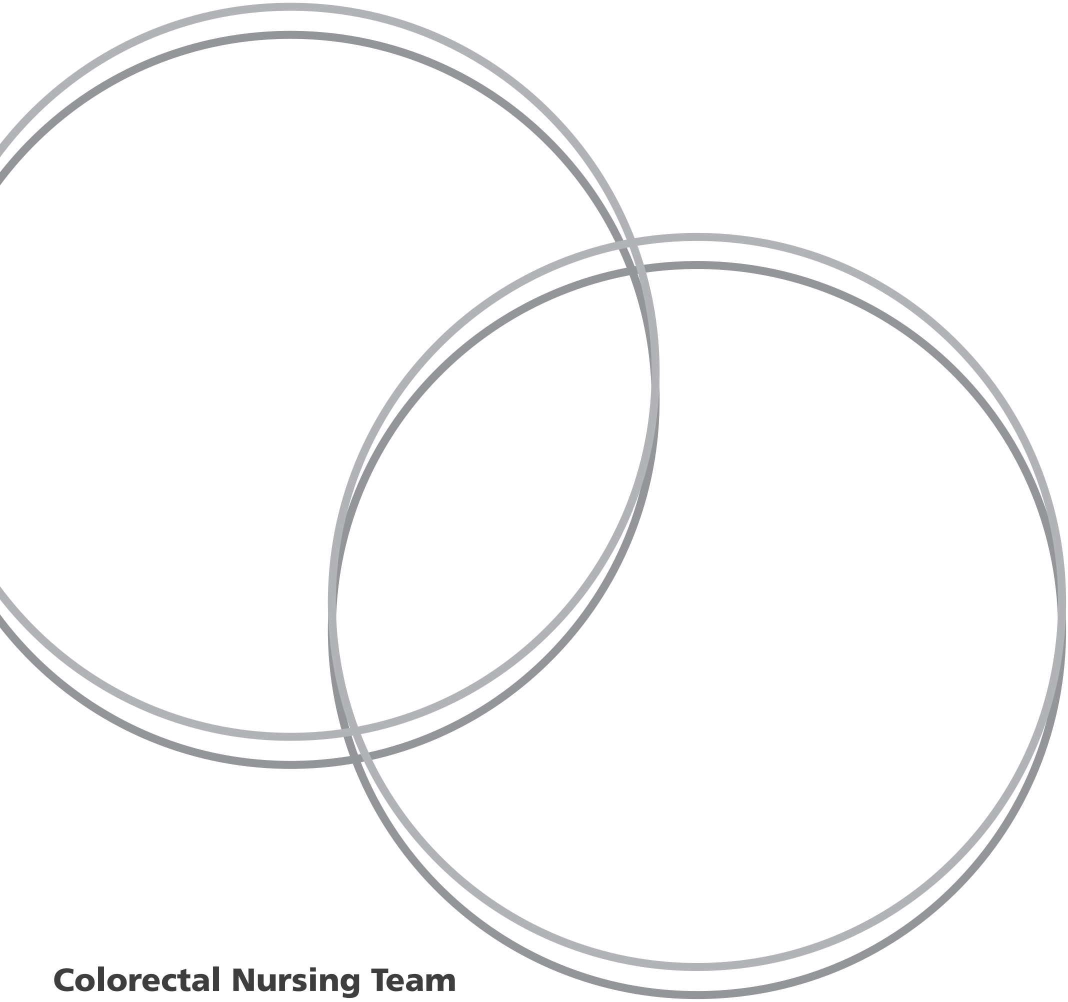
NHS
Oxford University Hospitals
NHS Foundation Trust

Ileo-anal pouch operation

Information for patients



Colorectal Nursing Team

You have been given this booklet because you may be suitable for this operation. Please speak with your specialist team if anything in the booklet is not clear. This booklet will explain about the operation and what to expect.

Contents

Chapter 1: Pre-operative pouch stages

Why is this operation done?

A restorative proctocolectomy or ‘ileo-anal pouch’ (IAP) is an option for surgical management of Ulcerative Colitis (UC) and Familial Adenomatous Polyposis (FAP). It involves removal of the colon and rectum and replacing the rectum with a reservoir (pouch) made of the small bowel. The aim of IAP surgery is to restore bowel continuity and is an alternative to a permanent end ileostomy.

What does the operation involve?

The operation may be undertaken laparoscopically (keyhole), as a laparotomy (open surgery) or robotically and can be performed in one, two or three stages. Your surgeon will discuss with you, which is the most appropriate surgical option for you, during your consultations. The ‘J’ shaped pouch is the most common pouch formed here in Oxford. The ‘S’ shaped pouch and ‘W’ shaped pouch configurations are the other surgical options available but performed less commonly.

Deciding to have further surgery is a big decision and should not be rushed into. You should not feel pressurised into having a pouch and some patients prefer to keep their stoma. It is important to make the decision that feels right for you. There are advantages and disadvantages of any operation, and the stoma/pouch nurses are here to help you make an informed choice. It may be helpful to ‘buddy’ up with another IAP patient or patient with a permanent ileostomy to discuss their journey and if it is something you would like to proceed with, let your stoma/pouch nurse know and an appropriate ‘buddy’ can be found.

Advantages and benefits of IAP

- Patient choice.
- Alternative need for a permanent ileostomy.
- Possible improvement of quality of life for some patients.
- Potential improvement with body image.
- The ability to live a more normal life is more achievable.
- The longevity of an IAP is starting to be better understood.
- No more worries about burning skin causing stoma bag leakage.
- The IAP is self-contained and an external stoma and bag is not.
- Not having to worry about the risk of bag leakage.
- No need to carry spare stoma supplies or to sort ordering stoma supplies.
- Potentially a greater sexual confidence.

Disadvantages or risks of IAP

- May require multiple operations and reviews.
- Should be completed in specialist centres, which may be far from home.
- Potential surgical complications.
- No guarantee of ‘good’ pouch function.
- Long term pouch health unknown and pouch longevity.
- Potential risk to fecundity (ability to conceive).
- Possible changes in sexual function.
- No improvement of quality of life for some patients.
- No improvement with body image.
- If pouch removed, or needs to be de-functioned, loss of this section of bowel could result in altered function.
- A formation of ileostomy if pouch removed, rested or taken out of use.

