

Contact Information

If you require further advice/information regarding the content of this leaflet, please contact your Colorectal Nurse Specialists on:

Pilgrim Hospital

Colorectal Nursing Team 01205 446466

Ward..... 01205

Grantham Hospital

Colorectal Nursing Team 01476 464822

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Lincoln County Hospital

Colorectal Nursing Team 01522 573776

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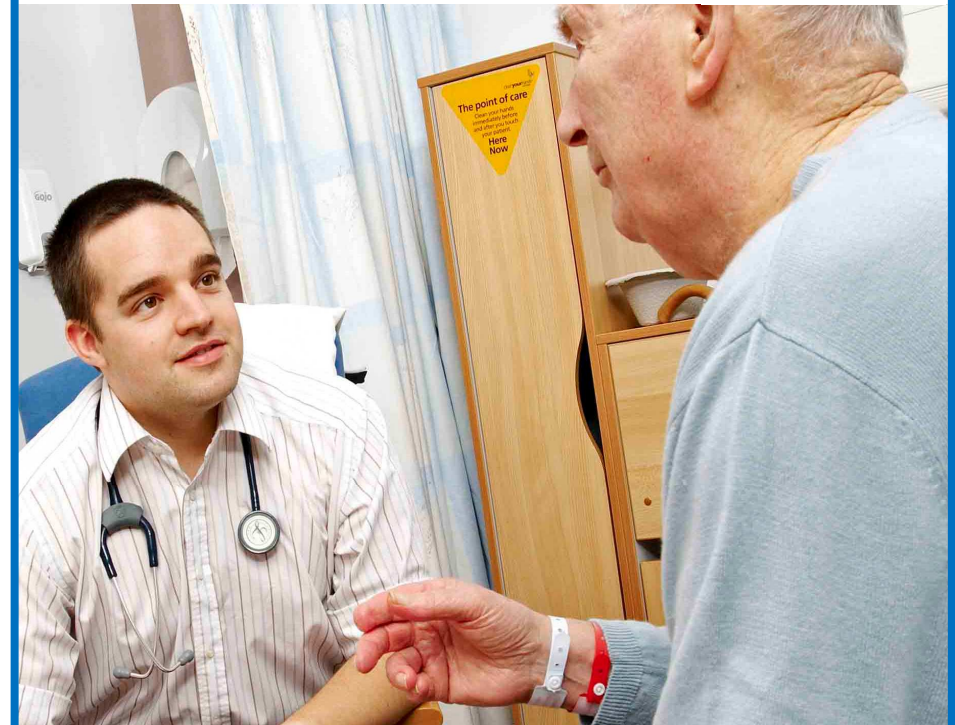
References

If you require a full list of references for this leaflet please email patient.information@ulh.nhs.uk

The Trust endeavours to ensure that the information given here is accurate and impartial.



If you require this information in another language, large print, audio (CD or tape) or braille, please email the Patient Information team at patient.information@ulh.nhs.uk



Pan-Proctocolectomy

Colorectal Departments

Pilgrim Hospital 01205 446466

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www.ulh.nhs.uk



Aim of the leaflet

The aim of this leaflet is to provide further information and to prepare you for a pan procto-colectomy operation.

What is it and why is it done?

The tests you have had show that there is a problem in your large bowel. This may be ulcerative colitis (where the whole of the large bowel is badly inflamed) which has not responded to medical treatment. In a small number of cases it may be that there are a number of polyps which could become cancerous if left and too numerous to deal with individually; or 2 or more cancers in different parts of the bowel.

Surgery to remove the large bowel (including the anus) is called a **pan procto-colectomy**. This means that you will have a permanent **ileostomy** as a result of this surgery. This is where the end of the small bowel is brought out on the surface of the tummy and your motions are diverted out into a 'bag'. Your surgeon will only do this operation if it is absolutely necessary.



What about after the surgery?

After discharge you will be phoned frequently by the colorectal nurses in the first 14 days after surgery, as this is when patients can be most anxious about the progress of their recovery. You are then encouraged to phone the colorectal nurses if you have ongoing worries. You will also have reviews of the stoma at regular intervals.

A routine post operative outpatients appointment will be arranged for roughly 4 to 6 weeks after discharge.

For those having surgery for cancer, all patients are discussed at a multidisciplinary team meeting (MDT) which takes place once a week.

Here the best course of follow up care or treatment will be identified. This treatment could consist of chemotherapy.

With prior discussion and your agreement, we normally inform you of the outcome of this discussion with a telephone call.

Present at this meeting will include:

- Your Consultant
- The Oncologist - a cancer specialist doctor
- The Pathologist - who examines the piece of bowel that is removed
- The Colorectal Nurse Specialist

If you do not require further treatment such as chemotherapy you will be followed up in clinic for up to 5 years.

With regards to the stoma management, you will be able to contact and arrange a review directly with the colorectal nurses if you are worried.

