

Patient Information leaflet for doctors, nurses and health care professionals re: internal ileo-anal pouch (J pouch)

This leaflet has been prepared by the Red Lion Group (www.pouchsupport.org), a registered charity that provides support and advice to people with (or those who are considering) an internal ileoanal pouch (as well as friends and family). The leaflet provides information for health professionals who provide medical care for people with an ileo-pouch-anal-anastomosis (IPAA) also known as J pouch

Information is derived from various referenced documents, from pouch patients themselves and from lectures from the multidisciplinary team at St. Mark's Hospital (delivered at the Red Lion Group Annual Information Days). Whilst the contents have been checked by medical professionals, it is not intended to be a replacement for personal medical advice. This leaflet provides information for health professionals who provide medical care for people with an ileo-anal anastomosis with a pelvic pouch.

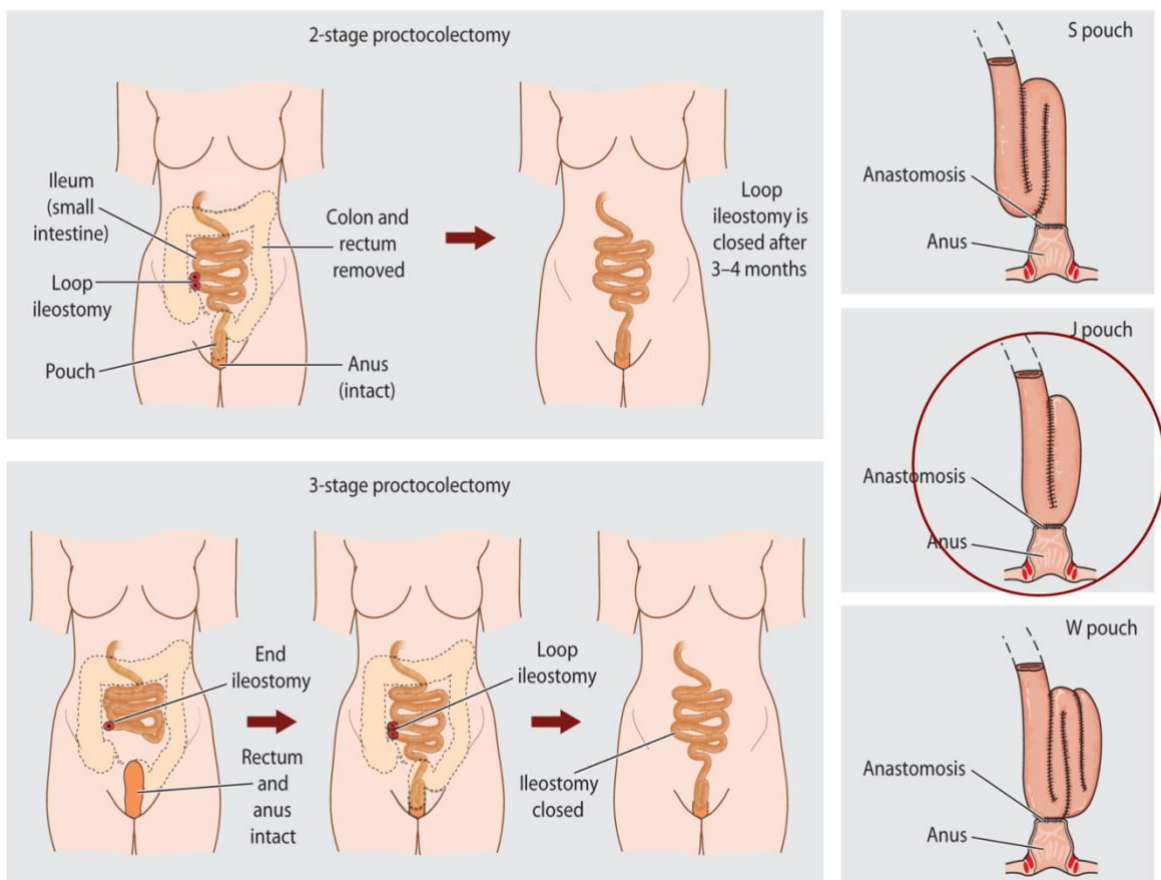


Figure 1

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What is an Internal Pouch?

The [ileal pouch-anal anastomosis \(IPAA\)](#), also known as an [ileo-anal pouch](#), [restorative proctocolectomy](#) or an [internal pouch](#) is an anastomosis of the ileum to the anus bypassing the former site of the colon in cases where the colon has been removed. It retains or restores functionality of the anus, with stools passed under voluntary control of the patient and serving as an alternative to an ileostomy. This is usually a two- or three-step procedure in which the first step is the removal of the large bowel, except for the rectal stump and anus, and a temporary ileostomy is made.