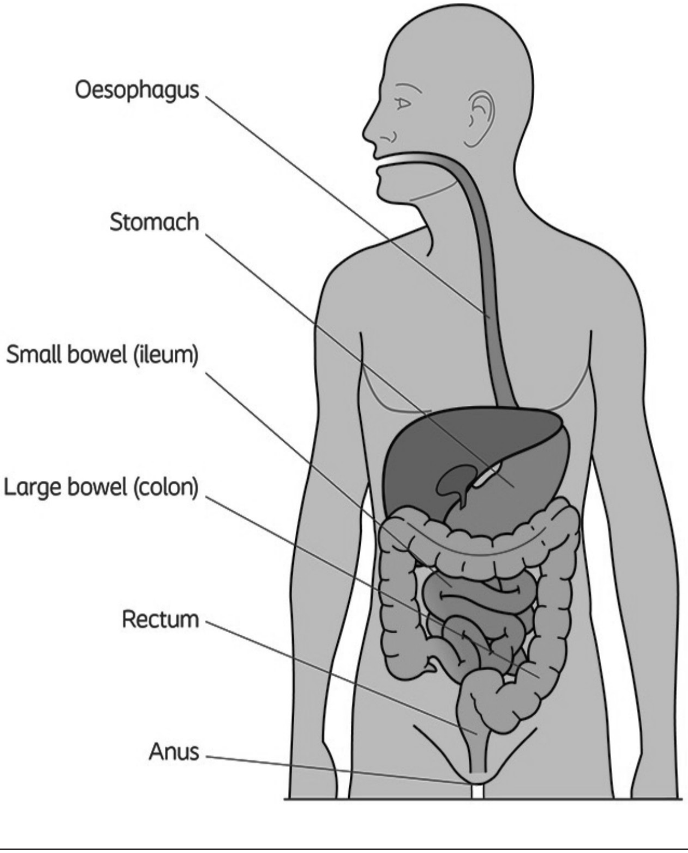
Despite all the issues mentioned above, it is our experience that pouch surgery, for the majority of patients, facilitates a return to what they perceive as a more ‘normal’ way of life.

You will be asked for your consent before any procedure or treatment is carried out. The risks, benefits and alternatives will be explained to you before consent is obtained. It is your choice to give consent or not. If you have any doubts or more information is required, please ask!

The three stage operation

Before the operation begins, the surgeon and stoma/pouch nurse will explain and discuss the anatomy of the bowel and which parts of the bowel will be removed (figure 1).

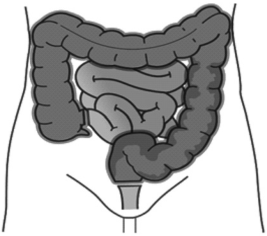
Figure 1: Anatomy of the bowel.
(pictures supplied with kind permission by Coloplast)



Some patients undergoing IAP surgery will have had their entire colon removed, with a formation of an end ileostomy, as an emergency procedure following an acute flare of UC (figure 2).

Figure 2: Anatomy of the bowel post colectomy,
the area in grey is the section of bowel that has been removed.
(pictures supplied with kind permission by Coloplast)

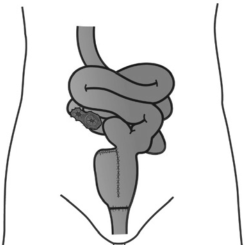
First operation -
Subtotal colectomy
and end ileostomy with
rectal stump preserved.



The second stage of IAP will be undertaken a minimum of six months following the first surgery. It is important that the surgery is performed when you are well and fully recovered. The healing process can be impeded by poor nutrition and certain medications; therefore, it is vital to ensure a return to health is achieved prior to further planned surgery.

Figure 3: Anatomy of the bowel following
ileo-anal pouch formation with a covering loop ileostomy.
(pictures supplied with kind permission by Coloplast)

Second operation -
Proctectomy (removal of
rectum), formation of ileo-anal
pouch with conversion of end
ileostomy to loop ileostomy.



The second stage of surgery (figure 3) involves removing the rectum, creating the ileo-anal pouch and attaching this new pouch to the cuff of the rectum, just above the anal sphincter. Occasionally, patients will pass some stool or mucus through their pouch at stage two. This is nothing to worry about and you can discuss it with your pouch/stoma nurse.

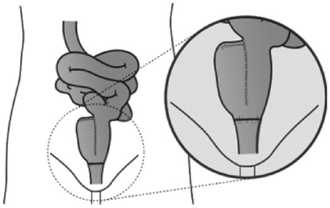
You may also have a drain (rectal drain) placed into your pouch through your back passage to help drain any excess fluid within your new pouch. This usually stays in for up to five days and the ward nurse may flush this catheter to make sure it does not get blocked. However, it will be at the surgeon's discretion when it is removed and if it requires flushing. It is also normal to have a catheter (tube into the bladder) to keep it empty. This will normally remain in place for two to three days after surgery.

A loop ileostomy is created higher up in the small bowel to create a temporary diversion to protect the new pouch and allow it to heal before stool passes through it. The new stoma may not look or behave like the previous one, often being flatter against your abdomen and not as well spouted. This can result in occasional leaks, and you may need to be reviewed by your stoma nurse following your discharge to determine the optimum appliance. The output from a loop ileostomy will be higher in volume, resulting in increased activity as the stoma is further upstream than the previous end ileostomy. Some patients will require medication and dietary changes to increase absorption of fluids and food.

Length of stay in hospital is expected to be 5 to 7 days, although everyone is different, and this may vary between individuals. During this time, a stoma nurse will support you with your 'new' stoma.

Figure 4: Anatomy of pouch post ileostomy closure.
(pictures supplied with kind permission by Coloplast)

Third operation - closure of loop ileostomy which leaves a functional ileo-anal pouch.



