nurses
- teachers
- massage therapists

We aim to provide high-quality support and information on both a practical, emotional and social level to help you adapt to a stoma, aid your recovery and help you to return to your daily life.

Why do I need information before my operation?

It will help with your recovery if you have good knowledge and information of what will happen from day to day, from your admission to your discharge. It also gives you and your parents a chance to talk things over and discuss any worries you might have. Our aim is to provide you with the pre-operative information well before your operation so you have enough time to get your head around the thought of having a stoma.

Usual questions on being told you need a stoma

What is a stoma?

The word 'stoma' comes from a Greek word meaning 'mouth' or 'opening'. To form a stoma, the bowel is divided and the ends brought out through the muscle and stitched onto the abdomen, either Loop or End.

The majority of stomas that are formed for patients with IBD are ileostomies; however, some people may require a colostomy. This booklet will focus on ileostomies and IBD.



What is an ileostomy?

An ileostomy is a stoma arising from the small bowel (*ileum*). The stool that comes through the small bowel is normally of a liquid consistency (*thickness*) which can vary from being as thick as porridge to being watery. Your stoma nurse/IBD or gastroenterology nurse/dietitian will be able to give you plenty of dietary advice on which foods and drinks will help thicken the stool.

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lift the flap to see a picture of a stoma



What is an ileostomy?

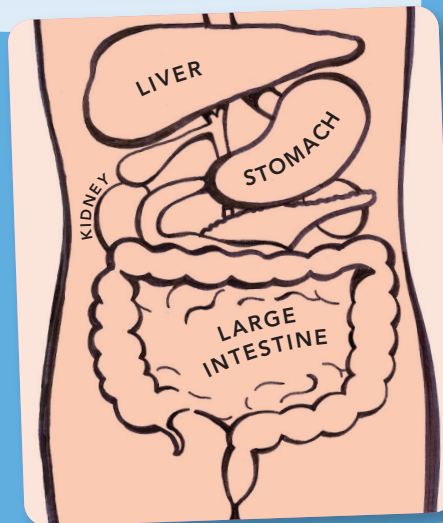
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Where will the stoma be?

An ileostomy is normally situated on the right-hand side of the abdomen (*tummy*), generally halfway between your belly button and the top of your hipbone. The position can vary depending on your waistline and where you would like the stoma to be placed. The stoma nurse will be able to advise you of the best position, as they take into account your clothing styles, particular hobbies, etc. An appropriately sited stoma will allow you to care for it more easily and ensure you have a better quality of life.

You also need to consider the fact that your body shape will change as you grow and develop into an adult.

The stoma nurse will draw a dot on your abdomen, generally the day before surgery, to let the surgeon know where the preferred site is.



Remember: If you are not happy with the site, please tell your stoma nurse, as they will always take your wishes into account – as much as possible!

What will the stoma look like?

A stoma is made from part of your bowel so it will look pink, soft and moist (*just like the inside of your mouth*) and it will have a spout.

The appearance of the stoma tends to be very individual, just like our face is. The reason the stoma has a spout is so that the stool doesn't come in contact with the skin and, instead, goes straight into the appliance (*bag*). The size of the spout will vary, depending on your surgeon. Even though the spout protrudes, it is not visible under clothing. Immediately after surgery, it is normal for the stoma to look swollen and this swelling reduces over the next 6–8 weeks.

What stops the stoma from moving?

The stoma is held in place by stitches (*sutures*). These stitches are normally dissolvable and so dissolve by themselves. As the stoma heals onto the skin, it is held in place – so don't worry about the stoma becoming dislodged or falling out.

What will it feel like?

As the stoma itself has no nerve endings, it will have no sensation or feeling. Otherwise, it feels soft to the touch.



Where does the stool go?

The stool that comes out of your stoma goes into a stoma appliance (*bag*) which sticks onto your skin around the stoma. It is usually a drainable appliance which is emptied approximately four to six times a day, on average, depending on what you eat and drink. The appliance can be changed daily, every second day, or as your stoma nurse advises you.

The appliance is very skin-friendly and does not normally cause any irritation. The stoma nurse will be able to show you examples of appliances before your operation – there are a broad range of appliances available. The stoma nurse will also teach you all you need to know about emptying and changing them (*i.e. caring for your stoma*) after the operation. While you are on the ward, after your operation, the ward nurses will assist you to empty or change the appliance.