It is important you are basically competent to change the stoma pouch before being discharged home, this normally takes 5 to 7 days.

You will be given supplies to take home with you and arrangements will be made for the colorectal nurses to see you following your discharge.

Recovery at Home (see your 'Going Home' leaflet for further advice)

It can take roughly 3 months before you feel fully fit again, during which time you will need to balance rest with regular gentle activity such as walking. Trying to push yourself to do a little more each day can have beneficial effects and can improve the tiredness, however, activity involving excessive strain on the abdominal muscles must be avoided for at least 6 weeks.

A leaflet for exercises to strengthen the tummy muscles may be provided to use in the early post operative days and weeks. You may also need to do pelvic floor exercises to help with any bladder issues. This will be discussed with you by your colorectal nurse.

Your risk of Deep Vein Thrombosis is raised for around 3 months after surgery and you may be given a supply of the anti-coagulant (blood thinning) injections to continue at home for 4 weeks. Long haul air travel is not advised for 3 months after the operation due to the increased risk of deep vein thrombosis.

You may get frustrated at not being strong enough to do what you want to begin with.

For the first 4 to 6 weeks you will be unable to drive.

If you find you have sexual or urinary difficulties caused by the surgery then this can be discussed and onward referrals made as required.

The operation will be done through the abdomen and also through the bottom. This means your bottom (perineum) will be sewn closed and you will no longer have an opening in your bottom.

Are there any alternatives to surgery?

If you have ulcerative colitis, surgery will be the last option if all medical treatment has failed or if you have developed a life threatening complication such as a perforation (hole in the bowel) or toxic megacolon.

An alternative to having the complete bowel and anus removed is to have a **sub-total colectomy** in which the rectum is left behind; discuss this option with your surgeon or colorectal nurse.

If you have a number of pre-cancerous polyps then surgery is the best option. Sometimes these can be removed via colonoscopy but can be lengthy and would need repeating frequently. This method can also run a risk of perforation and scarring of the bowel leading to longer term problems.

If you have more than one cancer in the bowel then surgery is normally recommended and can be completely curative. If surgery is not performed then it is likely that the bowel will become blocked by the growth(s). This would make you very unwell and may require emergency surgery which carries a much higher risk than planned surgery.

What are the benefits of surgery?

The benefit of surgery is that it will remove the diseased bowel. In the case of ulcerative colitis, it will hopefully mean you will no longer need drug treatment such as steroids and should be able to return to full health. In the case of polyps it will mean cancer could be avoided or if it has occurred already then surgery is the best chance of a cure.

What are the risks of surgery?

This type of operation is classed as major surgery and as with any form of surgery, carries risks (including risk to life).

The general risks are as follows:

- Post operative bleeding (haemorrhage).
- Wound infection (increased risk in bowel surgery and more common in obese patients and those with underlying medical conditions such as diabetes).
- Blood clot in legs or lungs (potentially life threatening).
- Chest infections, urinary infection.

Specific risks for this surgery are as follows:

- Risk of damage to the pelvic organs such as the bladder (and uterus/vagina in women) during surgery.
- Risk of damage to the nerve supply in the pelvis, which may cause sexual difficulties such as impotence in men and loss of sensation and vaginal dryness in women.
- In a small number of cases nerve damage may also lead to bladder difficulties such as frequency and urgency. In severe cases, incontinence and/or not being able to empty the bladder so requiring a long term catheter. This may be worse in those having radiotherapy prior to the surgery. **NB.** For many, these difficulties will be experienced in the early days to months after surgery but can improve longer term.
- Risk that a cancer may not be completely removed if it has already started to spread outside the bowel.

Things to avoid initially are fibrous food such as salad, raw vegetables/stalks, fruit skins and bran fibre.

For some, the bowel will have a delayed period of inactivity so you may find all is well for the first 2 to 3 days then you develop the nausea and vomiting for a few days. This generally settles by itself by resting the bowel with a period of no food or drink.

Staying out of bed and walking

We will help you out of bed and sit you in a chair the day after your operation. Early mobilisation after surgery has been shown to be of benefit so your hard work will pay off!

You will be encouraged to walk about 60 metres three times a day and sit out of bed for at least 8 hours each day in total if you are well enough. Being out of bed in a more upright position and walking regularly improves lung function and the circulation of oxygen through your body and reduces the chance of a chest infection.

You will have a catheter (a tube which passes up into your bladder) to drain urine. This is to measure your fluid balance accurately. This is normally removed after 1 to 2 days.

You may also have a wound drain (sometimes two). This is a tube which passes into your abdomen and drains fluid from under the wound. This fluid will be bloodstained to begin with which is entirely normal and nothing to worry about. The drains will be removed after 1 to 2 days.

In some cases a tube into the stomach through the nose may be required if vomiting develops and persists.

Stoma education

You are encouraged to use the training pack provided before the operation.

The ward staff and colorectal nurses will begin teaching you the day after surgery but will take it at your pace. You will be supervised to change the pouch yourself until able to do so independently.

