Reversal of Ileostomy

Introduction
This information booklet has been based around experiences of patients who have had their ileostomy reversed and how they have managed their new bowel pattern.

It is difficult for health care professionals to be prescriptive about the management of the bowel pattern because it is very individual. Hopefully you will find this booklet informative and reassuring as you are adapting to your new bowel pattern.

What will the Operation involve?
Prior to the operation you will need to attend the pre-operative assessment clinic similar to before your main operation. You will be admitted to hospital on the day of your operation.

The day before your admission you need to go onto a liquid only diet, i.e. do not eat any solid food. This is the only preparation that is required. No bowel laxative is needed this time.

The operation lasts approximately 60 minutes and requires a stay in hospital usually for about 3-4 days. This procedure will put your bowel back inside allowing the motion (faeces or stool) to flow through in the normal way.

In order to put the bowel back inside the surgeon makes a small cut either side of your stoma. This will result in you having a small wound in this area.

You will come back to the ward with a drip in your arm which gives you fluids. When you are awake, and if you don't feel sick, you will be allowed to have a drink. The following day you will be allowed to
increase the amount of fluids and start to eat. The drip will be discontinued when you are drinking adequately.

After this operation you may not have a catheter therefore, when you need to pass urine, you will need to ask the nurses to help you to the toilet.

Pain killers will also be prescribed for you to have on a regular basis. However if these are not strong enough then ask the nurses for a stronger pain killer.

Your bowels will usually start to work a couple of days after the operation and, when they do, you will be allowed to go home.

The main purpose of this leaflet is to explain more about the potential bowel pattern following the reversal and what can be done to help it.

**Your bowel before your Cancer Operation**

The large bowel, or colon as it is medically called, is the last part of your intestines. When you eat, the food passes down your oesophagus (gullet), into your stomach and then into your intestines. The first part (small bowel) is where the nutrients are absorbed and by the time it reaches your large bowel all the goodness has been taken into your blood stream.

The waste that enters the large bowel can be as much as 1-2 pints of thick liquid. Its journey through the large bowel can take a couple of days and, in this time, the water is reabsorbed and the result is a formed stool.

The end of the large bowel is the rectum and this is the storage part for the motion. When it is full a message is sent to the brain which tells you to go to the toilet and empty your bowels.
How has the operation changed your bowel function?
The operation to remove the cancer involves removing the rectum, i.e. the storage part. This will mean that the capacity to hold motion is smaller and may result in you having to make more frequent visits to the toilet.

In addition to this there is a smaller area for water to be reabsorbed back into the body and therefore the motion will contain more water and be looser.

For some patients the symptoms of bowel cancer may have been looser bowel movements and a change in frequency. Do not be alarmed if this seems to be the same as the cause is different.

What will your bowel pattern be?
After the ileostomy has been reversed different bowel patterns are experienced. You may encounter any of the following problems:

- frequency of stool
- urgency of stool
- diarrhoea
- fragmentation of stool (this is when you need to visit the toilet frequently and can only pass small amounts of stool)
- incontinence of stool.

It is a very individual thing and therefore it is difficult to predict what your bowel pattern will be like. Similarly, the remedies will differ and what suits one person won't suit the next. The bowel pattern usually settles quickly (in a matter of months) but it can take up to 2 years before you will learn what is normal for you.

This booklet has been written based on suggestions that previous patients have found helpful. The idea is that you try them and see what works for you. Trial and error is in the large part the management of your new bowel pattern.
Diet

Initially we recommend that you eat foods that are low in fibre. Fibre is a waste product, derived from food that cannot be digested and used by the body. Foods that are high fibre foods are fruit, vegetables and some cereals.

Different fibre foods have different effects on the bowel. Fibre that is found in cereals such as All Bran or brown bread will make the stool softer. Fibre found in vegetables and fruits help to stimulate the bowel and therefore make the bowel work more frequently.

