

## Patient information on Ileo-anal Pouch

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## What is an ileo-anal pouch?

The aim of this surgery is to remove the diseased colon (large intestine) and rectum (storage pouch leading to the back passage) without the need for a permanent stoma. The ileo-anal pouch or reservoir is made from loops of ileum (part of the small intestine), which are then joined to the anus (back passage) This creates a new rectum made from small bowel. The new pouch needs time to expand after the surgery. The function of the pouch should become manageable in a very short time, however, its function can improve for at least a year after surgery. You should expect to have more frequent, urgent and looser stools after this surgery. You may need to have a temporary ileostomy after the pouch is made; this is reversed when safe to do so—usually about three months after the pouch operation.

## What are the intended benefits?

The aim of the surgery is to remove the diseased colon and rectum, without the need for a permanent stoma. The passing of stool via the anus (back passage) provides a sense of normality, although bowel movements will be more frequent. There are various reasons for recommending the formation of an ileo-anal pouch including inflammatory bowel disease (ulcerative colitis) and some types of bowel cancer (e.g. familial adenomatous polyposis, FAP). This surgery provides a cure for the symptoms of ulcerative colitis and the risks of some types of bowel cancer are virtually eliminated.

## Who will perform my procedure?

We are unable to guarantee that a particular person will perform the procedure. However your surgery will be performed by a surgeon with particular skills and training in bowel surgery. This is usually a consultant surgeon or senior specialist registrar, under consultant supervision.

## Privacy and dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and / or specialist one to one care is required.

## Who can I contact if I have a problem when I get home?

If you experience any problems related to your surgery or admission once you have been discharged home.

Please feel free to contact 4A, 4B or 4C ward for advice from the nurse in charge.

They will assist you via the telephone, advise you return to your GP or ask you to make your way to the ED department at Whiston Hospital depending upon the nature of your concern.

4A Ward – 0151 430 1420

4B Ward – 0151 430 1637

4B Ward – 0151 430 1643

## Important things you need to know

Patient choice is an important part of your care. You have the right to change your mind at any time, even after you have given consent up until you are anaesthetised.

The only caveat to this if you are unable to make this decision for yourself either due to being extremely unwell or being confused or unconscious in which circumstances your doctors will make a decision in your best interests.

We will also only carry out the procedure on your consent form unless, in the opinion of the responsible health professional, a further procedure is needed in order to save your life or prevent serious harm to your health.

Sometimes during the operation it becomes apparent that the disease is more complicated than was anticipated: the type of surgery may need to be altered to achieve the desired result.

This may mean removing more bowel or part of a nearby organ.

There may be procedures you do not wish us to carry out, the reasons for which you are not obliged to provide.

These specifically disallowed procedures should be recorded on the consent form.

It is imperative that you are made aware of the risks and benefits of not carrying out certain procedures (as with performing intended procedures) so you can make an informed decision.

All information we hold about you is stored according to the Data Protection Act 1998.

## What happens before admission?

You will need to attend a pre-admission clinic, which is usually run by specialist nurses. At this clinic, we will ask for your details of your medical history and carry out any necessary clinical examinations and investigations.

We will ask if you take any tablets or use any other types of medication either prescribed by a doctor or bought over the counter in a pharmacy. Please bring any packaging/ prescriptions with you.

You will have blood tests, possibly an ECG (heart tracing) performed, and also swabs taken to screen MRSA. This Trust takes infection control extremely seriously for the benefit of all its patients.

You will be asked to attend Bowel School where you are given information regarding your recovery. Where possible we make use of enhanced recovery principles to minimise the impact of surgery on the body and enable a rapid return to normal activity.

There are many aspects to this process which includes a preoperative (before surgery), intraoperative (during surgery) and postoperative (after surgery) procedures.

If you smoke this should be stopped at least 2 weeks prior to your procedure. Your GP can help you stop smoking.

We aim to minimise pain; perform careful surgery; avoid unnecessary drips, tubes and drains; enable you to eat and drink straight after your operation; encourage early mobilisation to stimulate recovery and allow you to go home soon and safely. We want you to be involved with this and need your help and initiative to improve your recovery.

