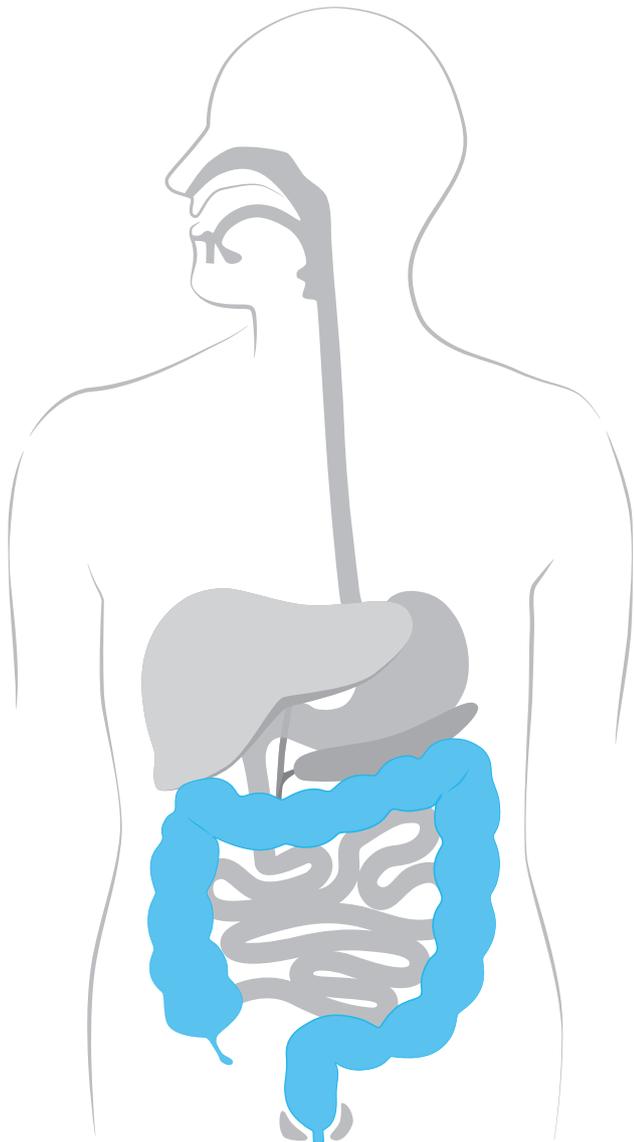


Panproctocolectomy

This information has been produced to supplement the discussions which you have had with your surgeon. Your surgeon will have discussed with you why you need to have this operation.

Panproctocolectomy is a procedure which is performed to remove the colon, rectum and anus.



This is likely to be due to either a cancer or a benign (non-cancerous) disease affecting the rectum. Following removal the rectum, colon and anus will be sent to the laboratory for further analysis.

An ileostomy stoma is made during the procedure, this will be permanent. The end of the small bowel (ileum) is brought up to the surface of your abdomen (tummy). This will mean that the faeces (bowel waste) can be diverted into a bag worn on the outside of your body instead of being passed through your anus (back passage). You will be introduced to a specialist nurse for advice and support with managing this.

What is the rectum?

The rectum is the last part of the colon where the faeces is stored prior to being passed through the anus.

What is the colon (large bowel)?

The colon is the part of the bowel before the rectum. The colon is the part of the bowel between the rectum and the end of the ileum. The colon's main functions are to remove fluid from your faeces and to store it until you are ready to go to the toilet to open your bowels.

How is the operation performed?

There are two methods which can be used and your surgeon will discuss these with you:

Laparoscopic (keyhole) panproctocolectomy

Laparoscopy is performed by passing a tube shaped telescope into your abdomen. This tube (known as a laparoscope) is connected to a high intensity light and a video camera so that the surgeon can see what is happening inside you. Several small cuts are made in your abdomen through which the laparoscopes are inserted allowing the surgeon to use small instruments to remove the bowel. The small cuts are then closed with either metal staples or surgical glue. There will also be a wound where your anus is removed (perineal wound). This will be approximately 10 centimetres long and will be closed with stitches. The whole procedure takes approximately 2 to 4 hours .

Open panproctocolectomy

If laparoscopic (keyhole) surgery cannot be performed, then it may be necessary for the surgeon to perform the procedure using an open (laparotomy) approach. This will mean having a larger cut on your abdomen. The procedure will take approximately 2-4 hours. As this is a bigger procedure it may mean a slightly longer hospital stay and recovery period.