The next part of the surgery can be done in one or two steps and is usually done at between 3- to 12-months following the initial surgery. This allows for the patient's general health to improve and allow gradual withdrawal from steroid treatment (in cases where the large bowel was inflamed), for example due to [ulcerative colitis \(UC\)](#).

In the next step of the surgery, an internal pouch is made from the distal end of the patient's own small bowel, and this pouch is then connected to the rectal stump so that the patient can once again have a functioning, internal bowel system. This may

be a “j-pouch”, “s-pouch” or “w-pouch” configuration, depending on how many ileal folds are used. W-pouches have greater capacity and can lead to a reduced frequency of bowel movement compared with the J-pouch configuration. The J-pouch configuration is associated with fewer complications as it is easier to create. The J-pouch is also the most common configuration in recent times.

The pouch and rectal stump anastomosis can be left inside the patient to heal for some time while the patient still uses the temporary ileostomy for collection of bowel motions. The final surgical stage involves closure of the temporary ileostomy to restore internal bowel function.

In experienced centres of excellence such as [St Mark's Hospital](#) in London, the three stages can be undertaken in two operations (sub-total colectomy first and then pouch creation and connection) using laparoscopic techniques to reduce recovery times and minimise risk to the patient. (See Figure 1).

Why is it performed?

The most common reason to perform a total colectomy is disease progression in [Ulcerative colitis](#) or indeterminate colitis that is resistant to medical management. Another reason for removing the colon is when there are precancerous cells in the colon during surveillance. This is mainly to reduce the risk of bowel cancer.

It may also be performed in cases of [familial adenomatous polyposis](#) (FAP) to avoid later development of bowel cancer, or indeed due to bowel cancer. In certain specialist centres, the patient may be offered the IPAA procedure to restore bowel function as an alternative to a permanent ileostomy.

Outcomes

Once the patient has recovered from surgery, normal pouch function is typically between 3-8 bowel movements per day (including occasional nocturnal motions). The stool is loose with a porridge-like consistency. Ability to defer defaecation is variable, with healthy pouches providing the ability to defer a bowel movement for 1 – 2 hours or so. There is not usually any faecal leakage in the day although this may occur at night.

It is important to note that there is significant individual variation in the extent and nature of toilet visits and each individual will have different experiences with their pouch.

Daily adjustments

Diet

Initially, patients are advised to eat a soft, low fibre diet to avoid blockages and encourage wound healing. A high protein/energy diet promotes wound healing, speeds up recovery and prevents weight loss.

Most patients can gradually eat a varied diet following pouch surgery, although new foods should be introduced slowly. Some high fibre foods such as apple peel can cause the pouch to go into spasm, causing temporary symptoms of blockage.

There are nutritional implications following pouch surgery, mainly reduced [Vitamin B12](#) absorption, bile acid/salt malabsorption and dehydration. Over time, the kidneys adapt and reserve more water and salts; the small bowel adapts and there is increased absorption of nutrients.

- Patients are generally advised to add salt to food or use a rehydration mix, especially in hot weather, and reduce high fibre and fatty foods.
- Reducing intake of pulses, fructans e.g. garlic, onions, brassicas e.g. cabbage, resistant starches and sugary, fizzy drinks can decrease issues with wind and leakage.
- Certain foods e.g. spicy food, seeds, nuts and coconut, etc. can cause anal skin irritation.
- Fish, eggs, onions and garlic can increase stool odour. Some patients carry odour reducing sprays especially when using public toilets.
- Eating bread, white rice, pasta, apple sauce, marshmallows and bananas can reduce frequency of bowel movements.
- Patients are advised to eat at regular intervals during the day and, for those experiencing night time bowel movements, to have their main meal early in the evening.

Some patients choose to use vitamin supplements, especially if they have to restrict intake of fruit and vegetables. These supplements are best absorbed in liquid or gel form.

Frequency and leakage

As detailed above, eating habits can greatly influence pouch activity.

Loperamide and/or codeine may be needed to reduce stool frequency. For some people, a fibre supplement such as Fybrogel can help thicken their stool so reducing frequency.

Leakage/seepage may be worse at night and can be made worse due to wind. In extreme cases an anal insert might be necessary to prevent leakage/seepage and to reassure the patient.

[Toilet urgency cards](#) can be obtained from various sources including The Red Lion Group (pouchsupport.org) and www.crohnsandcolitis.org.uk. These cards are widely recognised and effective in finding toilet facilities at short notice.

Hydration

Dehydration may be caused by water loss (for example during periods of increased frequency with loose stools, vomiting, sweating, heavy exercise and flu) or from not drinking enough liquids. Chronic dehydration can increase the risk of kidney stones.

As well as maintaining adequate fluid intake levels, loperamide and/or codeine may be necessary as well as electrolyte replacements.