The third stage, the last stage of the IAP process is normally 3 to 6 months after the second stage, as the pouch needs time to heal. The third stage is a smaller operation to close the loop ileostomy and restore continuity of the bowel to the IAP (figure 4).

The pouch nurse will see you after the operation and provide you with information and advice on your new functioning IAP. The length of stay is usually between 3 to 5 days; however, this can vary from person to person. Once the stoma has been reversed and you have a functional pouch, some patients feel this is the end of their journey. However, this is where a new journey begins. It will take time for you and your body to adjust to how to care for and empty your pouch effectively.

The two stage operation

There are some patients who have a two stage procedure. These patients will have had a colectomy (figure 2) and will have a functioning pouch created (figure 4) but they do not have a loop ileostomy formed. These patients' post-surgery may have a rectal catheter to drain off any fluid, but this drain is removed a few days post-surgery.

The one stage operation

There are some patients who have a one stage procedure. These patients will have had a colectomy (figure 2) but do not have a loop ileostomy formed and will have a functioning pouch created as an all in one procedure (figure 4). These patients' post-surgery may have a rectal catheter to drain off any fluid, but this drain is removed a few days post-surgery.

Important advice for patients who have had a one stage or two stage pouch procedure (i.e. a pouch formed with no covering ileostomy).

If you fall into this category, it is very important to ensure that you do not let your pouch overfill in the early days after the operation. For the first 4 to 6 weeks, once you get the urge to open your pouch, it is important to empty it every 2 to 3 hours (or more frequently if you have the urge), so that the new stiches/staples in the pouch do not overstretch. This will also involve getting up several times overnight. Often in the first 24 to 48 hours the urge to open your pouch could be wind rather than stool as you may not have had much to eat. After the six-week period, you can then start to extend the time in between emptying your pouch, which allows the pouch capacity to extend over time.

Chapter 2: What is the pouch clinic?

In Oxford, we have a team of specialist nurses who run the telephone (telemed) pouch clinic. A referral from the surgeon, gastroenterologist or your GP can be made to our clinic at:

Pouch Nurse Specialists
Colorectal Nursing Dept,
Level 6, Corridor 6C/6D,
John Radcliffe Hospital,
Headley Way,
Headington,
Oxford, OX3 9DU.

Email: colorectal.nursing@ouh.nhs.uk

Our referrals are mostly Oxfordshire patients or patients that have had surgery in Oxfordshire and have moved elsewhere. However, we do accept out-of-area referrals through the referral process. A new or reinstated referral into the clinic is made through the surgeon, IBD team or your GP. This clinic is for patients with a functioning pouch only.

Pouch clinic involves a telephone consultation at a pre-arranged date and time with us. However, if you have problems and are known to this service, you can call the pouch nurse for any advice in the meantime. The frequency of your pouch clinic appointment will be discussed with you, as some patients require annual appointments and some require less frequent follow up reviews. The clinic usually lasts approximately 20 minutes. We aim to ring you approximately 15 minutes either side of your allotted appointment time on the number that you have supplied to this hospital EPR (Electronic Patient Records) system. It is therefore essential that you keep your contact details up to date for our records.

Prior to the appointment, you will have received a letter requesting that you obtain a blood sample at your GP surgery annually. This is because some people with an IAP can have iron and Vitamin B12 deficiencies.

The blood test we ask you to obtain is:

- Full blood count (FBC)
- Vitamin B12
- Ferritin and Folate (Iron)
- Liver Function Test (LFT)
- Urea and Electrolytes (U and E's)

We anticipate that you have ensured that the blood tests are obtained annually and the results are sent through to us in time for any booked appointments at the address above.

If your GP declines to send the results, please ensure you are aware of the results to enable discussion. For those people who live within Oxfordshire and have an Oxfordshire GP, there is no need to send the test results to us as we can access them via the hospital EPR system.

As part of the consultation, we plan to discuss with you:

- Your current pouch function.
- How many times per day and night you may need to empty your pouch.
- If you have any concerns with soiling, urgency, or anal soreness.
- Your diet and hydration.
- Current medications and relevant interventions.
- Your quality of life with the pouch.
- Any surveillance that is required.
- Any further investigations that are required to improve your pouch function.
- Any other concerns that you may have regarding your pouch.

What happens if I have problems outside of my Pouch appointment?

You are welcome to contact us at the address shown on page 11, by telephone or email. We will aim to respond by the close of the next working day.

Telephone: **01865 235 367** or **01865 221 839**

Email: colorectal.nursing@ouh.nhs.uk (FAO pouch nurses)

Chapter 3: Getting to know your new pouch

Initial pouch function

Once you no longer have a stoma and your pouch is now fully functioning; here is some advice on how you can help to train your pouch and what it needs to do!

Remember your pouch output is initially going to be watery in consistency, until you start eating again. We advise initially for this to be a low fibre diet to reduce frequency and thicken stool consistency. It is quite normal for the output to be dark green in colour and may initially contain some blood. When you first start to empty your pouch, the output may be liquid and contain some mucus. Over a period of time, which seems to vary from one person to another, the output should thicken up and become a more porridge-like consistency. Nearly all people with pouches report that they pass loose stool. The consistency can also vary from one day to the next depending on diet.

You will usually feel the need to open your pouch within 24 to 36 hours after closure of your stoma. Initially following closure surgery your pouch capacity is reduced, therefore frequency is increased. However, over time and with training, the pouch capacity will increase.

The correct position

Do not strain when you empty your pouch. Sit down on the toilet with your back as straight as possible and try to relax, this can help to engage the correct muscles for effective pouch emptying. It is very important for anyone, whether they have an IAP or not, to feel relaxed and comfortable when passing motions. Remember this is a natural bodily function that we all do.

If you have difficulty emptying your pouch, paying particular attention to your posture can be beneficial, which is explained in figure 5.