You will meet members of the team who are vital in your recovery.

You may also be given carbohydrate drinks to optimise your health and this will be discussed with you at Bowel School. Please ask us any questions about the procedure, and feel free to discuss any concerns you might have at any time.

### Day of surgery

Most patients are admitted on the day of surgery. You may be given an enema on the ward when admitted to clear the lower bowel prior to surgery. In some cases, you may need to have temporary ileostomy (bag) to rest the join between the pouch and the anus. If this is the case, you will be seen by the stoma specialist nurse before your surgery.

You will see an anaesthetist before your procedure to discuss the best anaesthesia and pain relief options for you. To inform this decision, he/she will need to know about:

- Your general health including previous and current health problems.
- Whether you or anyone in your family has had problems with anaesthetics
- Any medicines or drugs you use
- Whether you smoke
- Whether you have had any abnormal reactions to any drugs or have any other allergies
- Your teeth, whether you wear dentures, or have caps or crowns.

Your anaesthetist may need to listen to your heart and lungs, ask you to open your mouth and move your neck and will review your results.

- Damage to lips or tongue (usually minor)
- Itching
- Aches, pains and backache
- Pain during injection of drugs
- Bruising and soreness
- Confusion and memory loss

### Uncommon side effects and complications (1 in 1000 people)

- Chest infection
- Muscle pain
- Slow breathing (depressed respiration)
- Damage to teeth
- An existing medical condition getting worse
- Awareness (becoming conscious during your operation)

### Rare (1 in 10,000 people) and very rare (1 in 100,000 people) complications

- Damage to the eyes
- Heart attack or stroke
- Serious allergy to drugs
- Nerve damage
- Death
- Equipment failure

Deaths caused by anaesthesia are very rare. There are probably about five deaths for every million anaesthetics in the UK. For more information about anaesthesia, please visit the Royal College of Anaesthetists' website [www.roca.ac.uk](http://www.roca.ac.uk)

### Information and support

If you have any further questions please contact one of the colorectal specialist nurses.

The risk of infertility in women with familial adenomatous polyposis (FAP) who have pouch surgery is twofold.

Most people will not experience any serious complication following their surgery. The risks increase for the elderly, or for overweight patients, and those who already have a heart, chest or other medical conditions such as diabetes or kidney failure. You will be cared for by a skill team of doctors, nurses and other healthcare workers who are involved in this type of surgery on a daily basis. Any problems that arise can be rapidly assessed and appropriate action taken.

### **What alternatives do I have?**

Potential alternatives to this procedure are panproctocolectomy or proctectomy. They will have already been discussed with you.

### **What are the risks of general or regional anaesthesia?**

In modern anaesthesia, serious problems are uncommon.

Risks cannot be removed completely, but modern equipment, training and drugs have made it a much safer procedure in recent years. Individual risks depend on your general health, surgery which is complicated, long or performed in an emergency.

**Very common (1 in 10 people) and common side effects (1 in 100 people).**

- Feeling sick and vomiting after surgery
- Sore throat
- Dizziness, blurred vision
- Headache
- Bladder problems

### **Moving to the operating room/theatre**

You will change into a gown before your operation and we will take you to the operating suite. Before you leave the ward and when you arrive in the anaesthetic room the medical team will perform a check of your name, personal details and confirm the operation you are expecting.

Once that is complete, monitoring devices may be attached to you, such as blood pressure cuff, heart monitor (ECG) and a monitor to check your oxygen levels (a pulse oximeter). An intravenous line (drip) will be inserted.

Your operation will require a general anaesthetic. You will be asked to breathe oxygen through a face mask before you go to sleep.

### **Anaesthesia and pain relief**

#### **General anaesthesia**

During general anaesthesia you are put into a state of unconsciousness and you will be unaware of anything during the time of the operation. Your anaesthetist remains with you at all times he or she monitors your condition continuously throughout surgery and gives you drugs and fluids to optimise your wellbeing.