Your bowel movements will dictate which foods you need to avoid. You may want to try not eating much fruit and vegetable for the first couple of weeks and then gradually introduce them into your diet (see leaflet on reintroduction).

Over the months you will become aware of what foods make your stools looser and how best to manage it. As your confidence improves you will find that you don't need to avoid the food but you will know what to expect in terms of bowel pattern.

Drinks

Some patients find that drinking lots of caffeine can affect their bowels and make them looser.

If you like lots of tea and coffee you may want to try and reduce the amount that you drink.

Alcohol can also make the bowels looser. This doesn't mean you can't have a drink, but just be aware that the day after may mean a looser day.

Fizzy drinks may make the bowel produce more wind and because some patients find their bowel pattern to be more explosive following their operation you may want to let the fizz out of the drink or try and avoid them.
The amount of wind that patients produce is also increased and can be quite strong smelling. Green leafed vegetables can be wind producing so if you find you do have a wind problem maybe cut them out of your meals for a couple of weeks to see if it improves.

Yoghurts with live bacteria or ‘friendly bacteria’ may help replace the bowel with bacteria that are helpful and that may have been removed due to antibiotics etc. Certainly trying them isn’t going to do any harm and you may find they help your bowel pattern generally.

**Medications**

If diet alone doesn't improve your bowel pattern medications may be needed. The two main types we use are either anti-diarrhoeal (Imodium/Loperamide) or bulk-forming agents such as Fybogel. It is important to speak to one of the Nurse Specialists (stoma care or colorectal) before taking them as it depends on what your stool is like as to which will be beneficial.

If diarrhoea is a problem i.e. you are passing frequent amounts of watery stool then Imodium will be recommended. If you find that you are visiting the toilet frequently but only passing small bits of stool then Fybogel will be recommended.

Occasionally a combination of both is needed. Both can be bought over the counter without a prescription however your GP will be able to prescribe them too.

Patients that talked about their experiences for the purpose of this booklet found that the medication helped but it was very much trial and error and juggling with the dose of the medications to suit them. Some found it reassuring to have Imodium in the cupboard in case of a loose day and also if they were going out, just to be on the safe-side.
How does Imodium work?
The bowel works by squeezing the food through in wave like movements. Imodium slows this action down thereby allowing the food to stay longer in the bowel and therefore longer for water to be reabsorbed. To allow the bowel to be slowing down prior to food getting to it we would recommend you to take Imodium 30-60 minutes before a meal.

On the packet instructions it will say to take it after every bout of diarrhoea but this tends to be for people who have got it as a result of a tummy bug.

How does Fybogel work?
This helps to bulk out the stool so if you are finding that you are passing small and frequent bits of stool, Fybogel may help to pass it all in one go.

Fibre in breakfast cereals is also bulk forming therefore you may want to try this first. All-Bran is highest in fibre content but not everyone likes the taste.

Cereal packets will say if the content is high in fibre, as these are the healthiest ones, so have a look and experiment.

Skin care
If you are having frequent visits to the toilet the skin around your back passage will get sore. The aim of skin care is to prevent it from getting sore.

Moist toilet paper wipes can be bought from the toilet paper section in most supermarkets. If your stool is very soft and you need to wipe the skin a lot, using the moist wipes will cut down on the amount of dry paper you need. Many of the main toilet paper companies now make paper that is very soft and some include Aloe Vera which is
soothing for the skin. Although they may be more expensive you may find having a packet in the cupboard for loose days is helpful.

Applying barrier cream onto the skin is also helpful in protecting it. Sudocreme is one of many over the counter creams that you can buy and is usually found in the baby section along with nappies and wipes etc.

**Protecting your underwear**

Although incontinence isn't a common problem the fear is that due to the urgency to pass a stool, patients will lose control. Wearing a pad in your underwear means that if you were 'caught short' you will have some protection.

All the patients that were interviewed for this booklet wore a pad of some description just to be on the safe-side. The common ones were ladies sanitary towels or sometimes just a thin panty liner was sufficient.