Your feet should be raised slightly off the ground e.g., on a small box or stool, as this adjusts your postural position so that you are more likely to evacuate your pouch using your abdominal (oblique) muscles, as opposed to any others. To feel these muscles, place your fingers on to your sides just below your rib cage and breathe in, push in slightly and then breathe out or give a gentle cough. When opening your pouch, it is essential to use your oblique muscles, rather than straining and pushing through your perineum (anus); straining will contract your anal sphincter muscles and inhibit pouch emptying, as well as potentially cause haemorrhoids.

Figure 5: Correct position for opening your bowels.
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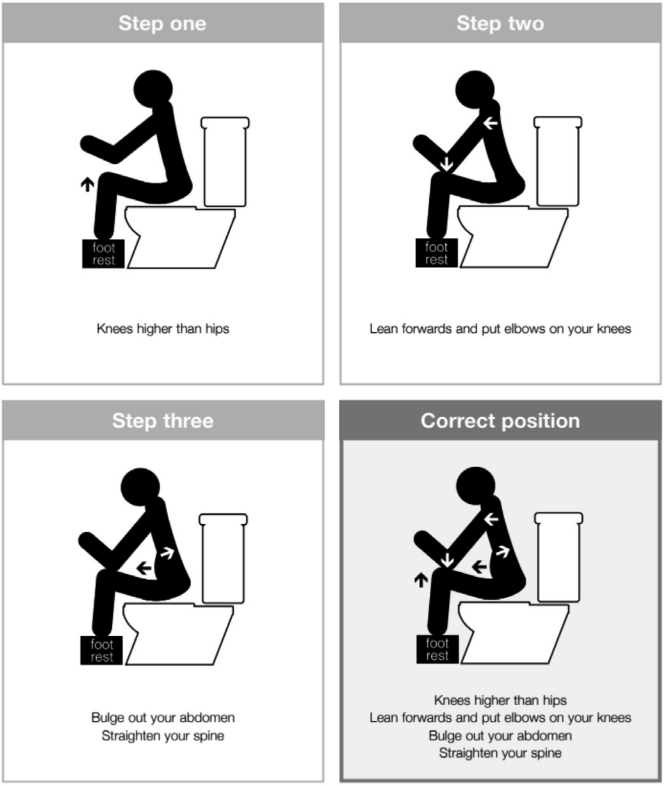

Step one

Knees higher than hips

Step two

Lean forwards and put elbows on your knees

Step three

Bulge out your abdomen
Straighten your spine

Correct position

Knees higher than hips
Lean forwards and put elbows on your knees
Bulge out your abdomen
Straighten your spine

It is important to allow plenty of time to pass stool and not feel rushed, as this can impede the process. Using the pelvic tilt technique may help. This is where you gently rock the pelvis forward or backward to adjust the angle of the pouch, thus aiding evacuation. If you have any mobility or health problems that restrict movement, please discuss this with your doctor before attempting.

Of course, there are other reasons which may be causing you difficulty with emptying your pouch. Occasionally the ileo-anal anastomosis (or the join) can become slightly narrowed and may need stretching (dilating). This can be done in the outpatients' clinic or sometimes requires a small operative procedure. If problems continue, you should seek advice from your surgeon or pouch nurse.

Ready, steady and open your pouch

From the first time that you feel the urge to open your pouch, we advise that you sit on the toilet every 2 hours during the daytime. Often in the first 24 to 48 hours the urge to open your pouch could be wind rather than stool as you may not have had much to eat.

After surgery, you may not be able to differentiate between stool and flatus. Over time some pouch owners report being able to differentiate between the two, whilst others will not. Don't worry if you are unable but be sure to sit on the toilet if you have the urge to pass wind, just in case!

If you feel the need to go to the toilet just before the 2 hour window, try to hold on for a maximum of 15 minutes to encourage your pouch to gently stretch and increase the capacity – this can take many weeks so don't try to rush it.

If you cannot, then that does not matter, just go to the toilet. However, if this is the case you may find it helpful to establish a 1 hourly pattern first and once this becomes easier recommence the 2 hourly emptying pattern again.

When you are able to wait the 2 hours comfortably before routinely going to empty your pouch, try to progress to emptying every 3 hours.

If you find you cannot hold on for the 3 hours, do not worry. Go back to the 2 hourly pattern again for a minimum of 24 hours or until you feel comfortable again with this. Then try again with progressing up to the 3 hours. When you are comfortable emptying your pouch every 3 hours, progress to every 4 hours.

Once again if you find you cannot hold on for 4 hours, do not worry. Go back to the 3 hourly pattern again for a minimum of 24 hours or until you feel comfortable again with this. Then try again with progressing up to the 4 hourly pattern.

You are likely to have to get up overnight to empty your pouch and some overnight leakage is not uncommon. The frequency of this can decline/stop once the pouch output has a chance to thicken up. However, it is not uncommon for patients to have to empty their pouch at night long term as well as experiencing some night-time leakage.

Please note: every person progresses from one stage to the next at different times. Patience is needed for you to feel comfortable with your pouch opening. Progress will occur with the support and advice of your doctors and pouch nurse.

Skin care for bottoms

It is important to know and realise that peri-anal skin (skin around your anus) irritation is reasonably common and can often be resolved with simple treatments. If after time this doesn't settle, then a physical examination may be required to assess for other potential causes.

Keep the area clean by gentle cleaning after every bowel action, as well as thoroughly each morning and night. A nightly bath is particularly helpful if you itch at night. A bidet can be useful but sitting in a bath is a good substitute. Keep the area dry afterwards by carefully dabbing with a towel, very soft toilet paper or moist toilet paper, whichever is more comfortable. Try not to rub and avoid using talcum powder on the peri-anal area and we would also suggest that you do not use perfumed soap as this may irritate the area.

There are many types of barrier creams available, either on prescription or off the shelf. It is advisable to try different creams to find the cream that suits you. Only use a small pea-sized amount of barrier cream and apply after each time you open your pouch. Avoid excessive amounts of cream as this tends to keep the skin soggy, which is what you are trying to prevent. Calamine Lotion can be very cooling and is dry and this may work for you if you experience soreness. Before you apply some more cream, ensure you have wiped off any old cream from a previous application.

