

Ileoanal Pouch Surgery

- Providing support and advice
- Helping you with your concerns
- Local organisations
- Contact information



**Ileostomy & Internal Pouch
Association**

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Introduction

Since the first description of the ileoanal pouch operation, or restorative proctocolectomy, in 1978, patients with ulcerative colitis and other colonic diseases have been able to undergo surgery without the prospect of a permanent ileostomy.

Experience with ileoanal pouch procedures has led to improvements in both short-term and long-term outcomes following surgery. The majority of patients are able to achieve a good functional result and quality of life. Unfortunately, however, the procedure occasionally fails and may require the formation of a permanent ileostomy.

When patients are considering ileoanal pouch surgery, they need to have as much information as possible about the procedure, the associated complications and what to expect from the functional result. The information in this booklet is designed to help supplement any discussions you may have with your local surgical team.

Normal gastrointestinal function

The intestines can be thought of as a long tube that starts at the mouth and ends at the anus. It is divided into several discrete areas.

The oesophagus allows the passage of food from the mouth to the stomach where it is mixed with acid to begin the process of breaking the food down. From here it passes into the small intestines, which are approximately 3-4 metres long. Digestive juices are added to the food to further break it down and allow absorption of the nutrient components into the blood stream. The small bowel contents remain liquid, and approximately one litre of fluid enters the colon each day. This fluid contains bile residue, which gives it a green colour, digestive enzymes and unabsorbed food.

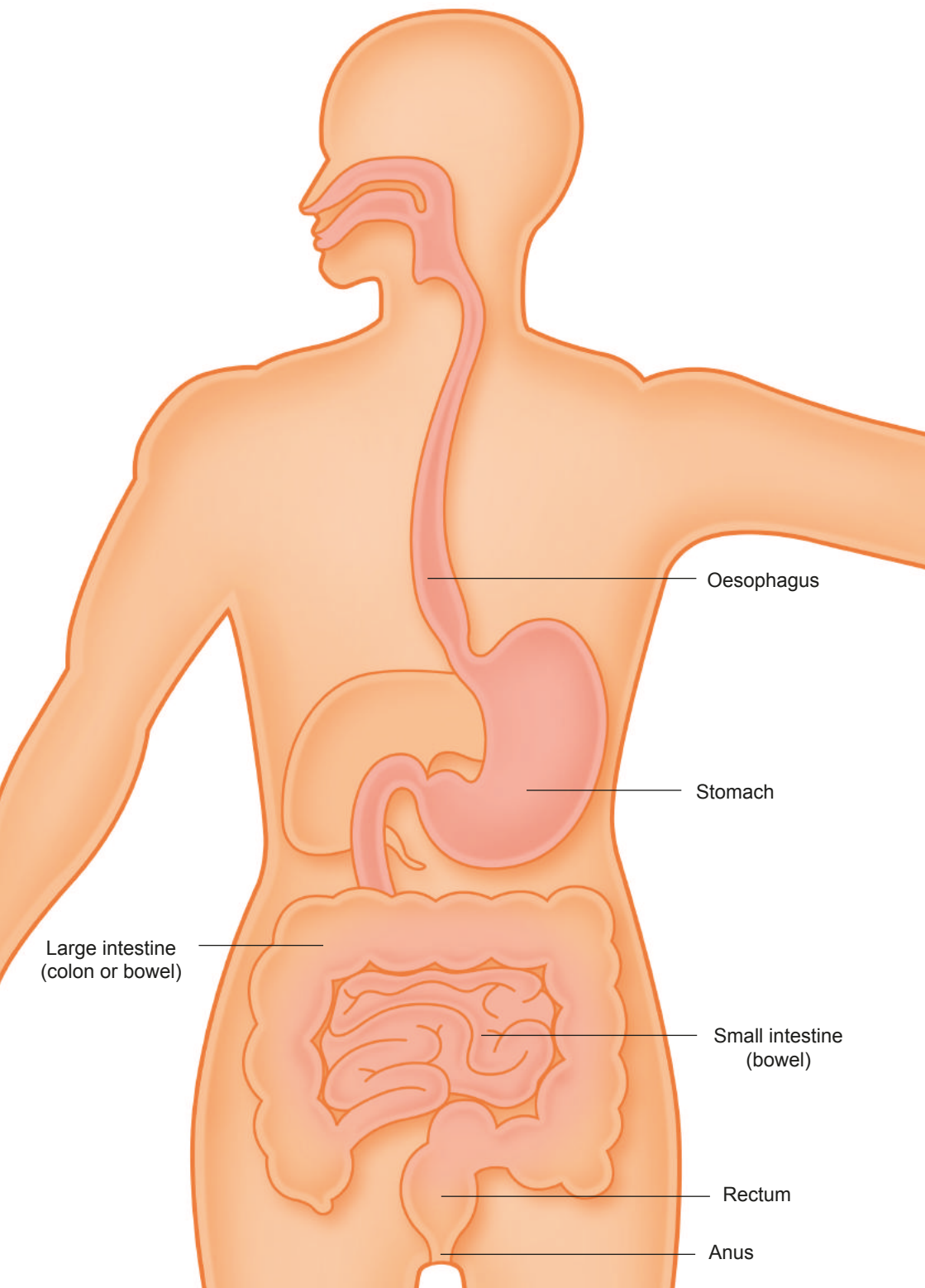
The colon is approximately one metre long and ascends from the lower right quadrant of the abdomen to the border of the right lower rib cage and across the upper portion of the abdomen to the left lower rib cage before descending along the left side of the abdomen. Here it passes into the pelvis and joins with the

