

Considering whether to have ileal pouch surgery

A guide for ulcerative colitis patients



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What are the main points I need to know about *ileal pouches*?

- This booklet is written for patients with *ulcerative colitis* considering *colectomy* and/or *ileal pouch* surgery.
- An *ileal pouch* is made out of *small intestine* and acts as a substitute for the *colon* when it has been removed.
- The main benefits of *colectomy* are that it gets rid of the *ulcerative colitis*, reduces the need for medication and eliminates your risk of *bowel cancer*.
- The main benefits of an *ileal pouch* compared to a *stoma* are that it allows you to look “normal” and pass bowel motions “normally.”
- The benefits of staying with a *stoma* are avoiding the risks of pouch surgery and the medium to long term problems with an *ileal pouch*.
- The quality of life after *ileal pouch* surgery is similar to that of a *stoma*. Whether a person has an *ileal pouch* or permanent *stoma* is an individual choice based on personal preferences surrounding body image and the willingness to have extra surgery
- The *ileal pouch* is made using the *small intestine* and is usually done with two to three separate operations (including the *colectomy*), often with ‘keyhole’ surgery.
- After both *colectomy* and *ileal pouch* surgery, you can expect to be able to eat after 2 or 3 days and have a 5-7 day stay in hospital, unless you have complications.
- In the long term with an *ileal pouch*, you can expect to have 4-7 bowel motions per day and 1 at night. Some dietary modifications are usually necessary.
- Complications can happen in the short or long term, but are usually treatable.
- *Ileal pouches* are not for everyone. They are not necessary if your *ulcerative colitis* is already well controlled and young women may wish to avoid having an *ileal pouch* until they have completed their family because it can affect their ability to become pregnant.

These points above summarise what is in this booklet but if you want to know more details, you should keep reading.

Why am I reading this booklet?

There are a few potential reasons you may be reading this booklet:

1. You have *ulcerative colitis* and your doctor has asked you to consider having surgery to remove your *colon*; this surgery is called a *colectomy*. There are a few reasons *colectomy* may be considered:
 - a) you have poorly controlled disease, which is either not responding enough to medication or can only be treated with *steroids* (which are not good to use long-term) or;
 - b) you have a high risk of *bowel cancer* because you have had *ulcerative colitis* for a long time and/or have precancerous or cancerous signs or;
 - c) you need urgent surgery because your *colon* is highly inflamed and at risk of *perforating*.
2. You have already had a *colectomy* and are considering whether or not to remain with a *stoma* (an opening in your intestine with a bag attached to your stomach to collect your waste) or proceed with having what is commonly called *ileal pouch* surgery.

No matter which of the above scenarios applies to you, this booklet will contain some relevant information for you, such as the risks and benefits of *colectomy* and *ileal pouch* surgery, what an *ileal pouch* actually is, what to expect in the short and long term, what the risks and benefits of undertaking the *ileal pouch* surgery are, whether having an *ileal pouch* is actually better than having a *stoma*, and what factors you should consider when making the decision.

The information provided in this booklet is based on up-to-date research findings both from New Zealand, and globally. The references used for this booklet are provided at the end; the references are linked to the text in this booklet using ^{superscript} numbers (e.g., ^{1, 2, 3}, etc.). Also at the end of this booklet are some good online resources you can go to if you want more information to assist you making this important life-changing decision.

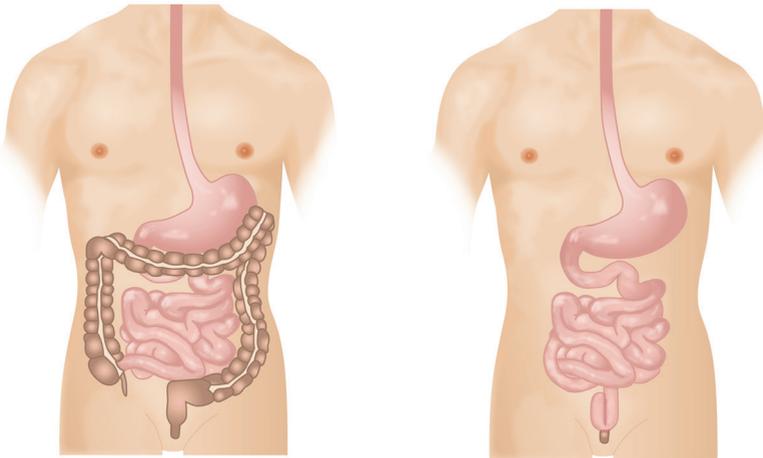
What if I don't understand a word or term in this booklet?