It is better for you to try and do this for yourself as it will help you gain more confidence with dealing with your stoma after you have been taught by your stoma nurse.

The first time you empty the appliance or change it may be difficult – do not get disheartened – just remember it is all new to you.

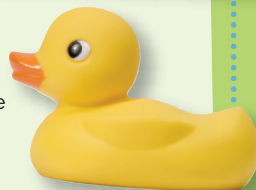
There are many different shapes and sizes to suit each individual.



Can I still have a shower/bath?

Yes

- Many of our patients like to change their appliance at the same time as they have a shower/bath.
- You can shower/bathe with the appliance on or off.
- As the stoma is active mainly after meals, people tend to have their shower/bath when the stoma is less active, either morning or evening, before meals.
- If you wish to leave the appliance on during a shower or bath, you may need to cover the filter so that it doesn't get wet – there are stickers provided for this.
- The appliance will not fall off in the shower or bath.
- The appliance can then be towel dried or a hairdryer can be used, if you prefer.



As you become familiar with your stoma, you tend to know when it will be active and when it will be quieter. The appliance may become more sticky and harder to remove after a shower or bath.

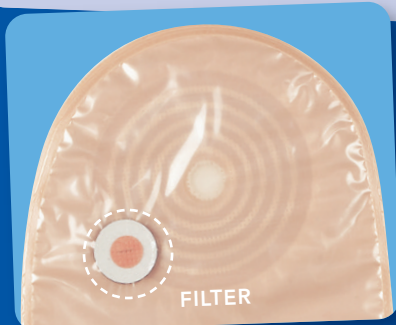
Do I have control over it?

You do not have control over the stoma working, as there are no sphincter muscles (*like the two in your back passage*) to allow you to stop the stool coming out. However, the stoma tends to work after meals (*approx. 1–3 hours*) and then quietsens down again.

Certain foods will slow the output and thicken it, and certain foods will make the output looser (*see page 13: "What can I eat and drink?"*).

Where will the wind go?

The wind will pass through your stoma along with the stool. Each appliance has a filter which allows the wind to pass through, while neutralising any odour. The stool will not be able to pass through the filter.



Will it smell?

It should not smell if the appliance is fitted correctly. As the stool is coming from the small bowel, it tends to have less of an odour than a normal stool would have.

How do I empty the appliance?

You can empty the appliance down the toilet, while sitting or standing, depending on what you prefer.

You may need to empty the appliance four to six times a day, depending on what you eat and drink. *(You may feel this is a lot. However, you will probably need to pass urine just as many times in a day.)* If you have a tummy bug, your output will be more. Therefore, you will need to empty your appliance more frequently. However, if you are concerned because your output has increased, please call your stoma nurse or IBD nurse specialist or doctor.

Will other people know

it's there?

The appliances these days are very discreet and are not visible under clothing, so other people will not know it's there unless you show it to them. (See page 9: "What do I tell my friends?")

Can I still wear my normal clothes?

You may need to adjust some of your clothes, depending on where the stoma is. But generally, the stoma is placed, whenever possible, in a place which will have minimal impact on your clothing style.

Examples of clothing you may need to adjust are: very low-cut bikinis, very tight tops, midriff, swimming trunks or low-cut jeans.



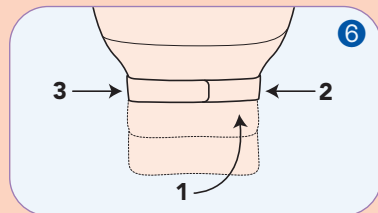
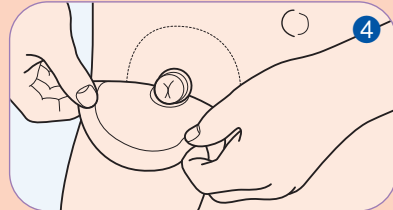
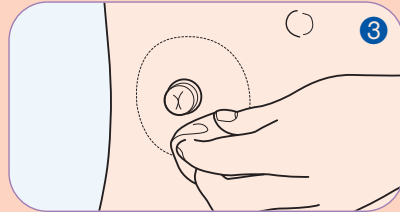
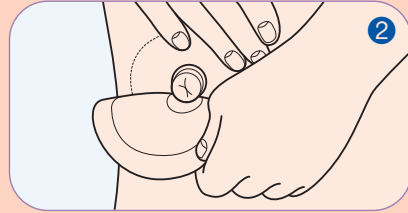
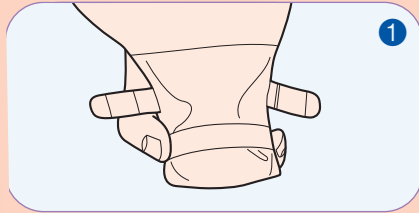
How do I change the appliance?