rectum, a 15cm long tube which exits through the anus. The function of the colon is to resorb the water content of the fluid that enters it, turning the liquid small bowel content into formed stool.

The lower part of the rectum has a rich nerve supply that allows you to know whether there is gas, liquid or solid stool within it. It also gives the sensation of wanting to open your bowels.

The anus comprises of a complex ring of muscles, known as the anal sphincter, which normally close off the exit from the rectum. This is what gives us control over our bowels, or continence. The mechanism normally works subconsciously, but can be overridden when we clench it closed to allow emptying of the rectum when it is socially convenient. When we wish to pass wind or stool, the sphincter mechanism relaxes allowing the contents of the rectum to pass through.

The diagram opposite illustrates gastrointestinal function.



Oesophagus

Stomach

Large intestine
(colon or bowel)

Small intestine
(bowel)

Rectum

Anus

The ileoanal pouch operation

The ileoanal pouch operation can be performed in a number of stages or as a single procedure, depending on your circumstances and the preferences of your surgical team. The aim of the operation, whether staged or not, is to remove all of the colon and rectum and create a reservoir (pouch) from the remaining small bowel and connect this to the top of the anus. The pouch acts a substitute to the rectum, allowing bowel content to be held internally prior to defecation.

Patients requiring surgery during an acute flare of colitis would normally have the majority of their colon removed (subtotal colectomy), leaving a rectal “stump” and have an ileostomy created in the lower right quadrant of the abdomen. Many centres can now perform this operation using laparoscopic (keyhole) surgical techniques, avoiding the need for a large abdominal incision, and normally aiding a quicker recovery. In some patients, biopsies taken at the time of colonoscopy may not be able to differentiate between ulcerative colitis and Crohn’s colitis and your surgeon may prefer to perform a subtotal colectomy first