If you don't understand any of the technical terms in this booklet, you can check Table 1 at the end, which is a glossary. Any words that appear in the glossary will appear in *italics* in the main text of this booklet.

In addition, Tables 2 and 3 outline the short- and long-term complications that can happen following *ileal pouch* surgery and so if you see a complication mentioned in this booklet that you do not understand, you can look it up.

What is an ileal pouch?

An *ileal pouch* is a surgically constructed internal (i.e. inside the body) reservoir for stool that is made out of the last part of the *small intestine*. The commonest type of *ileal pouch* is the *J-pouch*, which is called this because it is shaped like a J (as shown in Picture 1 below). See in Picture 1 that the *colon* has been removed on the right. In effect, the *ileal pouch's* job is to do what the *colon* used to (i.e. store stool). The steps involved in making the *ileal pouch* are described below.

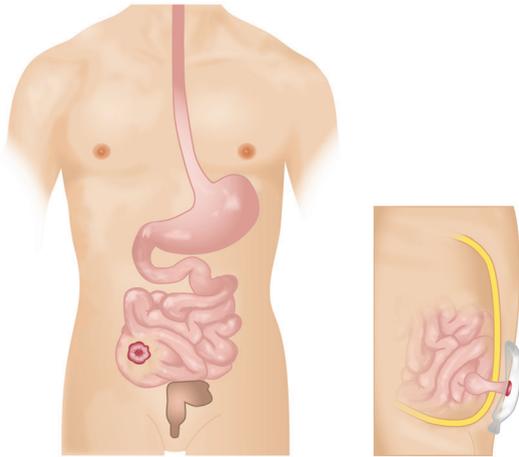


Picture 1: The *ileal pouch* on right (*colon* still intact on the left)¹

How is an *ileal pouch* made?

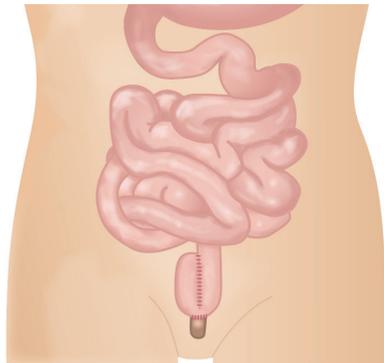
To remove the *colon* and obtain a fully functioning *ileal pouch* usually requires two or three operations, each performed some months apart:

- Operation 1: *Colectomy* and *end ileostomy* is the first step and normally takes 2-3 hours. The abdominal *colon* is removed, the *rectum* remains and the end of the *small intestine* is brought out as a *stoma* (see Picture 2). You wear a bag over the *stoma* to collect your stool and you will wear one of these until Operation 3 (described below) is complete.



Picture 2: **Colectomy** and **ileostomy** resulting in **stoma**

- Operation 2: *Ileal pouch* formation and *defunctioning ileostomy* is the second step, usually performed 3-6 months after Operation 1 to allow recovery from the *ulcerative colitis*. Once again it takes 2-3 hours. The *J-pouch* is created and joined to the low *rectum*/anal canal using a series of titanium staplers (see Picture 3). A *temporary ileostomy* is installed to collect the stool and allow the *ileal pouch* to heal without stool going through it. There is no maximum time limit for how long you can delay between Operations 1 and 2.