You should normally change the appliance in the bathroom. Here is a list of things you will need for an appliance change:

- new appliance, cut to size
- rubbish bag
- dry wipes
- small bowl of warm water
- scissors
- adhesive remover



- 1** It is generally a good idea to empty the appliance before changing it, as this makes it a lot easier.
- 2** Once you have all the things you need, you are ready to begin by gently peeling away the appliance. This is a painless thing to do if you spray adhesive remover as you peel the appliance off. The appliance can then be folded in two and placed in your rubbish bag.
- 3** Wet some wipes and clean around the stoma and surrounding skin. **REMEMBER, IT WON'T HURT YOU OR THE STOMA.** Once the stoma and the skin are clean, they can be dried with dry wipes.
- 4** The appliance is cut so that the stoma fits snugly into the hole in the appliance. The flange (*the sticky part of the appliance that attaches to your abdomen*) should be 2mm away from the stoma as we do not want to squeeze it and constrict blood flow.
- 5** To seal the appliance, press around the very edge of the stoma in a circular motion, working your way from the inside out.
- 6** Close the bottom of the appliance. The bag with all the rubbish is then disposed of in your normal rubbish bin.



How will I react to my new stoma?

You may not react the way you think you will. It is perfectly normal to feel upset and think "Why me?" But you are not alone and you will get through it. You may even want to talk to someone who has had it done and been through these emotions.

IT IS OK TO CRY. IT DOES NOT MAKE YOU ANY WEAKER ABOUT COPING MENTALLY.

How you will feel immediately after stoma surgery will vary. You may be relieved to no longer have diarrhoea, stomach pain or make constant visits to the toilet.

"The toilet will no longer feel like your best friend!"

It is quite normal to feel angry and resentful because you need to have a stoma. It is being done to help you get back to your normal life again and be able to enjoy all the activities you did before you were ill.

Try and remember the last time you really felt well and compare it to how you feel at this moment in time.

It is also normal to feel a little confused about having a stoma and how you will feel with one – and also to imagine life with a stoma.

These feelings are very natural and your team looking after you recognise this and is there to help you deal with these emotions. Talking about your anxieties will help you to overcome them and gain confidence with your appearance. Learning to live with a stoma does not happen overnight and it will take time. Sometimes, it can take up to



a year to feel you have got used to it. It is important to discuss any worries you may have either with your parents, the stoma nurse or any of the others involved in your care as this will help you to adjust. Also, getting these thoughts out in the open can feel like a weight has been lifted off your shoulders.

Counsellors are also available if you prefer to discuss your thoughts with somebody

not directly involved with your care. They are specially trained to help you deal with these feelings and they can help you come to terms with your stoma more quickly.

It can also be arranged for you to speak to another young person who has undergone similar surgery so you can 'swap' experiences with them.

Remember: Hiding your feelings, in the long term, will not help you



Patient experience of coming to

terms with their stoma/feelings

What do I tell my friends?

The comments below have come directly from patients who have had stomas formed for IBD.

I hated the thought of having a stoma, but now that I'm well and back at school, it doesn't bother me. My close friends know and they're really cool about it!

I don't know why I put it off for so long. Now that I'm better, I wish I'd had the operation ages ago.

All my friends wanted to see my stoma and look at my scar. They thought it was really cool and they were made up that I was getting better.

I don't have to go looking for the nearest loo any more.

Now that I've had my operation, I don't need to take any more medication.

Patient with UC

You can't tell I have a stoma, unless I have told you.

It gets easier to manage with time – and nobody has noticed that I have a stoma.

I found from my own experience that my closest friends have supported me through out my illness and nothing has changed since I have had my surgery. If anything they are more supportive.

Relationships

Relationships with loved ones, friends and peers are a very important part of people's lives. Lots of people with new stomas worry that, because they now have a stoma, it will spoil their relationships with other people. This booklet has some hints on how to cope with relationships now you have a stoma.

During adolescence, your body goes through many changes. This is normal, and all your friends are going through the same changes. For you, it may be more difficult to understand and accept these changes because of how you may now view your body with your new stoma.



