



The Ileo-Anal Pouch

Introduction

This leaflet supports the discussions you are having with your Colorectal Surgeon, Specialist Nurse and those close to you before deciding whether to have an ileo-anal pouch operation. You will be able to discuss the surgery, talk about living with an ileo-anal pouch and meet someone with a pouch if you choose to.

What is an Ileo-Anal Pouch Operation?

An ileoanal pouch operation involves the surgical creation of a new rectum or 'pouch' from a section of small bowel after removal of the colon and rectum. The internal pouch is sewn onto the anal sphincter muscles to restore bowel function.

You will usually have a temporary ileostomy for a few months to allow the pouch to heal. An x-ray pouchogram is arranged to check the healing is complete before a small operation is performed to close the ileostomy.

How is the Operation Performed?

The 3 stage operation:

1. Removal of colon and rectum, formation of ileostomy
2. Formation of ileoanal pouch with temporary ileostomy
3. Reversal of ileostomy

The 2 stage operation:

Less commonly performed than the three-stage procedure:

1. Removal of colon and rectum, formation of ileoanal pouch with temporary ileostomy
2. Reversal of ileostomy

The 1 stage operation:

Removal of colon and rectum, formation of ileoanal pouch without stoma. This is performed only in very select cases.

Will I need any Investigations?

The output from a pouch is loose so good anal muscle control is essential. Anal sphincter tests may be required to assess function.

What are the Risks?

As a general rule, it is estimated that around a third of patients will have good pouch function, a third will have reasonable function and a third will have poor function. This will be discussed in detail by your Surgeon and Specialist Nurse.

Information for Patients

During the operation the surgeon will check that the small bowel can reach the anus without tension. If this is not possible, the pouch surgery cannot be performed and your ileostomy will therefore be permanent.

Due to surgery, damage or bruising could occur to the nerves which also control your bladder or sexual function. This will be discussed with you in more detail. **You will also have the opportunity of referral to Andrology department for sperm storage if appropriate.**

Scar tissue forms bands inside the abdomen called adhesions. In some cases this can lead to further problems, which may present months or even years later.

The surgery is complicated and the risks are:

- Pouch anal stricture – incomplete emptying and pouch catheterisation
- The temporary ileostomy may not be closed as planned if there are surgical complications with the pouch.
- Some complications can emerge later on and require a temporary ileostomy again to rest the pouch or support further surgery.

What are the Benefits?

A pouch avoids the need for a permanent ileostomy so provides a normal external self image, as stool will now enter the pouch and will be passed via your anus.

NOTE: a tube may have been inserted into your pouch via your anus, during your operation. The catheter is a flexible tube that will allow drainage of the faeces into a bag to keep the pouch empty. The pouch catheter will be removed within a few days of the operation.

Caring for Your Bottom

Wash your anal area with baby wipes rinsed under the tap and apply a barrier cream to your external anal area every time you empty your pouch to help prevent skin soreness.

Opening your bowels (emptying your pouch)

In the early days after your pouch formation you will probably need to empty your pouch quite frequently. This can be 10 to 15 times a day and 2 or 3 times a night, often with some urgency. Always respond to the urge to evacuate at first to avoid accidents in the early stages. Things will usually get better. Be aware that you may need to protect your bedding and use pads if motion seeps from the pouch particularly at night time when sleeping.

Top Tips

Urgency

Go straight to the toilet but try and hold on. Gradually increase time spent holding. As your confidence grows move further away from the toilet until you can confidently hold on for 10-15 minutes. Contact your Specialist Nurse if this is an ongoing concern.

Incomplete emptying

Try to relax when emptying your pouch to ensure proper emptying. If your pouch does not feel empty, try standing up, sitting down and trying again. Contact your Specialist Nurse if the problem persists.

Information for Patients

Loose or high output

An antidiarrhoeal such as Loperamide may be used from time to time or regularly to thicken your output or reduce the frequency of visits to the toilet.

Long term function

It can take up to two years for pouch activity to settle down, but after then little improvement occurs. At this point, you can expect to empty your pouch 3 to 6 times during the day time and maybe once during the night. However, this is extremely variable. The output should thicken to a porridge-like consistency. It will never be formed and you should never be constipated. The consistency will vary depending on your diet.

Food and Drink

You will soon start a normal diet and this will help to thicken your bowel action. It is important to return to a healthy balanced diet to help you recover from your operation.