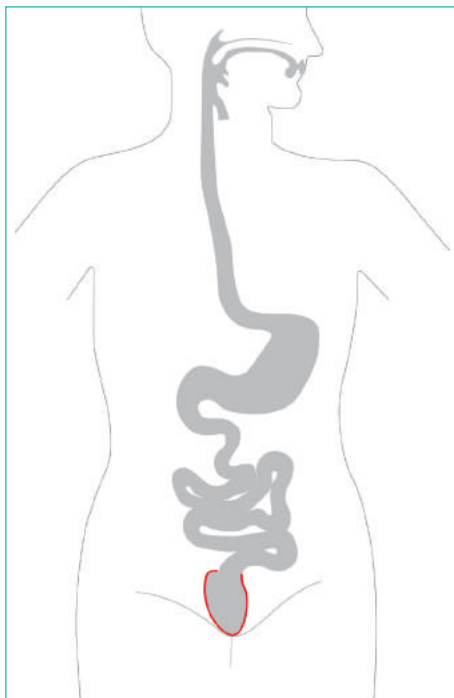


Diagram of the ileoanal pouch

Red outline indicates position of the pouch

in the hope of achieving diagnostic certainty. In addition, patients who have been on steroids for a long time, or who are on large doses of steroids would normally undergo a subtotal colectomy first in order to allow these drugs to be slowly stopped. Patients are normally given at least three months to recover from the first stage to allow return to good health. During the second stage of the



procedure, the remaining rectum is removed (Figure 1 below) and the ileal pouch created from the end of the small bowel.

The pouch is normally 15 – 20cm in length and is connected to

the top the anal canal (Figure 2 opposite).

A new ileostomy is commonly made at the time of this operation to allow the joins in the pouch to heal safely.

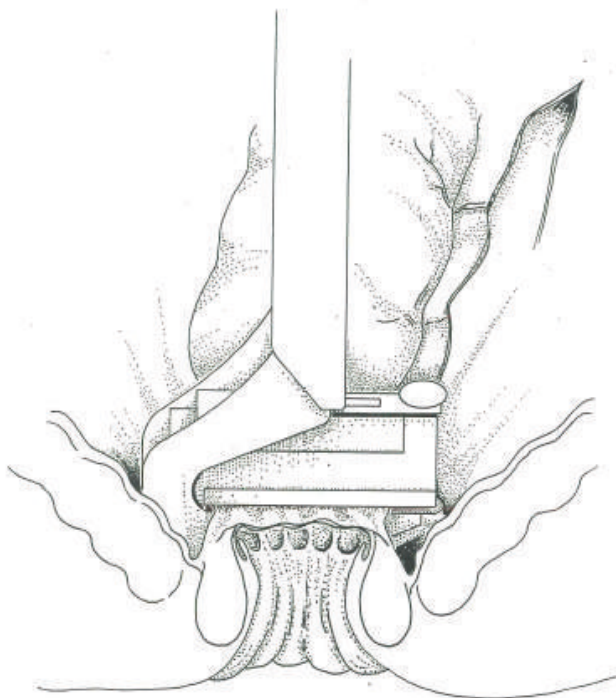


Figure 1: Division of the rectum at the top of the anal canal

The third stage of the procedure involves closure of the ileostomy; this can also be referred to as 'takedown'.

Prior to closure of the ileostomy, a special x-ray, called a

pouchogram, may be undertaken to check the pouch.

Closure can normally be performed by incising around the stoma and freeing it up, before joining the ends back together.