You may have been unwell, missed a lot of school or time spent with your friends, having to live your life controlled by where the nearest toilet is – and perhaps you felt less confident than your peers. Coming to terms with having a stoma is difficult at any age. But after you have a stoma, you will be able to socialise with your friends, go back to school full time and participate in other activities. On a bad day, try to remember what it was like before you had your stoma. You will find ways to accept the changes in your body and you can talk to your parents or a responsible adult e.g. aunt/uncle, teacher, stoma nurse, other specialist nurse or your doctor.

Returning to School

One of the biggest concerns for young people is how a stoma will affect them developing relationships or a love life in the future. Telling a new boyfriend/girlfriend that you have a stoma may be difficult but you need to be honest with them. You need to explain to them what having a stoma means. It will be important for you to tell them why you have a stoma and what life was like for you before the stoma.

You must tell them all of this before you start to get intimate or develop a long-term relationship. If you cannot work out what to tell them, you may want to get advice from your stoma nurse, support group, parents or friends. Before you tell your partner, you may also want to practice what to say, either with your friends, stoma nurse – or just by saying it out loud.

You may have been told that your medical and surgical treatment can affect your fertility. Having a stoma formed does not mean that it will definitely happen. You will be given information from your team, so please don't be afraid to ask questions.

If you are struggling to cope with having a stoma, you should contact your stoma nurse, nurse specialist or doctor as they will be able to support you or refer you to the appropriate service. You may also wish to contact one of the support groups, see the contact details at the back of this booklet.

Prior to your surgery, if you wish to be put in contact with someone of your age who has a stoma, please ask your stoma/specialist nurse. This person will be happy to discuss with you how *they* felt when they had to have their stoma, what it is like living with a stoma and all the issues you want to discuss.

Returning to school after any operation can be daunting, but after a major operation that has changed the way your body looks, it can be even more frightening. For the majority of young people who require a stoma, the operation will be planned. This means that support for your return to school can be planned before your surgery, making your return to school less daunting. It is very important to tell one member of the teaching staff that you have had surgery so that you can be supported upon your return. The reason you have had the surgery is to reduce your symptoms and to let you to have a better quality of life, allowing you to achieve your academic potential.



You do not have to tell all your teachers and classmates you have had surgery. You can choose who to tell. Ask your teacher to work with the school nurse/SENCO (Special Education Needs Coordinator) to devise an individual healthcare plan to ease you back into school full time.

Before your operation, you or your parents should discuss with your teacher that you will need 6-8 weeks off school after the operation. Hence, you will need home tuition. If this is discussed before your operation, it allows time for discussion about home tuition, which will make it more likely to be in place. Return to school part time, initially, for example, half days for the first two weeks, and build up the amount of time gradually. After 4 weeks, you should be strong enough to go full time. If you have not returned full time, you should contact your stoma/specialist nurse or doctor for advice.

- sometimes, our skin can change, which can result in your appliance not sticking to your abdomen properly
- hot weather and sports can also cause leaks due to the body sweating
- puberty (*excessive sweating, body hair growth and change in body shape*)
- loose/watery output will also increase your chances of leaks. A few simple changes to your diet could aid absorption and thicken up your output
- rarely, appliances can be faulty

It is not advisable to apply body moisturisers to the stoma site as it will make the area moist and prevent your appliance from sticking.

Your stoma care nurse will be able to assist and advise you. **All of these problems can be dealt with easily.**

Social Activities – Restrictions

A common question asked is: *“What can I no longer do now that I have a stoma?”*

The only restriction placed on social activities is boxing.

This is due to the body taking direct blows.



For further advice on other sports such as rugby, football, netball or martial arts, contact your stoma care nurse so that he/she can advise you on a stoma guard. You can continue to swim. Just ensure that you empty your appliance prior to entering the pool.

Rectal Discharge

Occasionally, some young people experience the need to sit on the toilet and pass mucous, which may have blood in it. This is usually old blood. Again, this can be dealt with, but you need to inform your doctor, stoma care nurse or IBD nurse specialist.

Sounds/Noise

Certain foods and drinks will affect people differently. Some noises from your stoma are to be expected, particularly during the period soon after surgery.

It can take eight weeks for your stoma to reach its final size due to inflammation caused by the surgery. During this time, as your bowel is adapting and starting to work again, you may find that it is producing a lot of wind and that it can be quite noisy when it's working.