Coconut, nuts, oriental vegetables, some raw fruits, vegetables, citrus fruits and bran foods have all been known to cause some degree of peri-anal irritation.

Wind related points

Most people experience wind discomfort following IAP formation. Many patients find it difficult to pass wind without sitting on the toilet and some report that it is difficult to distinguish between the two, particularly in the early days. It may help if you lie on one side with your knees up as this can make things easier and can relieve trapped wind without needing to sit on the loo! If you are unable to pass wind and it is making you feel uncomfortable, then try relaxing in a bath or lying on your stomach for half an hour or massaging your lower abdomen.

It is not advisable in the early days to drink fizzy (carbonated) drinks as this may cause some wind. Some pouch patients benefit from probiotics to control pouch function and wind issues. These supplements can be purchased over the counter, or the GP may prescribe a stronger dosage which is known as VSL#3. If you have any problems getting this prescribed there are alternatives, please ask the pouch nurses about this.

Leakage from your pouch

You may well experience this initially, especially overnight whilst sleeping and relaxed. However, it may just be the occasional leak. Approximately one in two people with pouches have experienced leakage, and the problem can resolve over a period with guidance and muscle control improvement. When you are getting used to the pouch, it is easy to confuse the feeling of wanting to pass wind with that of wanting to open your pouch. Beware, as this may be the cause of a leak!

Ways to cope with leakage are:

- Emptying your pouch before going to bed.
- Avoiding alcohol, sedatives, and food before going to bed.
- Eating marshmallows or jelly babies - they help to thicken the stool but not too many at once as they may contain a high sugar level or artificial sweeteners which can stimulate the pouch. If you are a diabetic, or want to reduce your sugar intake, sugar free alternatives are available.
- Avoid foods that loosen your stool (see following table).
- Discuss the use of Loperamide with your doctor or specialist nurse. Loperamide is an antidiarrheal that can be used to help slow down and thicken the output from your pouch. This can help to prevent dehydration and leakage from your pouch.
- Bottom clenching, bottom walking and pelvic floor exercises may help improve muscle tone and so help avoid leakage. We can give you additional leaflets on these if they are required. It is considered good practice for all ‘pouch owners’ to practice pelvic floor exercises to keep this area toned.

Diet

When the surgical team decides that you are ready to introduce diet, initially this is likely to be more liquid and soft foods like soup and pudding. For the first few meals try some foods that will help to decrease pouch output. Remember a balanced diet is important; ‘a little of what you fancy’ is the best advice and remember to chew well to aid digestion and absorption. It is initially advisable to have frequent, smaller meals and snacks rather than 3 larger meals. There are no specific rules- diet is unique to each person, it may be a case of ‘trial and error’.

Foods that may affect pouch function

<table>
<tr><th>May increase output</th><th>May decrease output</th></tr>
<tr><td>Beans
Beer
Caffeinated beverages
Chocolate
Leafy green vegetables
Raw fruits and vegetables
Spicy foods
Potatoes
Cereals
Alcohol
Citrus fruits and juice</td><td>Apple sauce
Bananas
White boiled rice
Cheese
Creamy smooth peanut butter
Tapioca
White bread
Potatoes
Suet pudding
White pasta</td></tr>
<tr><th>May cause anal irritation</th><th>May increase wind</th></tr>
<tr><td>Coconut
Nuts
Oriental vegetables
Some raw fruits or vegetables (e.g. Oranges, apples, coleslaw, onions celery, corn)
Citrus fruits and juices
Food containing bran</td><td>Beer
Carbonated drinks
Dried beans and peas
Milk and milk products
Onions
Salad
Vegetables in the cabbage family</td></tr>
<tr><th colspan="2">Foods which on rare occasions have blocked flow into the pouch:</th></tr>
<tr><td colspan="2">Mushrooms, Sweetcorn, Potato/Raw fruit skins, Nuts, Seeds, Pineapple</td></tr>
</table>

As you will be aware, dietary tastes, requirements, tolerance, and effects of digestion differ for each individual. Providing dietary advice is difficult unless you have very specific requirements or problems when specialist dietary advice should be sought from a dietician. It is important to remember that following IAP surgery, the digestive process remains the same. However, dietary adjustment can help influence pouch function.

As a general guide, new foods should be introduced slowly and in smaller amounts and one at a time, to enable affect to be assessed. Don’t discount foods which may initially affect pouch function as over time, as the pouch settles, they may be better tolerated. Ultimately some adjustment in diet is likely.

Try to eat main meals at regular times, eat at a steady rate chewing your food well. Don’t rush, skip or leave long periods between meals as this may increase wind production causing bloating. Eating smaller, more frequent meals can be helpful if you are unable to eat or tolerate larger meals.

If food travels through your bowel quickly, try only drinking small amounts of fluid with your meals. Drinking large quantities of fluid with meals speeds up food transit, therefore reducing digestive ability and increasing pouch function as stool is a looser consistency.

It is important to ensure good hydration. Remember that tea, coffee and alcohol DO NOT count as liquids for hydration as they may contain caffeine which is a stimulant, and are therefore likely to loosen stool and increase frequency, leading to dehydration. Some patients require rehydration fluids, your medical team, dietitian and pouch nurse can discuss this with you if this is required.

While you are still in hospital, the medical and nursing staff will initially want to monitor your fluid intake and also your pouch activity. This is to ensure that your fluid intake is enough to compensate for your output, to ensure that you do not become dehydrated. The doctor may prescribe Loperamide (imodium), a drug used for the symptomatic relief of diarrhoea that will slow the bowel and help thicken stool and reduce the number of visits to the toilet.

Discharge from hospital

Once you have achieved adequate pouch function, diet and mobility we will start to discuss your discharge home. Your pouch function will continue to improve once you are home but remember it takes many weeks to settle and can take up to a year to have optimal pouch function.

Growing older with your pouch

Some of our pouch owners are now 80+ years old and many still have a well functioning pouch. It has been identified through surveillance that some people with internal pouches can have iron and Vitamin B12 deficiencies.