What are the benefits?

The diseased area of bowel will be removed. You may ask your surgeon if there are alternatives.

What are the risks?

Most patients will not experience serious complications from their surgery but it is important that you are aware of the potential risks. You will meet the anaesthetist prior to your surgery who will explain in more detail the

type of anaesthetic you will receive and discuss any individual risks with you.

If you do have any questions about the risks mentioned in this booklet then please ask your specialist or a member of their team.

The risks associated with this operation include:

Formation of a permanent stoma.
As already discussed.

Urinary tract infection (water infection).
This is an infection in any part of your urinary system. Less than 1 in 100 people will experience this.

Retention of urine. This is the inability to pass urine. This is usually temporary and is resolved with a urinary catheter. It is possible that you will have to be discharged home with this to return a few weeks later for it to be removed.

Chest infection. An infection of the lungs or large airways. Stopping smoking before surgery, effective pain relief and early mobility after the surgery can all help to reduce the risk. This will affect about 1 in 20 people.

Wound infection. With any surgical wound there is a risk of infection and with bowel surgery there is an increased risk because the bowel is a 'dirty' environment. This will affect about 1 in 20 people.

Wound not healing properly. Depending on what level of wound healing occurs an operation to re-stitch the wound may be required. If the wound partially opens it can usually be managed with dressings and can take a number of weeks to heal.

This can also occur with your perineal wound (where your anus was removed). This is more likely to occur if you had radiotherapy prior to your operation. To try to prevent this it is important that you avoid pressure directly on this wound. When sitting it is best to

alternate from side to side and to avoid sitting for long periods.

Bleeding can occur from the external wounds or internally at the site of the operation. Occasionally a further procedure or blood transfusion may be necessary. This can happen to 1 in 100 people.

Pain will be experienced by most patients but this should be well managed by various pain relief methods. The anaesthetist and the pain team will discuss this with you in more detail.

Deep vein thrombosis (DVT). This is a risk of all major surgery. A DVT is a blood clot which forms in one of the larger veins in the leg. This can form immediately after surgery or up to a few weeks after. The use of blood thinning injections, compression stockings (where appropriate) and walking soon after surgery can reduce the risk.

Pulmonary embolism occurs when a blood clot becomes lodged in the blood vessels of the lungs. Often this blood clot can come from a D.V.T. The treatment is blood thinning medication. The same measures used to reduce the risk of D.V.T. are followed.

Internal collection. This is when some fluid, blood or pus builds up inside the body and sometimes a small procedure to drain it away is necessary. This will affect 1 in 20 people.

Paralytic Ileus. Following bowel surgery the bowel can take a period of time to 'wake up' and start to function again. This is usually managed by limiting the amount you are allowed to eat and drink until the bowel regains its function. If you are advised not to drink then fluids will be replaced by an intravenous infusion (drip) until you are able to drink normally. A naso-gastric tube is sometimes needed (a tube down your nose and into your stomach). This is to prevent large amounts of vomiting and distension of the stomach and bowel. The tube will be removed once the paralytic ileus has resolved.

Conversion from laparoscopic to open surgery. Occasionally when laparoscopic surgery is planned it is not possible and a laparotomy needs to be performed.

Damage to internal organs or structures. Whilst every effort is made by the surgeons to avoid this risk, this can occasionally occur due to the close proximity of surgical instruments to other organs and structures. Action or repair can be undertaken at the time of surgery if necessary. This may affect 1 in 100 people.

The intended part of the bowel cannot be safely removed. This is a rare occurrence as scans provide thorough information prior to surgery. In this instance another form of treatment would be offered or performed.

Heart attack and stroke. These are low risk possibilities following this type of surgery. The anaesthetist at the pre-assessment clinic will be able to discuss your individual risk further.

Adhesions. Scar tissue can form around the bowel and can possibly cause a restricted bowel function. This can occur at an early or late stage in your recovery. Adhesions rarely require an operation.

Incisional hernia. This occurs as a result of surgery weakening the muscles around your wounds. You will notice a bulge close to the wound site. Incisional hernias generally cause little trouble but they can cause discomfort. The size can also increase in time. Occasionally surgery is offered to repair the hernia but they are mostly managed by wearing abdominal support garments.

Nerve damage to the bladder. Damage to the nerves controlling the bladder can result in problems passing urine. This is usually short term and the problems resolve in time. If problems are persistent then a urinary catheter may be needed.

Damage to the nerves that control sexual function.