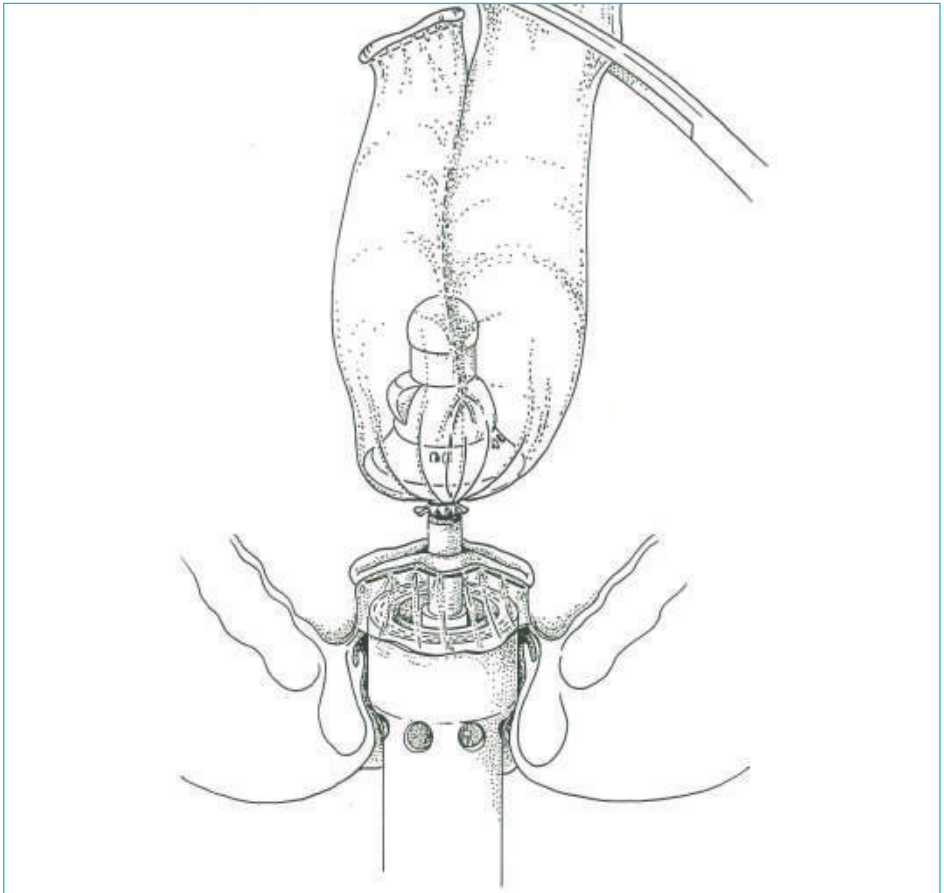


Figure 2: The ileal pouch being stapled to the top of the anal canal

In some patients, a more major operation may be necessary.

There is normally a delay of a few days before bowel content enters the pouch and it begins to function.

Once function starts, it is not uncommon for the faeces to be very liquid and frequent, and you may feel that you have little notice to reach the toilet. Control over your bowels can be difficult and you may experience some leakage of stool.

As your diet returns to normal over the following days, the pouch output begins to thicken and you should find that frequency decreases and control becomes better. This improvement continues over 12 to 24 months.

Who is suitable for pouch surgery?

Restorative proctocolectomy with an ileal pouch is suitable for many diseases of the colon where the whole of the colon and rectum need to be removed and the patient wishes to avoid a permanent ileostomy.

The majority of patients undergoing the operation have ulcerative colitis. It is also commonly used for patients with familial adenomatous polyposis and other similar conditions that predispose to large numbers of polyps developing in the colon and rectum, increasing the risk of bowel cancer. More rarely, it has been used in patients with very severe constipation who would otherwise require a permanent ileostomy.



Who may not be suitable for pouch surgery?

There are some circumstances where undergoing ileal pouch surgery is not advisable. These include

Crohn's disease

Just like ulcerative colitis, Crohn's disease is an inflammatory disease of the bowel. However, unlike ulcerative colitis, which is confined to the colon and rectum, Crohn's disease may affect any part of the bowel from the mouth to the anus. Many surgeons regard Crohn's disease as an absolute contraindication to the formation of an ileal pouch as the likelihood of the pouch developing a fistula or failing is greatly increased.

Increasing age

Pouch surgery is a major operation that is not without risks. Whilst patients in their 60's, 70's and even 80's have undergone ileal pouch surgery, with satisfactory outcomes, the impact of complications becomes more profound with increasing age. It may be considered safer to avoid having a pouch. Your surgeon will be able to discuss this with you in more detail.