Skin irritation

Many pouch patients experience peri-anal skin irritation, due to increased frequency of bowel movements, increased acidity of the stool and occasional leakage and seepage. This irritation can be a significant problem in the months following final surgery and is reported by many new pouch patients. The irritation usually improves with time as the skin becomes more robust.

Thorough cleaning of the peri-anal area with simple warm water after every bowel movement, with gentle patting dry (as opposed to wiping) will help to counter the irritation. Most patients will require some form of barrier cream.

If leakage / seepage is a continuing problem, then an anal insert / plug such as “[Renew](#)” may help.

Sexuality

There may be temporary changes after surgery due to inflammation and swelling around the nerves. Women are recommended to avoid intercourse for 6 weeks following surgery.

Men may experience some erectile dysfunction immediately following surgery but this usually improves as they recover. Long term issues are rare (1% of men) and may require specialist referral.

There may be fertility issues following pouch surgery, but many women have gone on to have healthy pregnancies. Laparoscopic (keyhole surgery) has been shown to reduce the fertility issues. Most women have caesarean sections to preserve the integrity of the pelvic floor.

Anal sex is not recommended. (*Special concerns for people with a J pouch: University of California San Francisco; Mayo Clinic*)

Fatigue

Patient fatigue is common after creation of an ileo-anal pouch. Interrupted sleep due to night time bowel movements may contribute to this fatigue.

Mental Health Issues

Adjusting to life without a colon requires patience and understanding. Research has shown that 95% patients are satisfied with the outcome of the procedure. (*Mayo Clinic: Journal of Crohn's and Colitis (2014)8,1261-1266*)

In patients who have suffered for years with chronic ill-health, the surgery to remove the colon can be viewed very positively. Adjusting to life with an ileostomy (albeit temporary) can be challenging for some patients.

Being tapered off steroids following surgery may significantly affect mood.

A patient support group such as the [Red Lion Pouch Support Group](#) based at St. Mark's Hospital, London (pouchsupport.org) can be a great help, both in the early days and living with a pouch long term. As well as newsletters and an excellent website with access to a wealth of information, they hold an annual Information Day

with speakers who are leaders in the world of pouch care plus patient and carers support sessions. In addition, the group organises virtual online meetings and seminars so pouch patients based in the more remote regions of the UK are able to access the latest in medical advances as well as advice, support and companionship from other pouch patients from the safety and comfort of their own home. Attendees find it very useful to be able to speak to fellow pouches face to face and receive a more balanced view of life with a pouch.

A professional mental health expert may also help during this difficult time.

Complications of an internal pouch

The types of complications following surgery fall in to two main groups, inflammatory and non-inflammatory.

Inflammatory issues include [pouchitis](#) and [cuffitis](#) in the very small amount of rectum that is retained: 20 – 50% of patients are likely to experience pouchitis/cuffitis at some time.

Common symptoms include frequency, loose stools, abdominal pain and cramping, feeling unwell, possible fever, possible bleeding with symptoms worsening over time.

First line treatment is antibiotics, usually [ciprofloxacin](#) or [metronidazole](#) alone or in combination for two weeks. If unresolved, then treatment with other antibiotic combinations, including [Tinidazol](#) and [Rifaximin](#) may need to be administered for a longer period. Antibiotic treatment disrupts the bacterial flora in the pouch and can lead to symptoms such as bloating and diarrhoea. Some patients may benefit from short-term consumption of probiotics e.g. [Vivomixx](#) or [VSL#3](#) to encourage a healthy gut flora after a course of antibiotics.

Fistulae can occur with vaginal/perianal discharge and symptoms of sepsis.

Non-inflammatory issues can be either [functional](#) or [mechanical](#).

[Mechanical problems](#) can be due to inflow/outflow obstruction, a small reservoir or a weak anal sphincter.

[Functional problems](#) may be due to an evacuation disorder or irritable pouch syndrome. This can lead to ineffective, frequent emptying, straining and not knowing if the pouch has been properly emptied, struggling with loose stools and leakage.

Investigations that may be required include pouchoscopy when biopsies may be taken to exclude or include pouchitis, cuffitis, pre-pouch ileitis, dysplasia, strictures and Crohn's disease and functioning defaecating pouchograms to assess function.

Treatment for narrowing at the pouch anal anastomosis can include dilation either surgically or administered by the patient, pouch irrigation and biofeedback.

Routine examinations

Due to the nature of pouch function and possible long-term issues with malabsorption, the following blood tests are recommended annually by the pouch nurse specialist at St. Mark's Hospital:

- Full blood count,
- Urea & electrolytes,
- Liver function tests,
- Calcium,
- Vitamins D & B12,
- Folate,
- Ferritin.