How your food affects your pouch function is unique to you, so try to experiment and add new foods to your diet, one at a time initially. If certain foods do upset your pouch function always remember that in time those foods may not have the same effect.

Hints and Tips

- ❖ Eat regularly-don't skip meals. If you are having frequent bowel movements and think that eating fewer meals will help, remember that more gas may be produced when your bowel is empty so don't avoid meals in an attempt to limit output. Also, eat foods that may decrease pouch output.
- ❖ Smaller meals may be better, but it is important to eat more often to ensure you have a good calorie intake.
- ❖ When you eat food high in fibre e.g. salads, pulses, be sure to **chew them well**, limit the quantity, and drink plenty of fluids.
- ❖ Late evening meals may increase your pouch activity throughout the night.
- ❖ If your pouch output becomes so thick that it is difficult to pass, you may be able to ease the problem by drinking more fluids-especially fruit juice. Also eat foods which may increase pouch output.

Foods that may affect pouch and bowel functioning:

May increase pouch output:

Beans	Raw fruits and vegetables
Beer	Spicy foods
Caffeinated drinks	Wholemeal food
Chocolate	Cereals
Leafy green vegetables	Alcohol
	Citrus fruits & juice

May decrease pouch output:

Apple sauce

Information for Patients

Bananas
Cheese
White bread

Potatoes
White Pasta

May cause anal irritation:

Coconut
Nuts
Oriental vegetables

Some raw fruits or vegetables
Citrus fruits and juices
Food containing bran

May increase wind / gas:

Beans
Onions
Cabbage
Sweet corn

Mushrooms
Cucumber
Radish
Eggs

Have on rare occasions been known to block the flow from the pouch:

Mushroom
Sweet corn
Potato skins

Nuts
Tomato
Raw fruit skin

Drinking

If you are experiencing a watery stool, vomiting or increased sweating then you should take extra fluid to prevent dehydration. If your symptoms continue contact your GP who may need to prescribe a rehydration solution for you. If your pouch output becomes so thick that it is difficult to empty your pouch, you may be able to ease the problem by drinking more fluids, especially fruit juice.

Alcohol

Some types of beer and wine may increase wind and pouch frequency. Take alcohol in moderation, keeping within recommended daily limits, but you do not have to avoid alcoholic drinks.

Living with your pouch

Pain

After the initial post operative pain has settled, 50% of people with pouches reported pain on some occasions from their pouch, although this usually does settle down with time. There are different types of pain which people have experienced, which they variously describe as spasms, cramps, rumblings, or colic

Anal soreness

Anal soreness and itching are quite common, and can occur even if you meticulously clean around the area. Having regular baths or using a bidet and patting the area dry afterwards are important. If the skin is not broken, wipe around the anus with a skin protective wipe which helps to form a "second skin" around the area.

There are several brands available on prescription. There are also several brands of barrier cream available which are effective in preventing and relieving soreness. It is strongly advised that you use a barrier cream from "day one" as it is easier to prevent soreness than cure it. Apply the cream sparingly after each time you have emptied the pouch.

Information for Patients

Avoid the use of soap around the anal area as it can be very irritating if left in skin crevices. Alcohol free and fragrance-free baby wipes are gentle and cleansing.

Pouchitis

Pouchitis is an inflammation of the pouch causing some or all of the following symptoms:

pain, bleeding, a raised temperature, diarrhoea, and a feeling of being generally unwell.

Fewer than 20% of people with pouches are likely to develop pouchitis. It is difficult to predict those who will develop the condition. Most episodes of pouchitis can easily be treated with antibiotics.

Travel Abroad

Many people travel abroad after pouch surgery. The important thing is to go prepared.

You may need to seek advice on travel insurance; the Ileostomy and Internal Pouch Support Group can provide help and advice on holiday insurance.

It may be advisable to take a course of antibiotics with you in case pouchitis occurs. Please ask your consultant or GP.

You are at increased risk of dehydration should you develop an upset tummy as the small bowel is not so good at reabsorbing water and salt.

Drink only bottled water. Be aware that certain foods such as salads could be washed in local water supplies and ice cubes may be made from local water supplies.

Ask your Specialist Nurse or GP about taking a stool thickener in case of diarrhoea. Take sachets of rehydration solution for the treatment of diarrhoea to prevent dehydration.

Always carry your medication, soft/moist toilet paper, barrier creams and protective pads or anything else you use on a daily basis in your hand luggage.