Weak anal sphincters

The success of ileal pouch surgery relies heavily on having good anal sphincter tone. Previous surgery to the anus, including for anal fistulas, haemorrhoids or episiotomy during childbirth may affect the integrity of the anal sphincter. Traumatic vaginal deliveries that result in tears around or through the anus can also have a significant impact on the way the anal sphincter works. More generally, anything which vigorously stretches the anal canal could cause a weakness.

If you have a history of these, your surgeon may arrange for some special tests, known as anorectal manometry, to assess the integrity and function of the anal sphincters. If the readings are lower than normal values your surgeon may recommend that you do not have a pouch as you may experience regular incontinent episodes.

Obesity

Ileal pouch surgery is more difficult in obese patients, and complication rates following surgery are generally higher in the presence of obesity.

What types of pouch are there?

The ileal pouch can be made in a number of different ways. The most common variant is a two-limbed J pouch. This is used because it has a simple structure that is easy and quick to create. Other commonly used variants are a three-limbed S pouch and a four-limbed W pouch. These both have more complex designs that take longer to create. The pouch can either be created using a sutured technique or using a sophisticated mechanical stapler. The pouch can also be joined on to the top of the anus using either sutured or stapled techniques. The choice of technique used rests with your surgeon, who will choose the most appropriate for your circumstances.

Will I need a temporary ileostomy?

Most surgeons performing ileal pouch surgery create a temporary ileostomy at the time the pouch is made. The ileostomy diverts bowel content away from the pouch whilst the joins around the pouch are healing. You would normally expect to have the ileostomy reversed 3 – 6 months following your pouch operation. Your surgeon will be able to advise you on whether they routinely create an ileostomy at the time the pouch is made.



How long will I be in hospital for?

Following the formation of your ileal pouch, you can expect to be in hospital for between 7 and 14 days, although most patients are ready to be discharged by day 10. When you are admitted for reversal of your ileostomy, if you have one, you can expect to stay in hospital for up to 5 days.

How long will I need off work / school / college?

Every patient is different in the way in which they recover from major surgery, and in the first few weeks following your operation you will find that you tire quickly following seemingly trivial tasks. By approximately 6 weeks following the operation you should be 90% recovered, and may still feel more tired than normal. You should feel completely back to normal by 3 – 6 months following the operation. Most patients are ready to return to work or education after 1 – 2 months.



What are the alternatives to ileal pouch surgery?

Proctocolectomy with a permanent end ileostomy is the main alternative to having an ileal pouch. This operation removes all of the colon and rectum, but does not involve the creation of a pouch. At the time of surgery, the anus is often excised as well to prevent any troublesome discharge. It is not possible to have an ileal pouch at a later stage if you change your mind.

Another alternative is a continent ileostomy (Kock pouch), which is performed at very few centres in the United Kingdom. It involves the creation of a pouch with an internal valve mechanism that is positioned behind the abdominal wall. A short length of bowel connects the bowel to the skin as a stoma. Unlike an ileostomy, the stoma is flush to the skin, rather than standing proud from it. It is necessary to catheterise (intubate) the pouch in order to empty it.

What sort of bowel function can I expect from my pouch?

Most patients are able to achieve a good functional result from their ileal pouch operation. Soon after the ileostomy is reversed, when the pouch starts to function, you can expect things to be a bit erratic. Your body needs to learn how to interpret when the pouch is filling up and when you need to defecate.

You may find that you experience urgency to defecate and that you may need to get up several times at night. It is not uncommon to experience some seepage of stool from the pouch as well. This normally settles down reasonably quickly over the coming weeks, and most patients find that they open their pouch 5 – 7 times per day and may need to get up once at night.

You would normally have complete control over your pouch. If you experience high frequency of defecation, your surgeon may start you on some loperamide (Imodium) or codeine tablets to try and slow things down.