There is some concern that in older people the anal sphincter or anal continence muscle possibly becomes weaker; there may be problems with pouch function and continence. There is no definite evidence to suggest that this is the case so far, however an increasing number of older patients have good pouch function. If you experience any problems with incontinence, it is advisable to speak to the pouch nurse as they will be able to discuss potential causes and advise you on some pelvic floor exercises to try and strengthen the muscles that control continence, as well as other methods to help improve the situation.

Chapter 4: Sex and relationships

Most people report experiencing a temporary loss of sex drive (libido) after any illness or operation, due to the anxiety and stress of surgery. This is quite common and in time should return to normal. Your surgeon and pouch nurse will explain the risks involved in pelvic surgery. If appropriate to you, it is important that you and your partner share time talking about your feelings. This will help you both to relax more and enjoy having sex when you are ready. It is advisable to empty your pouch before you start any intimacy.

Pre-operatively, if you are concerned about the small risk of potential impotence, if relevant to your anatomy, following pelvic surgery please discuss your concerns with your GP, surgeon, or pouch nurse. If necessary, they can refer you to your local fertility clinic for sperm banking (this may incur separate costs to you). After pouch surgery the nerves that control erection and ejaculation can be affected. If you are experiencing difficulties in achieving or sustaining an erection, please give yourself time to recover from surgery. If the problem continues, please discuss with your surgeon, pouch nurse or GP as there are treatments available to help improve the situation.

Following pouch surgery some report experience of altered nerve sensation, reduced ability to climax and/or dyspareunia (pain during sexual intercourse). Nervousness and anxiety can make you tense, so having sex may be more painful and the vagina, if relevant to your anatomy, can become dry. The more relaxed you can be the better. The use of lubricating gel into the vagina can be helpful. If discomfort does not resolve, medical advice should be sought to investigate further. If appropriate, the use of vaginal dilators may be helpful.

Please do not feel embarrassed to talk about sensitive issues with your pouch nurse or other healthcare professionals.

Chapter 5: Contraception, fertility, pregnancy and childbirth

Contraception

The oral contraceptive pill (‘pill’) is usually absorbed in the duodenum (part of the small bowel). However, due to the possible faster transit of foods through to your pouch, the pill may not be as well absorbed and be less effective for you. This may also be the situation with the morning after pill. There are alternative methods of contraception that may be more suitable to you.

The intra-uterine coil device (IUCD), referred to as IUD under the NHS site or coil or copper coil, is a contraceptive device placed inside the uterus. Although infection rates from this are minimal, there is a small risk that if an infection did occur, it may affect your pouch. Please consult your GP or pouch Nurse to discuss contraception in further detail if you have any concerns.

Fertility

Having an IAP can reduce the chances of getting pregnant. This is known as fecundity. It ultimately does not affect your fertility but may limit your ability to conceive. It is advisable to discuss this in greater detail with the surgeon and pouch nurse, especially if you have not yet completed your family or are concerned about this issue. It may be desirable to defer your pouch surgery until after you have completed your family. If you are having difficulty conceiving, referral to an obstetrician in conjunction with your surgeon should be undertaken.

Pregnancy and childbirth

During pregnancy, the frequency of pouch emptying may increase as the pregnancy progresses. This is because the baby takes up space inside the abdomen, putting pressure on your pouch.

Discussion between the option of vaginal or Caesarean section childbirth delivery methods should be undertaken between the obstetrician, surgeon, and pouch nurse to enable an informed decision by you. In Oxford, a Caesarean section rather than a vaginal delivery is advised. This is to avoid the risk of damaging the anal sphincter and the adjoining muscles that can occur with vaginal births. These muscles are important in maintaining continence.

Chapter 6: Complications and investigations

Pouch owners generally agree that they have an improvement in their quality of life with a pouch. However, some people may experience pouch problems immediately or problems can happen many months or even years later.

There are different reasons why your pouch may be misbehaving. The surgeon or pouch nurse may suggest some medicines or supplements that could help you.

Medications

Analgesia (pain killers)

There are a wide variety of analgesia available, from Paracetamol to opioid based drugs. Some people use codeine-based analgesia to reduce pouch function but this needs to be taken with careful guidance as these can be addictive.

Reduce/slow bowel transit

Loperamide (Imodium) reduces bowel transit, therefore slowing bowel function and helps to thicken stool. Loperamide is available as a tablet/capsule/liquid, or a form which dissolves on your tongue (called melts or instants). If you notice that the tablets/capsules that you are taking are coming out into your pouch, this indicates that Loperamide is not released effectively. If this occurs, contact your doctor as your antidiarrheal medicines are also available as liquid forms e.g., Imodium oral solution. Dosage depends on the type of preparation, and you as an individual, as everyone reacts differently. It is advisable to start with a low dose and increase, dependent on affect. A larger dose, taken at specific times for you, can be used to specifically influence function, e.g., pre-bedtime to reduce pouch function overnight.

Also, take Loperamide at least 30 minutes prior to meals as it starts to slow digestion prior to eating. Do Not exceed the maximum recommended dose without seeking advice from a medical practitioner, e.g., your surgeon, gastroenterologist or GP. Read the instructions on the label of the box/container. Additional information about Loperamide can be read on NHS Website: www.nhs.uk/medicines/lopermide/.

Metamucil (this is an American product which can be bought over the counter in the UK as Ispaghula husk/Psyllium e.g., Fybogel fibre supplements which has 3.5g Ispaghula husk) can be taken to quieten the gastro-colic reflex of your gut, therefore slowing everything down and bulking up your stool. It is a bulky laxative and has to be taken with water 30 mins to 1 hour before other medications. The anti-depressant, Amitriptyline, can be taken at a low dose to have a similar reaction. Speak to your surgeon/ gastroenterologist or GP for more information.

Treat inflammation (otherwise known as pouchitis and cuffitis)

Treating inflammation will be dependent on cause. Therefore, any signs or symptoms of inflammation should be discussed with your pouch nurse, GP or consultant and then treated appropriately under full medical guidance. The most common reasons for inflammation are cuffitis or pouchitis. The ileo-anal pouch is attached to the cuff of the rectum (please note some surgeons do not leave a cuff, to be certain discuss this with your surgeon) just above the anal sphincter, cuffitis occurs when this cuff becomes inflamed. Pouchitis occurs when the pouch lining becomes inflamed.