Picture 3: The **J-pouch** up close

- Operation 3: Closure of *ileostomy* is a less major procedure taking around one hour. Following this the *ileal pouch* begins to function normally and recovery from this surgery is much quicker than the above procedures. At least 6-8 weeks are required after Operation 2 before Operation 3 can take place. Picture 4 shows the expected leftover scars after *laparoscopic* surgery.



Picture 4: What scars will look like after all 3 operations are completed (1 and 2 *laparoscopically*)

If you are very unwell with *ulcerative colitis* at the time of initial surgery you will likely require the three stages described above to get to a functioning *ileal pouch*. If your condition permits, Operations 1 and 2 can be combined into one and then *ileostomy* closure can be performed as few as 6-8 weeks after this.

What are the risks and benefits of having a colectomy?

So as you can see, the first step towards an *ileal pouch* is deciding whether to have a *colectomy*. In some cases if your disease deteriorates acutely this may be necessary as an emergency lifesaving operation. In others, deterioration can be more gradual and the decision to proceed to *colectomy* rather than persist with medicines to treat the *ulcerative colitis* can be more difficult.

Some advantages of *colectomy*, regardless of whether you decide to have a permanent *stoma* or an *ileal pouch*, are:

- The *colon* is removed and so the *ulcerative colitis* is “cured.”
- There is a highly reduced likelihood of needing *immunosuppressant* medication, although this is not guaranteed.
- You can no longer get *bowel cancer*, which is at an increased risk in those with long term *ulcerative colitis*.

There are also some risks or disadvantages of having *colectomy*, regardless of whether you decide to have a permanent *stoma* or an *ileal pouch*. These include:

- The decision is irreversible; once your *colon* is removed it cannot be replaced.
- Major surgical complications after *colectomy* can occur including wound infection, bleeding, bowel obstruction and heart or lung problems. The frequency of these complications varies considerably depending on how well you are going in to the operation and your other medical problems. Therefore, the timing of *colectomy* can be crucial to your outcome and something to discuss with both your Gastroenterologist and Colorectal Surgeon.

What are the benefits of having an *ileal pouch* compared to a *stoma*?

Once you have had your *colectomy*, you will have a choice between staying with a *stoma* or progressing to an *ileal pouch*. You can stay with a *stoma* in the long term and many people choose this option. However, further surgery is often still required to remove the *rectum* if this wasn't done during the original *colectomy*.

The benefits of having an *ileal pouch* as opposed to a *stoma* are:

- You get to pass bowel motions in the “normal” way.
- How your body looks remains “normal.” It is impossible to tell if a person has an *ileal pouch* by looking at them (apart from abdominal scars from surgery, perhaps).
- You maintain the ability to wear normal clothing; finding compatible and comfortable clothing options might be an issue for some people with a *stoma*.
- There will be no need to change your *stoma* bag at least twice a week.

It may seem self-evident to some people that having an *ileal pouch* is better than having a *stoma*. However, studies have shown that the quality of life of people with *stomas* is, on average, the equivalent of those with *ileal pouches*.¹

Both *ileal pouches* and *stomas* are associated with their own set of risks. *Ileal pouch* risks are well documented in this booklet but note that in up to 50% of people, *stomas* are also associated with problems in the long-term such as hernias, prolapse, bowel obstruction, narrowing, leakage from bags, skin excoriation (i.e. red irritated skin) and dehydration. This is very much an individual decision that is influenced by your personal preferences regarding body image, bowel function, type of employment, types of hobbies, and your willingness to undergo the extra surgery required for an *ileal pouch* relative to a *stoma*. This decision is a personal choice and the information provided below will assist with this.

What can I expect early on if I get an *ileal pouch*?

After *ileal pouch* formation (i.e. Operation 2) but before *ileostomy* closure (i.e. Operation 3), you will have a *stoma* with bag to give the *ileal pouch* time to heal. After both *colectomy* and *ileal pouch* formation, you can expect to be able to eat after 2 or 3 days and have a 5-7 day stay in hospital; this is assuming there are no significant complications (described in Table 2) during or soon after the operation. Post-operative pain is effectively dealt with using local anaesthetic catheters, as well as spinal and intravenously administered morphine. By discharge you will be able to manage your *stoma* bag independently, be fully mobile and be able to do basic things for yourself. After discharge, you will need around 3-6 weeks off work (in particular heavy lifting). You will have the *stoma* with bag for at least 6-8 weeks after Operation 2 depending on individual circumstances.