Potential complications of ileal pouch surgery

Ileal pouch surgery is a major operation, and whilst every care is taken to perform this safely, complications, unfortunately, do occur. Every major operation in the pelvis carries a risk of causing deep vein thrombosis (DVT), which may lead to a pulmonary embolism (PE). There is also a risk of damaging the veins that surround the pelvis, leading to significant bleeding. In any operation where joins are made between bits of bowel, there is a risk of the joins not healing properly (an anastomotic leak). This can lead to an abscess developing in the pelvis that may need to be drained either in the operating theatre or by a radiologist under x-ray guidance. Fistulas can develop from the pouch that may extend on to the skin of the perineum or abdomen or into the vagina. You would be likely to require further surgery to deal with these.

Pouchitis is an inflammatory condition of the ileal pouch that can lead to an increase in frequency of defecation, blood in the stool and urgency to defecate. It may also cause pain

or discomfort in the pelvis. It occurs predominantly in patients who previously had ulcerative colitis, but can affect anyone with a pouch. Treatment is with antibiotics, and you should notice an improvement in symptoms after a few days.

Occasionally, patients have to have their pouch defunctioned or removed. This is known as pouch failure, and occurs in 5 – 7% of patients in the first 5 years following pouch surgery. This commonly occurs as a result of the complications described above, but may be necessary for persistent poor function. It may be possible to undergo further surgery in an attempt to save your pouch, and your surgeon may need to refer you to a more specialist centre for this.

Dietary modifications

You should be able to enjoy a full and varied diet after having an ileal pouch. Some patients find that certain foods can lead to an increase in frequency of defecation or bloating. This is most common with spicy and fibrous foods, respectively. If you experience these symptoms, then you may prefer to avoid these

foods completely or limit your exposure to them. Some patients find that maintaining a diet that is low in fibre (low residue diet) minimises symptoms of bloating whilst keeping their pouch working regularly.

Implications for sexual function or having children

Most patients are able to enjoy a full and active sexual life following their ileal pouch surgery. However, the procedure does carry some risks.

Pelvic surgery can result in injury to some of the pelvic nerves that supply the penis. This can result in difficulty achieving or maintaining an erection, or problems with ejaculation. This may be a temporary phenomenon, due to bruising to the nerve, or permanent. The risk of this occurring is very small. Younger patients who have not yet completed their families may wish to bank sperm in case of any postoperative difficulties. This can normally be arranged for you through your pouch team.

For those patients unfortunate enough to experience difficulties with erection postoperatively,

Viagra has been shown to be very effective at helping patients achieve and maintain an erection.

Pelvic surgery in women can lead to scar tissue developing within the pelvis that may lead to partial or complete blockage of the fallopian tubes, resulting in infertility. Women wishing to have children may want to consider deferring pouch surgery until after completing their family. Women who are struggling to conceive may require fertility treatment, which carries good rates of success in patients with a pouch.

Some women report pain or discomfort during intercourse following their pouch surgery, which in extreme cases can lead to avoidance of sexual activity. In most instances, the discomfort is minor and does not interfere significantly with intercourse.

Restrictions on sporting/ adventurous activity or travel

There are no restrictions on undertaking sporting or adventurous activity. Patients with ileal pouches cover the full range of activity from minimal to professional athletes. If you are travelling overseas you will need to ensure that your travel insurance company know about the surgery you have had. If you are travelling to parts of the world where diarrhoeal illness is common amongst travellers, you should ensure that you have antibiotics (metronidazole or ciprofloxacin) with you as well as electrolyte mix (eg Dioralyte).

What is the National Ileal Pouch Registry?

The National Ileal Pouch Registry, sponsored by IA, was established through the Association of Coloproctology of Great Britain and Ireland (www.acpgbi.org.uk) to collate outcomes after ileal pouch surgery. The registry collects anonymised data that is submitted by surgeons undertaking pouch operations and uses this to analyse the number of procedures being performed and the rates of complications.

