Building healthier lives

Panproctocolectomy

This leaflet tells you about the procedure known as a panproctocolectomy. It explains what is involved and some of the common complications that are associated with bowel surgery. It is not intended to replace any discussion between you and your healthcare team, but is to be used as a guide in addition to what we discuss with you.

The digestive tract

To help you understand your operation you may find it helpful to have some understanding of how your digestive system works.

When you eat food it travels down your oesophagus (food pipe) and from here it passes in to your stomach. In the stomach food is turned in to semi- liquid. It then continues through the small intestine (small bowel) a coiled tube many feet long where food is digested and nutrients are absorbed. This semi-food is then passed into the colon (large bowel), a wider, shorter tube, where it becomes faeces (stools). The main function of the colon is to absorb water into our bodies making the stool more solid.

The stools then enter the storage area called the rectum. When the rectum is full, we get the urge to open our bowels. The stools are finally passed through the anus (back passage) when going to the toilet. The diagram below helps to explain this process.



What is a Panproctocolectomy

The operation being planned for you is called a panproctocolectomy. It is an operation to remove all of the colon (large bowel), rectum and anus.

This is usually for non-cancer (benign) bowel disease but it can be done for a cancer (malignant disease). Two cuts are made- one in your abdomen (tummy) and one between the cheeks of your bottom. The surgeon removes the whole of the large colon, rectum and anus, and creates an ileostomy (stoma) on the right hand side of your abdomen. This will be permanent.

An ileostomy means bringing the end of the small bowel out through an opening on your abdomen (tummy). Bowel waste passes out through this into a pouch (bag) that you stick to your tummy. Your nurse specialist will explain more about this.

The diagram below demonstrates what is removed during the operation.

The wound on your abdomen is usually closed with clips, and these are removed after 10 days.

The wound on your anus (bottom) is stitched. These are usually left in for a little longer and your surgeon will advise on when they should be removed.



It may be possible to do your operation using keyhole surgery. In this instance, you would avoid having an open wound on your tummy. Instead, you would have 3 to 4 smaller ones. The benefits of keyhole surgery are:

- A shorter hospital stay
- No large open wound, only 3-4 small ones
- Less visible scarring
- Less pain from incisions

These options will be discussed with you by your medical team.

What risks are involved with this procedure?

Surgery to remove part of your bowel is a major operation, and there are risks associated with it that you need to be aware of. Some of these risks are discussed below:

Chest infection: it is important to be able to deep breathe and cough after your operation to avoid developing breathing problems. The physiotherapist and nursing staff will help you to do this.

Wound infection: if you do develop a wound infection, you may require antibiotics via a drip in your arm or tablets. Your wound will be reviewed regularly during your stay and will be dressed as needed. With this operation you will have a second wound between the cheeks of your bottom, and this can sometimes take a while to heal. Again, this will be reviewed regularly by nursing staff.

Ileus (paralysis of the bowel): this is a particular risk of bowel surgery. Sometimes, the bowel is slow to start working after your operation, or can be obstructed. If this occurs, the bowel may need to be rested and a drip (fluid given via a vein in your arm) is used to replace fluids instead of drinking. You may also need to have a tube in your nose that will prevent you from vomiting. This will stay in until your bowel starts to work again.

Thrombosis (blood clot in the leg): major surgery carries a risk of clot formation in your leg. You can help yourself by mobilizing as quickly as possible following your surgery and doing leg exercises in bed. Again, the physiotherapist and ward staff can help you with this. It is advisable to wear the support stockings that you are given for the duration of your stay. You will also have daily injections that will help to thin your blood. These may continue when you go home and the ward will discharge you with your own supply. You will be shown how to do the injection so that you can inject yourself at home.

Pulmonary embolism: occasionally, a blood clot can break off from your leg and travel to your lung. This does not happen very often but if it does, we would be able to treat you.

Bleeding: bleeding is rare, but if it does occur a blood transfusion may be required.

Risk to life: abdominal surgery is major surgery, and this can carry a risk to your life. This risk increases for those who already have medical conditions such as diabetes, breathing problems or a heart condition. Your risk also increases if you smoke or are overweight. However, it is important to note that most people will not experience any serious complications, but it is something you need to be aware of. If you do have any serious medical conditions, it may be that we plan for you to go to intensive care following your surgery for a day or two before returning to the ward.

Nerve damage: your operation is very close to your bladder and the nerves responsible for sexual function. These may get damaged during the operation. Your bladder function could be disturbed. Men may have problems with erection and ejaculation. In women, sexual response may be affected and there may be discomfort during sexual intercourse. These problems may be temporary or permanent. Your surgeon and nurse specialist will discuss any problems or queries you may have. Your surgeon will discuss the risks with you pre operatively so that you can make an informed decision about the surgery and the risks to you personally.

What are the benefits of this procedure?

This operation is to remove the diseased bowel. This will give you significant improvement in your quality of life. It will offer you a cure if you have ulcerative colitis. This will help you to feel well again

so that you can begin to lead a normal life and resume activities that you have previously not been able to do.

What are the alternatives?

If this operation has been offered to you by your surgeon as the best treatment, not having this surgery is very likely to lead to further worsening of your health. Depending on what is wrong with you, you may develop a blockage of the bowel, leakage of the bowel content into abdomen, or an abcess, all of which can be life threatening. If you have cancer the longer it remains the more likely it will spread and become incurable.

Before the operation

It is important beforehand that you try and prepare yourself physically. If you are able, try and maintain a balanced, healthy diet. Try and take some gentle exercise, and if you smoke it is strongly advised that you try to stop.