Leakage

While you have been in hospital, you will have been taught how to change your appliance and to care for your stoma.

However, you may occasionally find that your appliance leaks and this can be due to:

- sore skin (*if your stoma has changed shape*)
- tummy shape has changed (*caused by weight loss or gain*)
- bad technique
- excessive wind

Travel/Holidays

You will pass wind through your stoma, just like you passed it through your bottom. The difference is that you will not have any control because you are not using your sphincter muscles. There should not be any odour due to the charcoal filters in your appliance. Eating regular meals may help reduce wind and noise.

Wind may sound loud to you, but may not be obvious to others. It is entirely up to you what you choose to tell your friends regarding your surgery. If you feel that your ileostomy is noisy when working or passing wind, then by explaining your stoma to your close friends, they would be able to support you by either not commenting on it or by lightening the situation.

If you find that your stoma is particularly active with wind, it may be as a result of your diet. Your stoma care nurse will be able to advise on your diet to help reduce wind. If you continue to pass a lot of wind, he/she will also be able to advise you about a more suitable appliance – for example, dual filters.

Emergency Kit

You will always need to carry extra supplies with you, just in case you have a leak. By having a kit with you, a leak can be dealt with quickly and calmly, which will reduce any distress caused by the incident.

Some people use a small wash bag or a pencil case to hold their extra supplies. Within your kit you should have: *a few wipes, a waste (disposal) bag, a pre-cut stoma appliance and a small air freshener.*

You do not need to take a large number of your supplies with you – just the bare essentials. Your kit should be discreet and should not mean that you have to take a bigger bag out with you.

There are no restrictions on travelling if you have a stoma, but you will need to carry supplies with you. If travelling by plane, it is advisable to carry 7 days' worth of supplies (approx. 5 appliances) in your hand luggage, in case your main luggage gets lost. Ask your stoma care nurse as there is a lot of written information available on travelling, as well as language cards with useful phrases.

If you are travelling to warm countries, you will need to take extra stoma supplies as your skin will sweat more and you may therefore need to change your appliance more often. It is advisable to keep your next appliance either in the fridge or in a cool box to prevent it from being too warm and to protect the flange.



Apply sun cream/block (depending where you are going) to scars, for protection.

It is also worth taking rehydration salts, such as Dioralyte, and medication to thicken the output, such as Lopermide, just in case your stoma output gets very loose.

Also, in warm climates, you will sweat more and you may need to add a little salt to your diet and drink more fluids (**caution with excessive water intake**). If you feel very thirsty and tired, with a dry mouth, you may be dehydrated and, if you don't have rehydration salts, then a can of cola (not diet; wait for fizz to disperse) and a packet of ready salted crisps are a good substitute.



What can I eat and drink?

Output can vary for many reasons, but certain foods will help to thicken output. It is still important to eat a balanced diet.

You may find that you can eat a lot, if not all, of the same things that you ate before. It takes time for your body to get used to having to work in a different way, so it will take a little time to get it right.

You may be referred to a dietician or you can request to see one.

FOODS TO CHEW WELL

sweetcorn, peas, mushrooms, brussel sprouts, beans, lentils, onions, grapes, cherries, nuts, popcorn, pineapple

HINTS & TIPS

- chew food well
- eat small amounts, and often
- remove skins
- avoid raw celery and carrots as they are not digested easily and may block your stomach
- cola and ready salted crisps are a good emergency substitute if you don't have any rehydration salts



FOODS THAT THICKEN

- generally low-fibre foods
- white bread, pasta, rice
- refined cereals – rice krispies and cornflakes
- boiled, mashed, roast potatoes (no skin) or chips
- root vegetables – without skin
- stewed apple
- bananas
- yogurt
- peanut butter (smooth)
- jelly babies/marshmallows, anything with gelatine
- dry foods – crisps, crackers, rice cakes, cakes, arrowroot



- cous cous
- cheese
- eggs



FOODS THAT GIVE WIND

- fizzy drinks – try pouring into a glass and let it stand for 5 minutes
- onions, leeks
- brussel sprouts, cabbage, cauliflower, spinach, broccoli,
- beans, lentils and pulses
- eggs
- cheese
- nuts
- dried fruit
- curry
- sweetcorn



FOODS THAT LOOSEN

- generally high-fibre foods
- fruit – try eating without skin
- apples, oranges, pears, grapes, cherries
- fruit juices – pure fruit juices or try smoothies instead
- vegetables – green vegetables, peas, cabbage, onions
- caffeinated drinks e.g. Red Bull