#### **Regional anaesthesia**

Regional anaesthesia includes epidurals, spinals, caudals or local anaesthetic blocks of the nerves to the limbs or other areas of the body. Local anaesthetic is injected near to nerves, numbing the relevant area and possibly making the affected part of the body difficult or impossible to move for a period of time. Regional anaesthesia may be performed as the sole anaesthetic for your operation, with or without sedation, or with a general anaesthetic.

Regional anaesthesia may also be used to provide pain relief after your surgery for hours or even days. Your anaesthetist will discuss the procedure, benefits and risks with you.

If you are having an epidural/spinal as well this may be put in before you go to sleep in the anaesthetic room. You will need to have a catheter inserted into your bladder so we can measure urine output. This will be removed with the first few days after the operation.

### Local anaesthesia

In local anaesthesia drug is injected into the skin and tissues at the site of the operation. This area of numbness will be restricted and some sensation of pressure may be present, such as stitching a cut, but may also be injected around the surgical site to help with pain relief. Usually a local anaesthesia will be given by the doctor doing the operation.

### Should I remove any body hair before an operation?

If you need hair removal from the surgical site this will be done using an electric hair clipper with a single-use disposable head, after you have been anaesthetised. Please do not shave the hair yourself or use a razor to remove hair, as this can increase the risk of infection.

It may be necessary during the procedure to shave other areas of your body to allow equipment and/or monitoring devices to stick to your skin to achieve the best and safest performance.

### Who will perform my procedure?

We are unable to guarantee that a particular person will perform the procedure. However your surgery will be performed by a surgeon with particular skills and training in bowel surgery.

Further surgery is sometimes required to put right such complications. As with all prolonged procedures, a very small number of patients can develop high pressures in the limb muscle compartments and this will require surgery to release the pressure. Therefore if you develop pain in the legs after the procedure, make your doctors aware immediately.

Sometimes during the operation, it becomes apparent that the existing disease is more complicated than was anticipated (for example Crohn's Disease in the small intestine, FAP patients). If this is the case, the type of surgery might need to be altered to achieve the desired result or a pouch cannot be fashioned. This can mean we need to make a temporary or permanent stoma, even if it was not the planned intention. Your surgeon will have discussed with you whether it is intended to have a temporary stoma for this stage of treatment. It might also mean removing part of a nearby affected organ (for example bladder or ovary). When you complete this consent form, there is a section where we can document any part of you that you specifically do not wish to be removed.

In this kind of surgery for men there is a risk of impotence (failure to achieve an erection) and of retrograde ejaculation (semen going into the bladder instead of out of the penis during ejaculation). Every effort is made to minimise the risk, but you need to be aware of it. Sometimes, you can make use of a sperm bank prior to surgery—this will be discussed by your surgeon or nurse specialist before your admission. In women, there is a risk of dryness or discomfort during sexual intercourse, and some women no longer experience sexual orgasm.

The formation of a pouch is associated with a risk of infertility in women. There is a threefold increase in infertility in women with ulcerative colitis who undergo pouch surgery, even though great care is taken during the operation to protect the tubes and ovaries.

You may be contacted by a specialist nurse if you need to know your results sooner this may help with your expectations of whether further treatment is necessary.

### What are the significant risk of this procedure?

Most people will not experience any serious complications from their surgery. The risks increase for the elderly or overweight and for those who already have heart, chest or other medical conditions such as diabetes or kidney failure. There is a very small risk of death. We cannot get rid of all risk but we take patient safety very seriously and take every possible precaution to minimise risk. You will be cared for by a skilled team of doctors, nurses and other health care workers who are involved in this type of surgery on a daily basis. Any problems that arise can be rapidly assessed and appropriate action taken. These include the risks of surgery in general, the risk particularly associated with bowel surgery and the risks of anaesthetic described in more detail later.

#### General risks

- Wound problems—infection, bleeding, fluid / abscess collection, dehiscence (opening up)
- Breathing problems—chest infection
- Heart problems—abnormal rhythm, angina, heart attack
- Kidney problems—low urine output, blood salt abnormalities, kidney failure
- Blood clots—in the legs (DVT) or occasionally in the lung (PE).