Medication

Frequency and loose output:

Many patients will require long term use of [loperamide](#) (up to 16mg 4 times daily) and/or [codeine](#) (up to 30 – 60mg four times daily). These treatments may achieve better outcome in combination.

Some patients benefit from the use of [Fybrogel](#).

Dehydration:

Some patients take rehydration preparations e.g. [Dioralyte](#) especially in hot weather or if they participate in sporting activities. There is also a recommended St. Mark's hospital "do it yourself" mix. See <https://pouchsupport.org/are-you-getting-enough-hydration-how-to-make-st-marks-solution/>

Pain relief

Some patients may experience persistent pain and appropriate pain medication may be required e.g. [amitryphaline](#).

Skin care

Most patients experience sore anal skin due to the acidic nature of frequent, loose stools and so will require barrier creams.

Dietary supplements

[Vitamin D](#) is absorbed in the [jejunum](#) and [B12](#) in the [end of the ileum](#) so patients may require supplements, potentially administered by injection. There may also be issues with calcium levels which may have also been depleted by previous long-term steroid use.

Medication for other pathologies may target receptors in the GI tract so there may be issues of absorption. If this is an issue, then a consultation with a pharmacist is recommended to discuss alternative preparations or means of administration.

Vitamin B12 deficiency

Vitamin B12 is absorbed in the end ileum, which in the case of pouch patients has been removed. It is therefore very common for pouch patients to suffer from Vitamin B12 deficiency.

Furthermore, routine blood tests to show B12 deficiency can be unreliable as described in the NHS paper on the subject:

<https://www.nhs.uk/conditions/vitamin-b12-or-folate-deficiency-anaemia/diagnosis/?fbclid=IwAR3TT9rY71H3Gr7evLFa-rIW1Jccw8n8huWvs9Sk-B5bHoewQluh5x7Y>

In particular, this paper explains that

- *A particular drawback of testing vitamin B12 levels is that the current widely used blood test only measures the **total** amount of vitamin B12 in the blood*
- *This means it measures forms of vitamin B12 that are "**active**" and can be used by the body, as well as the bound or "**inactive**" forms, which cannot be used by the body*
- *If a significant amount of the vitamin B12 in the patient's blood is inactive, a blood test may show normal B12 levels, even though the patient cannot use much of it and might have Vitamin B12 deficiency*
- *This is why it's important for symptoms to be taken into account when a diagnosis is made*

This last point is particularly relevant for patients with a pouch, and if a patient presents with relevant symptoms they might well benefit from B12 supplements (usually in the form of B12 injections), even if the B12 level is within the normal range.

Drugs to avoid

It is known that NSAID's such as [ibuprofen](#) and [voltarol](#) can irritate the pouch and lead to pouchitis, so they are not recommended for this group of patients.

Medications for other issues can also affect pouch function but this is individual to each patient.

Co-existing morbidities

The gastrointestinal aspects of Ulcerative Colitis can be resolved by surgical removal of the large bowel but extra intestinal symptoms may persist. Many people find that with the removal of their inflamed colon, these extra symptoms may decrease.

These can include:

- Primary Sclerosing Cholangitis (PSC) with inflammation of the liver and the bile duct (affects 1:25 patients with UC)
- Sero-negative arthritis 1:10
- Ankylosing spondylitis, discitis & sacroiliitis

- Mouth ulcers
- Itchy skin – panniculitis, erythema nodosum 1:10, rarely pyoderma gangrenosum,
- Eye problems – episcleritis, uveitis, scleritis
- Osteoporosis due both to systemic autoimmune disease and previous steroid use
- Heart and circulatory problems; patients with UC are twice as likely to develop blood clots including DVT
- Autoimmune haemolytic anaemia due to lack of iron in the diet or lack of absorption
- Bowel cancer – the risk is greatly lessened with removal of the large bowel, although screening may be needed if there is incomplete removal of the rectum

(Co-existing morbidities with Inflammatory Bowel Disease: Crohn's and Colitis Foundation)

Most pouches live a full, healthy and active life and 85-90% of cases are considered to be successful. However, there are some who may experience health issues either directly or indirectly related to the removal of their colon and/or having an internal pouch and/or an underlying inflammatory disease process and 10-15% of pouches fail and need to be resected.

With an estimate of between 6,000 and 10,000 pouch patients out of a population of over 66 million, you may be the only patient with an internal ileo-anal pouch that most non-pouch specialist medical staff will ever see so, hopefully, the above advice will be of help for both you and them.

(Ileo-anal pouch report 2017: Association of Coloproctologists of Great Britain and Ireland)

This leaflet has been reviewed by medical professionals, but is not a replacement for individualised medical advice. Hopefully, you will find it a good starting point for more informed discussion with your health care provider, both for specified pouch issues and generalised health problems that may be related to life with an internal pouch.

This information leaflet is available online at pouchsupport.org/medic



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