FOODS THAT REDUCE WIND

- peppermint tea/tablets/water
- charcoal tablets
- fennel tea
- small meals – often
- chewed cardamom seeds
- probiotic drinks
- natural yogurt



MEDICATIONS AND FOODS THAT ALTER OUTPUT

- iron – may make stool dark
- antibiotics – change colour, smell, thickness
- beetroot – may make stools look red
- fish – may alter smell
- Ribena – may make stools look red

Salt (sodium) replacement

Salt is lost through your stoma output and, as you do not have a colon (*large bowel*) to reabsorb the salt, you may need to take sodium supplements. However, there are alternatives such as adding extra salt to your food, eating salty crisps or drinking Dioralyte. Your team will advise you regarding your specific need for sodium replacement.



Transition to Adult Services

Your transition to adult services is important, to ensure that your care and support are continuous. Your transition will be coordinated by your IBD team, and starts 6 months after you are diagnosed with IBD. Please see *Transition Inflammatory Bowel Disease Transition to Adult Healthcare – Guidance for Young People*. Copies are available from www.ibdtransition.org.uk



Issues that accompany transition

Prescription exemption: when you were in school and college full time, there was no charge for your appliances. However, when you move to the adult services, you need to be aware that if you have a *permanent* stoma there will be no charge, but if you have a *temporary* stoma, the cheapest method of payment is a pre-payment certificate (3-monthly or yearly). The prepayment certificate is available on the internet (on your local health authority website) or you can get a form at your GP's surgery or a large post office.

Other issues such as contraception, pregnancy, alcohol consumption, drugs and any other issue you would like to bring along, will be discussed on an individual basis during your transition process.

Parents' section

General

You should discuss this page with your parents

- listen to your child
- allow your child to ask questions
- allow your child time with the health care professionals on their own
- you need to ask questions
- seek support from support groups
- you need to be prepared for your child becoming an adult and asking questions regarding:
 - education
 - employment
 - relationships (including sex)

Doctors will discuss the operation in more detail with you and your child, including the risks and benefits of the operation and it is normal for them to discuss these with you and your child.

Alcohol

The legal drinking age for alcohol is eighteen years old. Excessive alcohol intake can result in severe dehydration.

- Alcohol will make the ileostomy output watery
- Beer/lager/cider will also produce wind
- When preparing for an evening out, make sure that the stomach is full – this aids absorption
- The appliance will need to be emptied more frequently
- It would be advisable to limit alcohol intake during a night out to prevent dehydration
- A can of cola (not diet) – wait for fizz to disperse – and ready salted crisp will aid rehydration.



Bullying

Any child can be bullied and they are bullied for many reasons. Being different can make young people more of a target for bullies.

If you require further information, please contact your child's school. Your GP, school nurse, a social worker or educational psychologist will also be able to offer support. You can also discuss this with the team caring for your child in hospital.



Sources of further information

ChildLine provides a free and confidential telephone service for children:
Helpline 0800 1111; www.childline.org.uk

Or you may want to look at these websites:
www.antibully.org.uk
www.bullying.co.uk

Parentline Plus is a free, confidential, 24-hour helpline for parents concerned with a wide range of issues, including bullying. Call 0808 800 2222; www.parentlineplus.org.uk

Useful resources

Disability Discrimination Act (2005)

Education Act (1996)

National Service Framework for children,
young people and Maternity services (2004)

Disability Equality Act (2006)

**Department for Children, Schools and
Families:** www.dfes.gov.uk

www.diseed.org.uk

Contacts

Children with Crohn's and Colitis

*This is a support network for children with
IBD and their parents:* www.cicra.org or
email: support@cicra.org

**smiley people – National Association for
Crohn's and Colitis:** www.nacc.org.uk

**National Association for Crohn's and
Colitis:** 01727 830038; www.nacc.org.uk

**Young ia at The Ileostomy and Internal
Pouch support group**

**ia – The Ileostomy and Internal Pouch
support group**
0800 0184724; www.the-ia.org.uk

British Colostomy Association
0118 939 1537; www.colostomyassociation.org.uk

**The Red Lion Group Ileal-anal Pouch Support
Group** www.redliongroup.org

The Kangaroo Club
www.kangarooclub.org.uk

Transition www.ibdtransition.org.uk

*This leaflet has been written by the following
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