Treat cuffitis: It is advisable to ask your pouch nurse, surgeon or inflammatory bowel disease specialist teams what to do if this is suspected. A topical local anaesthetic gel or topical steroid cream/ suppository may be recommended.

Treat pouchitis: It is advisable to ask your pouch nurse, surgeon or inflammatory bowel disease specialist teams what to do, if pouchitis is suspected there is an OUH Pouchitis protocol available, advising on the correct pathway and antibiotic cover recommended.

Rehydration fluids

Referred to as isotonic fluids e.g. Lucozade Sport usually with half a teaspoon salt to each 500ml bottle (or as advised by the medical team).

Vitamins and minerals supplements

Eating a varied balanced diet should provide you with all the vitamins and minerals required, provided you have a reasonably good pouch function. If you experience a constantly looser stool, you may be at risk of deficiencies. Blood tests should be able to determine this. Specialist dietary advice can be sought from a dietician. Supplements can be used to boost vitamin and mineral levels.

Use of Hagar dilator or medina catheter

After medical consultation, if a patient has a narrowing in the pouch-anal join, and experiences some difficulty in emptying their pouch, they may be advised to try a medina catheter (under the support and guidance of their pouch nurse) to help in draining the pouch.

There are many different lubricating gels available to use to lubricate a medina catheter. Some patients will be advised on use of a dilator, which can be used to stretch a tight pouch-join. This should only be used under the support and guidance of the pouch nurse.

Tests and investigations if you have pouch problems

In some cases, diagnostic tests need to be undertaken to determine a cause of the problem.

The most common problems can be because of an infection, inflammation of your pouch (pouchitis), an inflammatory bowel disease such as Crohn’s Disease or a sinus or fistula where a channel may have developed in or around your pouch.

Your surgeon, gastroenterology team or pouch nurse may suggest that you need to undergo various tests to determine what is going on with you and your pouch. These may include:

Blood tests

You will be asked to undergo a blood test which will assess your state of health and highlight any problems, which may result in more tests or treatments that can correct any nutritional deficiencies.

Digital examination

Your surgeon may need to check your back passage for any problems. They will ask you to lie on your left side and they will insert a lubricated finger into your back passage. This test should only take a few seconds to do.

Pouchoscopy

This is an endoscopic procedure where a doctor or specialist endoscopist inserts a thin, flexible tube, with a small camera on the end, into your pouch to visualise the inside. During this procedure they may need to take samples (biopsies) of the pouch lining to diagnose any concerns.

Frequency of pouchoscopy

Within the pouch clinic we will discuss with you about what surveillance you require and whether you require a routine pouchoscopy. They are dependent on why you required a pouch and if you have any symptoms. Some patients require annual surveillance pouchoscopy to check that it is all healthy.

If you live outside of Oxfordshire, the pouchoscopy may be able to be performed locally, with the request being undertaken by your GP.

Contrast pouchogram

This is a radiology (X-ray) procedure to visualise the inside of your pouch. A doctor or specialist inserts a dye (contrast) into your pouch or veins. This dye can be seen moving through the pouch on a screen and can highlight any problems within your pouch.

Small bowel Barium enema and follow-through (Barium examination)

This is an X-ray examination of your small bowel in which a doctor or specialist will insert a dye or ask you to drink the dye (contrast). This dye flows down your gastrointestinal system, revealing any problems in your small bowel through to your pouch.

Magnetic Resonance Imaging (MRI) pelvis

This is a scan which uses strong magnetic fields and radio waves to visualise the inside of your body. It looks for problems within or around your pouch.

Computerised Tomography (CT) or Ultrasound (US)

This scan uses X-rays to build up a picture of the inside of your body, that can highlight any problems within or around your pouch or abdominal area. An Ultrasound uses sonic (sound) waves to create an image of your pouch.

Abdominal and pelvic X-ray

These are non-invasive tests which create images of the selected area of your body using X-ray radiation and a detector plate.

Anorectal physiology

There are muscles in your back passage called anal sphincters, which control the continence of stool. This test can assess the strength of these muscles and nerves around the anus and can detect any abnormalities.

Examination Under Anaesthetic (EUA)

This is a minor procedure where your surgeon investigates your pouch under general anaesthetic. They may be able to identify and repair some problems during this procedure.

In some cases, when all options have been explored, your surgeon may decide with you that further surgery is required to remove the pouch completely or divert the pouch with a temporary or permanent stoma (loop ileostomy).

For further information and department locations, please use the department directory on the Oxford University Hospitals NHS Foundation Trust website:

www.ouh.nhs.uk/services/departments

Alternatively, you can find more information about your test on the NHS website:

www.nhs.uk

Chapter 7: Lifestyle

Deciding when to return to work post-surgery is an individual decision. Initially you may feel tired and if you have a physically active job and care should be taken until a full recovery has been achieved. If your job involves lifting, pulling, pushing, or stretching, then it is best not to return to work for at least 6 to 12 weeks, and possibly ask for lighter duties or reduced hours to begin with. However, you can return to work whenever you feel ready.

A gradual return to your normal lifestyle is recommended. Many patients with an IAP can lead a “normal” lifestyle, undertaking a wide range of activities or travel as they did prior to their surgery. We encourage our patients to lead a fulfilling life.

Driving

Most insurance company policies state that you are not covered to drive for 6 weeks after abdominal surgery; please check your own policy for exact details. After this period and if you can safely perform an emergency stop, with no pain from surgery when doing so, you should be safe to drive, although care should still be taken. You will also need to consider any medication you are taking and whether this may impair your driving safety. Ultimately if you are not safe to drive it may invalidate your insurance policy.

Travel and holiday information

The best advice is to be prepared. Think about the journey or holiday that you are taking and if you are concerned and need further advice discuss this with your pouch nurse or surgeon. Remember, the overall aim is to enjoy yourself!