These data can be used to see how a colorectal department or an individual surgeon compares to other departments and surgeons. Additional data is collected to allow analysis of functional outcomes following pouch surgery. Similar registries maintained by cardiothoracic (heart) surgeons and bariatric (obesity) surgeons have led to significant improvements in the standard of care being delivered.

Where else can I get information?

Other sources of information include:

Crohn's and Colitis UK - a national charity supporting people with inflammatory bowel disease
www.crohnsandcolitis.org.uk

References

Available upon request. Please contact IA for further information.

Comments or Feedback

If you would like further information or wish to comment on the content of this booklet, our contact details can be found on the back of this booklet.



About IA

IA (Ileostomy and Internal Pouch Association) is a support group which has the primary aim of helping people who are living with an ileostomy or an internal pouch; their family, friends and carers.

It was started in 1956 by ileostomy patients and members of the medical profession. It was the first ostomy association in the UK and is a registered charity.

Certain inflammatory bowel diseases, such as ulcerative colitis and Crohn's disease sometimes cause such damage to the patient's large intestine (colon) that it is necessary for the surgeon to remove it entirely.

With a Brooke ileostomy, the lower end of the small intestine (ileum) is brought out through the abdominal wall and the body's waste matter is collected in an externally attached bag. Alternatively, the patient, depending on the reason for surgery, may be able to choose to have an internal pouch, which involves the construction of a reservoir from a section of the ileum. Someone who has an internal pouch does not need an external bag.

It is estimated that there are more than 9,000 new ileostomy operations carried out in England alone each year (source: NHS 2018) and around 400 internal pouch surgeries (source: Ileoanal Pouch Registry 2017). This means that you will almost certainly have met someone who has an ileostomy or internal pouch, as they lead perfectly normal lives.

What are IA's aims?

Any serious illness will disrupt a person's normal lifestyle, especially if it has lasted many years and has led to major surgery resulting in a change of body function and body image.

IA aims to help anyone living with, or supporting somebody with, an ileostomy or an internal pouch to return to a fully active and normal life as soon as possible.

IA aims to help them with all aspects of their rehabilitation including social activities, and relationships with their families, friends, employers, colleagues and members of the general public.

IA aims to work in close co-operation with the medical authorities as part of a team

whose primary aim is the complete rehabilitation of every ileostomy or internal pouch patient.

IA aims to promote and co-ordinate research – not only into ways of improving the quality of life with an ileostomy or internal pouch, but also into the illnesses which lead to these operations.

IA aims to improve knowledge about the management of ileostomies or internal pouches and encourage development of new stoma equipment and skin care preparations.

IA Activities

Hospital and home visiting

to give confidence and encouragement, by example, and practical help in living with an ileostomy or an internal pouch.

Members' meetings are arranged throughout the country by IA's local member organisations. A medical adviser or stoma care nurse may be present to give advice if necessary and there may be a guest speaker, either on a medical subject or one of general interest.

Equipment exhibitions are often held at members' meetings, with manufacturers' representatives present to give advice and answer questions. Members have the opportunity to examine and compare all the alternative brands to find the ones best suited to their individual needs.

The **IA Journal** is published quarterly and is sent to every member free of charge. It is full of articles of interest, news and views, exchanges of correspondence, and advertisements by equipment manufacturers of their latest products. Other literature is also available from national office.

Medical research is carried out into the illnesses which lead to ileostomy or pouch operations, and into many aspects of life without a colon.

Lectures and demonstrations are often given by IA members to groups of doctors, surgeons and nurses, to assist them in gaining more knowledge about ileostomies or internal pouches for the benefit of future patients who need such operations.

IA Organisation

IA is represented by a network of local member organisations across the UK and Ireland.

Each group offers support to its members, prospective members and other interested parties on a local level.

IA Membership

IA membership is open to anyone living with, or due to have, an ileostomy or an internal pouch; to family, friends and carers or anyone who may be living with any other type of stoma or is interested in the work of IA.

To join IA visit www.iasupport.org or contact us for an application form using our contact details on the back of this booklet.

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