Fortunately, both *colectomy* and *ileal pouch* operations can be performed with *laparoscopic* (“keyhole”) surgery if your surgeon and team has sufficient expertise and experience with this technique. This results in much smaller incisions with less pain, quicker recovery and a better cosmetic result.

Once the closure of *ileostomy* (i.e. Operation 3) is performed, you can expect to start off with very frequent bowel motions per day and for the functioning of your *ileal pouch* to get progressively better as time goes by with improvements for up to a year after surgery.

What can I expect long-term if I get an *ileal pouch*?

As time passes, you can expect the function of your *ileal pouch* to improve; most patients will have an average of 4 to 7 bowel motions, ideally with a porridge like consistency, per day. It should take 6-12 months after Operation 3 for it to reach a steady state. Some patients will need to regularly get up during the night-time to empty their *ileal pouch* although you can take an antidiarrheal tablet (e.g., loperamide) to slow down your bowel motions at night time. Mild incontinence is possible with an *ileal pouch*, especially when asleep; the *ileal pouch* patient can wear a small pad if this is a problem.

The encouraging thing is that *ileal pouch* patients usually report a very normal quality of life a long time after *ileal pouch* surgery and whilst complications (especially pouchitis, strictures, and perianal disease which are described in Table 3) are more likely to occur as more time passes, there is nothing to suggest that an *ileal pouch* only has a limited lifespan; indeed many patients in a Canterbury study have lived with an *ileal pouch* for more than 20 years and still have a normal functioning *ileal pouch*.² On the other hand, not all people have a perfect outcome due to complications; these are described below.

What are the risks of having an *ileal pouch*?

While an *ileal pouch* allows for removal of all bowel involved with *ulcerative colitis* (except for the final 2cm of *rectum*) and maintenance of continence, it involves major surgery of which there is the potential for complications.

Complications are most frequent near the time of surgery but can also occur many years later. The complications that can happen near the time of surgery are described in full in Table 2 at the end of this booklet and the complications that can happen a long time after surgery are described in Table 3 (note that some complications can happen at any time and so appear in both tables). You can choose to read these tables if you want to know all the potential complications and/or understand more about the complications mentioned below.

If you do read the tables, please note that most complications are not overly common (i.e. less than 20%) and so you should try not to be too anxious about them and remain open-minded about having *ileal pouch* surgery.

Major complications that can occur in hospital soon after the surgery are pelvic sepsis, haemorrhage, or anastomotic leak (see “Leak” in Table 2) but all are quite uncommon, happening in less than 10% of cases. Death resulting from surgery is very rare (in less than 1%) and will generally occur because of a secondary underlying condition in addition to the *ulcerative colitis*.

The most common long-term complication is pouchitis which can be treated with antibiotics (to gain remission) and probiotics (to maintain remission). Another complication to be aware of is reduced fertility in women; traditional *ileal pouch* surgery triples the risk of infertility and half of women with an *ileal pouch* are unable to become pregnant. Note this risk may be reduced with *laparoscopic* surgery^{3,4} and most women with this complication will respond to fertility treatment.⁵ In some cases, women may defer *ileal pouch* surgery until their family is complete. Men can get erectile dysfunction or retrograde ejaculation but this risk is not as pronounced as infertility in women.

Fortunately, most long-term complications have good treatment options. This includes small bowel obstruction which is most often managed conservatively (i.e. waiting for the obstruction to pass), and occasionally with further surgery. Moreover, stricture can be treated using dilators at home or, in more serious cases, with dilation under anaesthetic. Cuffitis can happen and has symptoms that mimic pouchitis; this is usually successfully treated with topical *steroids* or *5-ASAs*.