Before you set out:

- When seeking travel insurance, ensure that you state your pouch and why you had this surgery, e.g., for Ulcerative Colitis (a pre-existing medical condition may need to be mentioned and checked that this is covered).
- Ensure you have a supply of Loperamide (Imodium) and re-hydration sachets in case of diarrhoea and a course of antibiotics (e.g., Ciprofloxacin or Metronidazole) in case you experience the symptoms of pouchitis.
- Have a prepared pack containing moist wipes, toilet paper, barrier cream and pads (+ anything else that you use on a daily basis). Keep this in your hand luggage.
- Booking an aisle seat allows easy access to the toilets.
- Book rooms with an en-suite toilet.
- If driving, plan your route to ensure access to toilet facilities.
- Carrying an IA pouch information card is useful and reassuring in case of illness or accident. Some people may want to wear a Medical Alert tag.

When travelling

Choose your food carefully – plan a sensible meal before you leave that will help to reduce your pouch function. It is sensible not to eat just before you leave.

Reduce intake of caffeine

Limit your intake of carbonated drinks prior to and during flying. On a flight, you can feel quite bloated due to cabin pressure which can lead to increased discomfort and more frequent trips to the toilet.

Try not to eat foods rich in fibre, as they can increase pouch activity, therefore increasing the frequency of trips to the toilet.

When abroad

Be careful what you choose to eat. Care should be taken with ice cubes and foods washed in local water.

Dependent on location, drinking bottled water may be advisable. Choose food that have been freshly prepared and well cooked. Be careful with food that may have been standing on hot plates for long periods of time.

Ensure you maintain your hydration. This is particularly important in hotter climates. Therefore, increase fluid intake, the use of isotonic fluids is useful.

Remember tea, coffee and alcohol **do not** count as liquids for hydration as they may contain caffeine, which is a stimulant, and are therefore likely to loosen stool and increase frequency, leading to dehydration.

Carrying a copy of your medication prescription will help validate and explain any medications you carry.

Remember pouch owners do successfully travel Nationally and Internationally. A little forward planning will help ensure that you experience an enjoyable holiday.

Sport and exercise

Returning to sport and exercise is possible, but you will need to take it gently at first, taking some time to recover from your surgery. How long will depend on how fit you were pre-operatively, how active the sport and how strong you are feeling; your overall fitness may have reduced. Many people find it is 4 to 6 weeks before they feel able to get back into sports and exercise.

Returning to sport and exercise can be one of the goals that you set yourself to help in your recovery and integrate back into your normal lifestyle. However, it is important to remember to initially reduce the intensity of the activity, be it cardiovascular or weights/resistance, then slowly increase it as your fitness and strength returns. If you go to a gym, the instructors should be able to assist you with this process.

It is important to be aware that certain sporting activities need to be entered into with a degree of caution. It depends on your level of experience as there are sporting professionals competing at National or International level with an IAP.

Water skiing can have an enema effect on some people, so wearing a wet suit may be advisable. Scuba diving is slightly different and you will need to seek advice before returning to this sport. You must be able to pass wind easily to scuba dive with a pouch. If you have any problems passing wind, please seek advice from a doctor who is certified to perform Diving Medicals.

The British Sub Aqua Club:

www.bsac.com/home

SSI:

www.divessi.com/en/home

PADI:

www.padi.com

Restrictions and necessary medical permissions for diving may differ in each country. Check if there are any specific regulations or compulsory documents for that country before you travel.

Any exercise that will make you sweat profusely will necessitate fluid replacement. Maintaining good hydration is vital. Drinking lots of plain water is counterproductive, as this has a negative osmotic effect on the body, loosening stool consistency which results in dehydration. Therefore, drinking a mix of different fluids is required. Signs of dehydration may include: dry mouth, increased thirst, light-headedness, fatigue, headache, muscle cramps and reduced urine output. Therefore, hypotonic drinks like water, tea, coffee and fizzy drinks should be limited to 500 to 1000ml per day (unless your doctor advises you otherwise) and be balanced or replaced with isotonic oral solutions instead. If you experience dehydration, the use of oral isotonic fluids should be used as explained previously.

Many people find that having had pouch surgery provides them with a new lease of life as they no longer have the effects of their illness to contend with. Participating in sport and exercise can be seen as a method to recovery, but eventually it can be part of just living life to the full. It is also known that sport and exercise can benefit and improve our mental health.

FAQ

Hopefully, your questions about the IAP have been answered. However, there are some useful FAQ, written by patients, within the ‘Kangaroo club’ support group website for pouch patients: www.kangarooclub.org.uk which you may find useful to read.

Feedback

Your opinions and views are important to us. Please ask us about the NHS Friends and Family Test which gives you the opportunity to tell us what we did well and what we can do to improve. You can also have an informal conversation at any point if there is something you would like to ask or tell us about.

Chapter 8: Useful contacts / charities/ support groups

To contact the pouch team in Oxford:

Email: colorectal.nursing@ouh.nhs.uk
Telephone: 01865 221 839 or 01865 235 367
For bookings/cancellations: Please refer to details at top of your letter.

IA - The Ileostomy and Internal Pouch Association Support group

Telephone: 0800 0184724
Website: www.iasupport.org
Email: info@iasupport.org

Kangaroo Club

For patients with internal pouches
Website: www.kangarooclub.org.uk

Talking Space Plus

Free NHS Talking Therapies for people in Oxfordshire. (Self referral)
Telephone: 01865 901 222
Website: www.oxfordhealth.nhs.uk/talkingspaceplus
There is a self-referral form through the website.

Radar Key Information:

R.A.D.A.R key company, 11 church street, Exmouth, Devon, EX8 1PE
Telephone: 01395 222 588
Email: sales@radarkeys.org
Website: www.radarkeys.org

Which consumer magazine info on RADAR key:

www.which.co.uk/later-life-care/home-care/out-and-about/radar-keys-and-locked-toilets-apsxd1p6br8k

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My notes and questions

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Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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May 2024
Review: May 2027
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Leaflet reference number: OMI 92437