In men this may cause reduced sensation, erectile dysfunction or retrograde ejaculation (the semen goes back into the bladder and will come out with your urine).

In women this can cause reduced sensation and vaginal dryness. Also occasionally if the surgery dictates then some of the vaginal wall may need to be removed resulting in a narrowed vagina.

For men and women your fertility may be affected. Your surgeon will discuss this with you if this is a concern for you.

Risk to life. All major surgery can carry a risk to your life. With major bowel surgery this is in the region of 1 in 20 people for cancerous bowel disease and 1 in 100 people for not cancerous disease. This also depends on individual circumstances. Your surgeon will have discussed this with you.

Risks and Complications specifically related to a stoma:

Stoma retraction. The stoma dips below the level of the skin. This is usually managed with specialist stoma products.

Necrotic stoma. Describes when the blood supply is poor to the stoma. The appearance of the stoma is monitored by the doctors and nurses to ensure the blood supply improves. Rarely further surgery may be needed.

Stoma stenosis. This is when the opening to the stoma narrows. The stoma nurse will advise how to manage this. Occasionally further surgery is required to widen the opening.

Parastomal hernia. this is a weakening in the muscles around the stoma. A bulge is seen under the stoma. Support underwear is advisable as this can help to prevent hernia and also help with any discomfort experienced. Gentle abdominal exercises can help to prevent a parastomal hernia. The colorectal nurses

will give you written information regarding this. Surgery to repair the hernia is sometimes offered but this is not without its own risks.

Stoma prolapse. This is when a length of bowel protrudes via the stoma. This can make the stoma a little more difficult to manage. The stoma nurse advice will provide further advice. Occasionally surgery is offered to rectify the problem but it can recur.

Are there any alternatives to surgery?

Surgery is usually recommended as the last treatment option, if all medical treatment has failed, or if you have a life threatening condition.

Unfortunately this often means there are no alternatives. If you chose to decline surgery then you could discuss your individual options or possible outcomes with your specialist.

What happens before the operation?

You will likely be admitted to the hospital on the day of your surgery.

Prior to this you will need to have a pre-operative assessment to make sure you are fully prepared for your operation.

The pre-operative assessment team will help you with any worries or concerns and will give you advice regarding any preparation needed for your surgery.

Before the date of your admission please read carefully the instructions given to you. You will be advised when to stop eating, drinking and taking medication and whether or not any medicine to clear the bowel is needed. Failure to follow these instructions may prevent the surgery from being able to take place.

Enhanced recovery

At Bradford Teaching Hospitals NHS Foundation Trust, your treatment may follow an Enhanced Recovery programme. The aim of this is to ensure you are as fit as possible before having your surgery and to help you to get back to normal as soon as possible afterwards. Also it can minimise post-operative complications. This programme involves a large team of people including surgeons, nurses, doctors, anaesthetists and where needed physiotherapists, dieticians and most importantly you.

Further information about enhanced recovery will be given to you in the pre-assessment clinic and also on the ward following your surgery.

For enhanced recovery to be successful it is dependent upon your co-operation and participation. The key elements for success are early mobilisation (getting up and walking) and deep breathing exercises, the ward nurses will advise you re this. Your surgeon will advise you about eating and drinking immediately after the surgery.

There is a separate written guide about enhanced recovery that you can request if needed.

Routine “drips and tubes” after the operation.

During the first few days following your operation it is routine to have a number of “tubes” attached to you.

You may have an oxygen mask over your nose and mouth.

You will have an intravenous infusion (a drip), where a fine plastic tube is placed in a vein, usually in your arm and attached to a bag of fluid. This drips slowly into your vein until you are allowed to drink normally. This is to prevent dehydration.

You will have a urinary catheter.

Painkillers will usually be given either through a continuous infusion which might be an epidural (a fine catheter introduced into your epidural space through your back) or via a pump called Patient Controlled Analgesia (PCA) that you control yourself by pressing a button. This is until you are able to manage pain killers in tablet form.

These tubes generally stay in place for two to three days after the operation but can vary in individual circumstances.

When will my ileostomy stoma start to work and what will my ileostomy function be like long term?

Bowel function is disturbed as a result of surgery and it is normal to expect your bowels to take a couple of days to begin to function, however this can vary from person to person. During the time when your bowels are starting to function, it is normal to feel nauseous and occasionally vomit. You will be prescribed anti sickness medication if needed. Your surgeon may also restrict what you are allowed to have to eat and drink until they are satisfied that your bowel is beginning to function again. Walking around can stimulate the bowel to start working again.