Despite these good treatment options, pouch failure, which happens when the *ileal pouch* needs to be diverted or removed, can sometimes occur. Common causes of pouch failure are the diagnosis of *ulcerative colitis* being changed to *Crohn's disease*, fistulae, and pelvic sepsis. The risk of pouch failure over many years is around 10% for *ulcerative colitis* patients. A failed pouch means reverting to a *stoma*, the default position if *colectomy* is performed without an *ileal pouch*. There is some evidence that people with failed pouches do not have lower quality of life than those with functioning pouches.²

Who should avoid having an *ileal pouch*?

You should consider having an *ileal pouch* if you have poorly controlled *ulcerative colitis*; there is no need to consider having an *ileal pouch* if you have well controlled *ulcerative colitis* unless your doctor determines you are at high risk of developing *bowel cancer*. Caution needs to be exercised in patients with *Crohn's disease* and pouches can only be used in special circumstances where the *Crohn's disease* has not affected the small bowel or perianal region. Lastly, young women may wish to avoid having an *ileal pouch* until they have completed their family because it can affect their ability to become pregnant,⁶ although about half of women with *ileal pouches* can become pregnant⁷ and early studies do suggest that having *ileal pouch surgery laparoscopically* may negate some or all of the risk of infertility from surgery.^{3, 4} Please note that it is not the *colectomy* (i.e. Operation 1) per se that leads to increased risk of infertility but rather the removal of the *rectum* involved with Operation 2 that leads to the increased risk. Therefore, some females may wish to delay Operation 2 until they have completed their family.

What food can I eat with an *ileal pouch*?

There is no special diet for a patient who has undergone the *ileal pouch* operation. There are some foods which may cause difficulty, such as an increase in the number of bowel movements, anal irritation and/or increased gas. These are listed below, as well as foods that may decrease output or control diarrhoea. Most patients can tolerate a variety of foods without difficulty. It is best to add foods to your diet gradually. You will then be able to know how specific foods affect your bowel movements. Also remember to drink plenty of fluids every day.

Foods that may increase output or cause diarrhoea:

Lettuce, cabbage, caffeine, spicy foods, raw fruit, broccoli, beans, chocolate, and beer.



Gas producing foods and drinks:

Milk, dried beans and peas, strong cheese (Roquefort, Blue), melons, asparagus, onions, nuts, beer, carbonated drinks, broccoli, cabbage, and cauliflower.



Foods that may cause anal irritation:

Popcorn, spicy foods, nuts, coconut, raw vegetables, foods with seeds, and oriental vegetables.



Foods that may decrease output or control diarrhoea:

Bananas, porridge, low fat cottage cheese, white rice, mashed potatoes, and creamy peanut butter.



Where can I look for further information?

There are many places to find further information and perhaps even network with people who have *ileal pouches*. These include:

- jpouch.org
- dennisfrolich.com/ucvlog.html
- www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease/publications/surgery-for-ulcerative-colitis
- crohnsandcolitis.org.nz

Explanatory Tables

Table 1: Technical terms glossary

| Term | What is the term related to | Definition |
|-------------------------|-----------------------------|--|
| 5-ASA | Medication | This is a topical drug used to treat ulcerative colitis. It can be taken orally or rectally. |
| Bowel cancer | Disease | This can also be called colorectal cancer. It is cancer of the bowel that ulcerative colitis patients are at increased risk of getting. Among other things, it can cause symptoms like blood in stools, change in bowel habit, stomach pain, lumps in the abdomen, and weight loss. |
| Colon | Body part | Colon can also be called the large intestine and is the organ most affected by ulcerative colitis. |
| Colectomy | Surgery | This is removal of the colon by a surgeon. It precedes the ileal pouch surgery in ulcerative colitis patients. |
| Crohn's disease | Disease | An inflammatory bowel disease which can occur in any part of the gut, including the small intestine and anus, and not just the colon like ulcerative colitis does. Sometimes the diagnosis can get changed from ulcerative colitis to Crohn's disease a relatively long time after surgery. |
| Defunctioning ileostomy | Surgery | This is an ileostomy that is installed as a way of diverting stool away from the normal path which is usually temporary. |
| End ileostomy | Surgery | This is an ileostomy that occurs at the end of the small intestine. This is in contrast to a loop ileostomy which occurs before the end of the small intestine. |
| Ileal pouch | Surgery | Short for "restorative proctocolectomy with ileal pouch-anal anastomosis", this is a surgery often performed for ulcerative patients wherein the end of small intestine is remade as a pouch and does the job the colon used to before it was removed. The commonest type is the "J-pouch" which is called this due to its shape. Other types include the "W-pouch" and "S-pouch." |