#### Operation-specific risks:

Include infection in the pelvis (an abscess or leak from the join up of the pouch to the anus), poor function of the pouch (for example incomplete emptying or frequency and urgency), fistulae formation (abnormal channel caused by infection), blockage of the bowel, and inflammation of the pouch (pouchitis).

This is usually a consultant surgeon or senior specialist registrar, under consultant supervision.

### What does the operation involve?

Surgery for ileo-anal pouch can be performed by a standard 'open' operation with an incision in the abdomen or by laparoscopic 'keyhole' surgery. Key hole surgery still requires an incision through which the bowel is removed. The choice of method depends on a number of factors including your build and coexisting medical conditions, any previous operations on your abdomen, and surgeon preference.

Please feel free to discuss this with your surgeon if you need clarification. With keyhole surgery it is sometimes not possible to complete the procedure using this technique; there would be a need to convert to an open operation in this case.

At the beginning of the operation we check the contents of your tummy to be sure that the operation is feasible. If you have a pre-existing ileostomy then this will be disconnected from the skin to be used to make the pouch. If you have not had previous surgery your entire colon and then the rectum will be removed. When removing the rectum we make every attempt to preserve the nerves around it. The 'pouch' is then made from the ileum, wither by stapling the bowel together or sewing it. This is then joined to the anus, either by stitches or by staples. To protect the pouch a new ileostomy might be made. You might have a tube inserted through the anus into the pouch at the end of the operation. This is left in place for up to 10 days to keep the pouch empty.

### After the procedure

Once your surgery is complete you will be transferred to the recovery ward where you will be looked after by specially trained nurses, under the direction of your anaesthetist.

The nurses will monitor you closely until the effects of any general anaesthetic have adequately worn off and you are conscious. They will monitor your heart rate, blood pressure and oxygen levels. You will be given oxygen via a facemask, fluids via a drip and appropriate pain relief until you are comfortable enough to return to your ward. You will also have a tube (catheter) in your bladder to drain away urine – this enables careful measurement and avoids the need for you to get out of bed to urinate. After certain major operations you may be transferred to the intensive care unit (ICU/ITU), high dependency unit (HDU).

### Enhanced recovery

Most people who have this type of procedure will need to stay in hospital for three to six days after the operation. Those patients with medical problems, special needs or complications from the operation may need to stay in hospital longer.

### Eating and drinking

It is safe to drink and even eat after surgery providing you feel the desire to do so. You should not eat or drink if it makes you feel sick or bloated.

### Getting about after the procedure

We will help you to become mobile as soon as possible after the procedure. This helps improve your recovery and reduces the risk of certain complications. You will have daily injections and will usually wear special stockings which reduce your chance of blood clotting in your legs (DVT). Typically, you will be helped into a chair the following day. If you have any mobility problems, we can arrange nursing or physiotherapy help.

### Pain control

This is usually with either an epidural, spinal injection or by a pain killer pump which you control in the first 48 hours.

You will be given regular simple painkillers as well.

### Special measures after the procedure

Most people will feel fine after their operation. Some people may feel dizzy, sick or have general aches and pains. Others may experience some blurred vision, drowsiness, a sore throat, headache or breathing difficulties. You may have fewer of these side effects after local or regional anaesthesia. If you feel sick, please tell a nurse and you will be offered medicine to make you more comfortable.

### Resuming normal activities including work

Most people who have had this procedure can get back to normal activities within a few weeks. Initially you will feel more tired than usual but this should not stop you from doing anything, because activity is beneficial. For driving you need to feel safe and to be able to brake in an emergency—this often takes two to four weeks. When going back to work see if you can start half days or work from home until your energy levels are improved.

### Leaving hospital

Most people who have this type of procedure will need to stay in hospital for 3 to 6 days. Sometimes complications arise and these will delay discharge. When you go home we would expect you to be mobile, comfortable and able to eat safely. The actual time that you stay in hospital will depend on your general health, how quickly you recover from the procedure and your doctor's opinion.

### Check up and results

Before you leave hospital, we will give you details of when you need to return to see us, for example outpatients clinics or for the results of your surgery. At this time, we can check your progress and discuss with you any treatment we recommend.