With both approaches to surgery there will still be a 3 to 4 inch wound in the bottom where the rectum is removed.

Recovery

Once you have returned to the ward or ICU we monitor your recovery closely. The things we monitor include:

- Fluid intake
- Food eaten
- Fluid out
- When you have your bowels opened
- Pain assessment
- Number of walks
- Time out of bed

Pain control, sickness and diet

You will be given regular pain relief and also medication to combat any feelings of sickness or nausea.

Effective pain control is an essential part of the programme. We use a number of different pain killers to reduce your pain levels. If your pain is controlled this will allow you to breathe deeply, make you feel more relaxed, enable you to start walking early and also help you sleep well.

You will have an intravenous infusion to give you fluids for the first 24 to 48 hours but this will come down as soon as you are able to drink enough fluids without being sick.

In most cases you will be encouraged to start eating as soon as you feel able after the operation. Appetite can be variable in the beginning as the bowel can take time to begin functioning properly. During this time you may feel bloated and feel or be sick.

Small amounts of nourishing and easily digestible foods are advised when you begin eating. These might consist of lean meat, mashed potato, gravy, milk puddings.

- Small risk of damage to other internal organs such as the small bowel, the spleen, which may result in its removal, or damage to the ureter (tube between kidney and bladder).
- Risk of complications with the stoma itself such as loss of blood supply (necrosis), retraction, prolapse, muco-cutaneous separation (where the bowel edge becomes slightly detached from the skin edge) and hernia formation in the longer term.
- Increased risk of the bottom (perineal) wound breaking open; especially so in those having radiotherapy, obese patients and in diabetics. If this happens it will need to heal with the aid of special dressings and can take some time, but would not mean you have to stay in hospital. This wound/area can also be very painful for many weeks after the surgery and may need strong pain killers to manage this. This will be monitored by your colorectal nurses.

Longer term risks:

- Adhesions - this is scar tissue which forms into tough fibrous bands inside the abdomen. In some people this can lead to further problems such as intermittent temporary blockages. This is less likely with laparoscopic surgery, can take days or years to develop, if ever, but in a small number of cases may need further surgery.
- Incisional hernia formation - where the weakened abdominal muscles allow the bowel to form a bulge under the skin; these sometimes require surgical repair.

What does the surgery involve?

Preparation

We want you to be in the fittest possible condition prior to your operation so we may need to ask your own doctor to help us achieve this. If you have high blood pressure or are anaemic for example, together we shall try to improve these conditions before your operation.

You can help yourself by trying to be as physically active as you can prior to admission, reducing cigarette and alcohol intake and maintaining a healthy nourishing diet.

If you are having difficulty with eating and have significant weight loss or need further advice regarding a low fibre diet (for management of bowel function) please speak to the colorectal nurses.

You will be required to attend for a pre-assessment which involves checking you are fit and well enough to undergo the surgery, information giving and carrying out relevant tests such as an ECG (heart reading) and blood tests.

At this appointment you will be given a carbohydrate drink called Pre-Load to take home with you. It needs to be taken the day before your operation and also on the day of your operation. This drink helps to reduce some of the acute physical responses your body goes through due to surgery (similar to the effects of running a marathon).

In some cases you may also be prescribed bowel preparation or enema(s).

You will also be offered and encouraged to take home a Stoma Practice Pack to help become familiar with managing the stoma. The colorectal nurses will go through this with you.

Enhanced Recovery Programme

Most patients will follow an enhanced recovery programme, the aim of which is to get you back to full health as quickly as possible after your operation.

The programme is research based and has been shown that the earlier you get out of bed, start moving, eating and drinking, the quicker your recovery and less likely complications will develop.

During your hospital stay you will have daily goals which you will be encouraged to achieve. A team of doctors, nurses and other health care professionals will be monitoring your progress and will support you in reaching your goals.

It will mean a stay of approximately 5 days in hospital. Most patients can be admitted on the day of surgery but in a small number of cases admission the day before the operation may be necessary. On admission, the colorectal nurse will mark a spot on your tummy for the stoma.

Many patients are suitable to have laparoscopic (keyhole) surgery but not all. It is generally dependant on what previous surgery you may have had, your body mass index and complexity of the operation.

There may be other reasons why the operation cannot be completed laparoscopically but the surgeon will discuss this with you.

The surgery is done under general anaesthetic and from leaving the ward to returning can take most of the day. Laparoscopic surgery takes longer in general than open.

Open surgery

The cut in the tummy is around 8 to 10 inches long. This will potentially mean a slower recovery, increased discomfort and a longer hospital stay but the enhanced recovery programme helps to reduce this.

Laparoscopic (keyhole) surgery

If the surgery can be performed by the 'keyhole' method then you will have 3 to 4 very small cuts and a slightly larger one across the lower abdomen. You generally have less discomfort, are able to move more freely and go home a little sooner on average.