Driving

You may drive a car after 3-4 weeks, if you feel strong enough and if you are able to carry out an emergency stop safely. Please contact your insurance company to check your insurance cover after abdominal surgery.

Work

Take advice from your Consultant and GP regarding your return to work. Some people return to work in between each stage of their operations. On average, people return to work between 6-8 weeks after the final operation, depending on the demands of the job.

Sports

You will need to build up your activity slowly, to take time to recover from your operation. How long will depend on how active the sport and how weak you are feeling. If the exercise makes you sweat excessively you will need to replace fluid lost, to prevent dehydration.

Information for Patients

Scuba diving is slightly different in that you must be able to pass wind easily with a pouch. If you have any problems passing wind, please seek advice from a medical officer attached to the British Sub Aqua Club.

Sexual Health

Most people experience a temporary loss of libido or sex drive after an operation. Give yourself time and try to discuss how you are feeling with your partner. Sexual activity can resume when you both feel ready. Empty your pouch before sexual activity to prevent any leakage.

If you feel there are any problems with your confidence or ability to resume sexual activity, or you experience discomfort or pain, please discuss your problems with your Consultant, GP or Nurse Specialist.

Surgery to the rectum can affect bladder control, lack of vaginal sensation or cause erection problems. Please try to discuss any concerns you may have.

Contraception and Pregnancy

Please ask your Consultant or GP on the best form of contraception for you. Remember that certain oral contraceptive pills will not be absorbed and will not be an effective contraceptive. Uterine devices, such as the coil, are not recommended in case of damage to the pouch. Please ask for advice.

The ability to become pregnant should not be affected. Doctors agree that it is advisable to wait at least 12 months after pouch construction before considering pregnancy. In the UK, pregnant women who have undergone pouch surgery are advised to have Caesarean section deliveries to avoid anal sphincter damage. However, studies from the USA and Canada have reported on women who have had successful vaginal deliveries with no lasting disruption to pouch function.

During pregnancy the frequency of pouch emptying may increase due to the baby taking up space and pressing on the pouch. Possible alterations to sphincter control and perianal irritation may also occur.

Contact us

Colorectal Nurse Specialists	(24hr answer phone)
Heartlands/Solihull Hospital	0121 424 2730
Good Hope Hospital	0121 424 7429
Queen Elizabeth Hospital	0121 371 4501 colorectalnursingcns@uhb.nhs.uk

Follow us on Twitter [@uhbcolorectal](https://twitter.com/uhbcolorectal)

Other useful addresses

Ileostomy Association

Birmingham branch: 0121 3552745/07842 555070

Email: Mike Jameson mike.jameson@iasupport.org
www.birmingham.iasupport.org

The Ileostomy and Internal Pouch Support Group

Tel: 0800 0184724

Website: www.the-ia.org.uk

Information for Patients

National Association for Colitis and Crohns Disease (NACC)

Tel: 01727 830038

Website: www.nacc.org.uk

National Key Scheme

From RADAR

Tel: 0121 616 2942

Website: www.radar.org.uk

Our commitment to confidentiality

We keep personal and clinical information about you to ensure you receive appropriate care and treatment. Everyone working in the NHS has a legal duty to keep information about you confidential.

We will share information with other parts of the NHS to support your healthcare needs, and we will inform your GP of your progress unless you ask us not to. If we need to share information that identifies you with other organisations we will ask for your consent. You can help us by pointing out any information in your records which is wrong or needs updating.

Additional Sources of Information:

Go online and view NHS Choices website for more information about a wide range of health topics <http://www.nhs.uk/Pages/HomePage.aspx>

Dear Patient

We welcome your views on what you thought of this patient information leaflet, also any suggestions on how you feel we can improve through our feedback link below:

- Patient Information Feedback email:
patientinformationleafletfeedback@heartofengland.nhs.uk

If you wish to make any other comments this can be done through the links listed below:

- Patient Opinion: www.patientopinion.org.uk
- I want great care: www.iwantgreatcare.org (Here you can leave feedback about your doctor)

Be helpful and respectful: think about what people might want to know about our patient information and this hospital and how your experiences might benefit others. Remember your words must be polite and respectful, and you cannot name individuals on the sites.

If you have any questions you may want to ask about your condition or your treatment or if there is anything you do not understand and you wish to know more about please write them down and your doctor will be more than happy to try and answer them for you.

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.