Before your operation you will meet with one of the colorectal nurse specialists, who will be able to discuss with you any questions that you may have about the surgery and the stoma. If appropriate the nurse specialist will provide you with a teaching pack that prepares you for how to care for your stoma.

Pre-screening clinic

About a week before your operation you will have an appointment to attend the pre-screening clinic in Outpatients. At this appointment a nurse will discuss your admission and tell you what to expect. They will complete a health questionnaire with you. They may also carry out a number of tests. This appointment is to check that you are fit to be admitted for your surgery, and to understand what help and support, if any, you will need on your discharge from hospital. It is therefore very important that you attend this appointment.

Your admission to hospital

It is most likely that you will be admitted to the admissions lounge on the day of your surgery. You will receive a letter in the post to confirm this.

In the admissions lounge you will meet with a member of nursing staff who will get you ready for theatre. You will also meet with an anaesthetist where you will have the opportunity to discuss any concerns. A member of the medical team will also meet with you and you will sign a consent form if you have not already done so. Lastly, the colorectal nurses will visit to put a mark on your tummy where the stoma will be.

If your admission letter does not ask you to come to the admissions lounge, it means that you will be admitted to a ward, usually the day before your surgery. The letter will tell you to phone the ward before you come into hospital to check that a bed is available.

After your operation

When you return from theatre you will have several drips and tubes attached to you. These are all necessary for your recovery, but will be removed after a couple of days as your condition improves. You may have:

A catheter: this tube is put in to your bladder to allow your urine to flow freely without having to go to the toilet. This is used so that your kidney function can be monitored

Naso-gastric tube: this tube is put in to your nose and sits in your tummy to prevent you from being sick

Drip: you will have a drip connected to a tube in your hand/arm or neck that will give you fluids to keep you hydrated. This will be stopped once you are eating and drinking sufficiently

Epidural or PCA: to manage your pain you may have an epidural. This is a small tube that sits in your back which delivers continuous pain medication. If the anaesthetist decides not to give you an epidural you will have a PCA (patient controlled analgesia). The PCA is connected via a tube in to your vein, and pain killers are delivered each time you press the button. This means that you will be in control of the amount of pain relief you receive. Initially, the specialist pain nurses will review your pain on a daily basis and discuss any concerns with you. Whilst you have your PCA or epidural you will be attached to a monitor that will record your pulse, respiration rate and blood pressure. These readings will be recorded very frequently when you first come back from theatre. Around 2–3 days following your surgery, the epidural/ PCA will be stopped and you will be given oral analgesia to take for your pain

Drains: initially, you may have a drain in your abdomen but this will be removed after a few days

Stoma: when you return from theatre you will have a clear bag on your stoma, and it will be checked by the nursing staff to see if it is healthy

Abdominal wound: if you have had an open procedure, you will have a cut on your abdomen. If your operation was keyhole, you will have 3–4 small wounds

Diet and fluids: you will be allowed to eat and drink straight away following your surgery. We advise that to begin with you have a low fibre diet (food that is easy for you to digest). If you are not sure what options to choose from your menu sheet, please ask the nursing staff for advice. Initially you may only be able to take small amounts, but this is normal. Your appetite will gradually return as you improve

Stoma care and what to expect from your ileostomy

Initially, you may only have wind (flatus) passing in to your stoma bag, and the stoma will be swollen with stitches around it. This swelling will reduce over time and the stitches will dissolve. It should be pink in colour, similar to the inside of your mouth. The waste that comes in to the bag is normally a porridge consistency, although it may be liquid initially. The stoma will work throughout the day and you will need to wear the bag all the time. The bag will need to be emptied 4–6 times a day on average.

Most patients change the bag approximately every other day, depending on personal preference.

As you recover from the operation the nurse specialists will begin to teach you how to look after your stoma. You will be encouraged to participate until you are able to manage it independently. Once you are confident that you will manage at home we will start to plan for your discharge from hospital. Information will be provided to you regarding your stoma bag supplies and prescription details. Once at home you will receive an appointment to attend stoma clinic for follow up so that the nurse specialists can check that you are managing your stoma care at home. You will also be followed up by your surgeon who will see you in clinic.

It may take 2–3 months before you feel fully back to normal and have your usual strength. Any effort such as climbing the stairs will leave you feeling very weak but this is normal and you will gradually improve. Your appetite will also improve as time passes. Most people are able to eat regular meals and know when to empty the bag before it gets too full.

The information in this booklet is not intended to be exhaustive, and we understand that you may still have many questions. We are available to discuss your surgery and concerns before and after your operation. If we are unavailable we will return your call if you leave a message.

| Contact us | |
|------------------------------|---|
| Colorectal Nurse Specialists | (24hr answer phone) |
| Heartlands Hospital | 0121 424 2730 |
| Good Hope Hospital | 0121 424 7429 |
| Queen Elizabeth Hospital | 0121 371 4501 colorectalnursingcns@uhb.nhs.uk |
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Follow us on Twitter @uhbcolorectal

Other useful addresses

Ileostomy Association

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Birmingham branch: 0121 3552745/07842 555070 Email: Mike Jameson <u>mike.jameson@iasupport.org</u> www.birmingham.iasupport.org

National Association for Colitis and Crohns Disease (NACC) Tel: 01727 830038

Website: <u>www.nacc.org.uk</u>

National Key Scheme

From RADAR Tel: 0121 616 2942 Website: www.radar.org.uk

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email patientexperience@uhb.nhs.uk.