**Exercises**

Please refer to the separate information leaflet regarding exercises to help improve your back passage muscles.

**Will my bowel pattern affect my social life?**

Due to the erratic and unpredictable nature of the bowel pattern some patients don't feel confident enough to go out much in the early weeks. There are no magic words that we can say that will make you feel safe and confident. It all comes with time and, by trying the various remedies described, you will develop a protection package that suits you.

For the vast majority of patients who have had this operation they look forward to getting on with their lives without their stoma. Having
a positive attitude helps you to adjust to your new bowel pattern and knowing that what you are experiencing is normal is also reassuring.

Patients look forward to getting back to 'being normal' again and for most of us that means going to the toilet once a day after breakfast. Due to the changed anatomy of the bowel this is very unlikely to happen.

Striving to achieve what you were like before the cancer operation will mean you will only be disappointed when it doesn't happen. Try to forget what was normal for you pre operation and instead think that your new bowel pattern is the new norm. However, as mentioned earlier, it may take months before you can be confident to say what is normal.

By the time you have read this booklet you may well be feeling daunted and disheartened about what the future holds in terms of bowel function. Please don't be.

This booklet is aimed at giving you top-tips and reassurance. There are patients who, following their stoma reversal, have a very good bowel function and it doesn't disrupt their social life at all, so please keep positive as it will improve.

**What are the risks and benefits of this operation?**

**Benefits**
The aim of this operation is to remove the stoma and therefore enable you to go to the toilet in the normal way again. It also means that from an appearance perspective you will not have to wear a bag.

**Risks**
With any operation there are risks. These can be general or specific and it is important that you are informed of them.
Before your consultant decides to arrange for the operation he will have performed a special X-ray (loopogram) to check that the join up inside has healed.

General risks are those that anyone having an anaesthetic is exposed to. They include chest infection, heart attack, stroke and blood clots in the leg.

This operation is a relatively small operation and therefore your recovery time is quicker than with major surgery. The risks are therefore reduced but still there.

Specific risks are those that are related to the operation itself which include wound infection and a leak from where the bowel has been reconnected.

In some patients the bowel can take a while to 'waken up' and therefore the doctors will keep the drip up until it shows signs of starting to work.

If there are concerns about reconnection an X-ray will be performed and if it has not healed then it may require an operation to form another stoma.

Please do not be alarmed at these risks as they happen only in the minority of cases and methods of prevention are implemented prior to your operation.

If your surgeon is concerned about your health prior to surgery it will be investigated thoroughly beforehand.

Are there any alternatives?

The only other alternative is not to have the ileostomy reversed and living permanently with the stoma. This is completely your choice we will respect this.
Further Information

Please feel free to contact either the Stoma Care Department or the Colorectal Cancer Nurse Specialists with any further questions you may have. We are used to dealing with this problem so you will not be bothering us by telephoning.

**Stoma Care Department** (Sarah, Carol, Sally, Helen)
01932 722636

**Colorectal Cancer Nurse Specialist** (Lynn, Marguerite)
01932 723245

Additional information regarding bowel cancer can be obtained by logging on to the following websites:

- **Bowel Cancer UK**  [www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)
  080 840 3540

- **Beating Bowel Cancer**  [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)
  0845 719301 (low cost rate)

- **Macmillan Cancer Support**  [www.macmillan.org.uk](http://www.macmillan.org.uk)
  0808 8080000 (Booklet – Managing the late effects of Bowel Cancer Treatment)

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Further Information

We endeavour to provide an excellent service at all times, but should you have any concerns please, in the first instance, raise these with the Matron, Senior Nurse or Manager on duty. If they cannot resolve your concern, please contact our Patient Advice and Liaison Service (PALS) on 01932 723553 or email pals@asph.nhs.uk. If you remain concerned, PALS can also advise upon how to make a formal complaint.
We can provide interpreters for a variety of languages, information in larger print or other formats (e.g. audio) - please call us on 01932 723553.
To use the Text Relay service, prefix all numbers with 18001.

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