Initially following surgery you may have very loose stools (diarrhoea). You should find that this will settle over a period of weeks as you recover. However, long term your ileostomy will likely pass semi liquid faeces. Normally you would expect a volume of 800mls in 24 hours. You can discuss this further with your colorectal / stoma nurse specialist, your bowel specialist or G.P.

What can I eat?

Immediately after surgery eating and drinking may be restricted. The doctors and nurses will advise you regarding this.

You do not need to follow a special diet but while your bowel function is variable in the recovery period, it may be helpful to avoid certain foods that may make your symptoms worse. eg high fibre, spicy foods and salads. These foods can be re-introduced to your diet gradually as your bowel function settles.

Eating regularly is important to help you recover. If you find your appetite is poor, you may find eating smaller portions more frequently throughout the day will help.

As an ileostomy is necessary then a few small dietary changes will be advised. These changes will be discussed with you by the nurse specialist.

Perineal wound

It is important not to sit directly on this wound as it can affect healing. It is advisable to alternate your position from side to side when sitting. Try to avoid sitting for long periods. At home your district nurse may be able to provide you with a specialist cushion but a soft pillow is helpful. Once this wound is fully healed and pain free you will be able to sit normally.

How long will I be in hospital?

The expected length of stay can vary however, the average length of stay for laparoscopic surgery is 4 to 7 days and for open surgery is 7 to 14 days.

Your recovery will continue at home over the next 6 to 8 weeks and you may not feel like you have fully returned to 'yourself' until after about 2 to 3 months.

Getting back to normal

During your recovery time at home it is important that you gradually build up your daily activities and exercise. Initially it is natural that you will feel more tired than normal, even after completing small activities. Resting in between activities is a good way to aid recovery. It is also advisable to arrange support from family or friends to help with heavy domestic chores such as shopping, cleaning and gardening before you are admitted for your surgery.

- Avoiding heavy lifting for 6 to 8 weeks following your surgery will reduce the risk of developing a hernia.
- It is advisable to avoid driving for 4 to 6 weeks until you are able to perform an emergency stop without fear of pain stopping you. It is also advisable to contact your insurance company as they may have other restrictions.

Returning to work is usually possible after 2 to 3 months and when you feel able to manage. This can also depend on individual circumstances. You may wish to ask your employer if a phased return to work is possible.

If you need a sick note/fit note then ask before you are discharged from hospital or you will need to ask your GP following your discharge from hospital.

It is important to remember that this is a major operation even when it is performed laparoscopically. During your recovery period, your performance status (your ability to perform daily normal living activities) may be reduced. Particularly in the more elderly patients this may never fully return back to normal.

Further information

Your GP will be told that you have had this operation. If you require district nurse or practice nurse care, this will be organised by the ward before you leave.

Your surgeon will arrange to see you in the outpatients department a number of weeks after you have gone home. This will be to discuss your recovery. If you have any concerns or queries before this appointment please contact your G.P.

If you have any urgent problems, for example fever (temperature), vomiting or severe pain within 14 days of discharge home then you may contact Ward 20 the acute surgical admissions unit on 01274 383253 for advice.

We use Next Generation Text for people with hearing difficulties. To contact us please ring 18001 01274 383253.

If you need this information in another format or language, please ask a member of staff.

Smoking

Bradford Teaching Hospitals NHS Foundation Trust is a smoke-free organisation. You are not permitted to smoke or use e-cigarettes in any of the hospital buildings or grounds.

Wristbands

When you are in hospital it is essential to wear a wristband at all times to ensure your safety during your stay.

The wristband will contain accurate details about you on it including all of the essential information that staff need to identify you correctly and give you the right care. All hospital patients including babies, children and older people should wear the wristband at all times.

If you do not have a wristband whilst in hospital, then please ask a member of staff for one. If it comes off or is uncomfortable, ask a member of staff to replace it.

Useful contacts

Macmillan Cancer Support
T. 0808 808 0000
macmillan.org.uk

Beating Bowel Cancer
T. 020 8973 0011
beatingbowelcancer.org

Ileostomy and internal Pouch Association:
T. 0800 018 4724
info@iasupport.org

Colostomy Association
T.0800 328 4257
www.colostomyuk.org/

Crohn's and Colitis UK
T. 0300 222 5700
www.crohnsandcolitis.org.uk/



Review Date: May 2022
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MID Ref 20021131