| | | |
|---------------------|--------------|---|
| Ileostomy | Surgery | A surgical operation in which the small intestine is brought outside the abdominal wall via an artificial opening called a stoma. |
| Immunosuppressant | Medication | A drug used to slow down the immune system. Because ulcerative colitis may be caused by an overactive immune system, immunosuppressants can be useful for its treatment. Examples include azathioprine, infliximab, adalimumab, and cyclosporine. |
| J-pouch | Surgery | The commonest type of ileal pouch (see above). It is called this because it is shaped like a "J." |
| Laparoscopic(ally) | Surgery | Also called 'keyhole surgery' where the belly is inflated with gas to create a working space and the surgery done via small cuts with long thin instruments. |
| Perforating | Complication | Perforation of the colon occurs when the ulceration is so deep that holes appear in the colon. This is a very serious situation and requires urgent medical attention. |
| Rectum | Body part | The final section of the large intestine, terminating at the anus. It is about 12cm long. |
| Steroids | Medication | Steroids are medications (e.g., prednisone) commonly used to treat ulcerative colitis and work by immunosuppression. They can be topical or systemic. Due to their bad side effects, their use should be limited as much as possible. |
| Stoma | Surgery | In the context of ulcerative colitis, a stoma is the artificial opening on the abdomen that is created when an ileostomy is made. |
| Temporary ileostomy | Surgery | An ileostomy that is intended to be reversed in the future. |
| Ulcerative colitis | Disease | A disease that causes ulceration in the colon and sometimes requires the patient to have their colon removed. |

Table 2: Detailed description of complications that can happen soon after ileal pouch surgery (most common at top and least common at bottom)

| Name of complication | How common is it | When it can happen | Description and Symptoms | Treatment or prevention options |
|-------------------------|--|--|---|--|
| Small bowel obstruction | 15 to 44% overall and 5 to 20% requiring surgical intervention. ⁸ | Half of small bowel obstructions will occur in the first 30 days after surgery and half will happen in the long-term. ⁹ | Small bowel obstruction is the term used to describe when there is a blockage in the small intestine that is keeping food or liquid from passing through. The symptoms include abdominal pain or cramping, nausea, vomiting, diarrhoea, constipation, inability to have a bowel movement or pass gas, and swelling of the abdomen. | Depending on the severity, treatment options include conservative management (most commonly) or further surgery (rarely). |
| Leak | 5-18%. ⁸ | Detected immediately following surgery | Leaks may develop from the pouch-anal anastomosis (called “anastomotic leak”), from the pouch itself, or from the tip of the J pouch. An anastomotic leak occurs when there is leakage of bowel content from the staple lines of the ileal pouch. Patients with a leak that has developed into an abscess present with abdominal pain, fever, an elevated white blood cell count, or a combination of these symptoms. ¹⁰ | Treatment options include antibiotics, bowel rest, putting in a drain, and further operation. ⁸ |
| Anal stricture | 8 to 14%. ⁸ | Can happen soon after surgery but more common in the long-term after surgery. | This is a narrowing of the anus often caused by scar tissue from the surgery. Symptoms include pain with bowel movements, bleeding, difficulty evacuating stool, constipation, and a feeling of anal discomfort. | Sometimes a finger dilation is all that is required and other times the patient can be given something called a Hegar dilator to take home and gradually dilate mild strictures. In more severe cases of stricture, surgical intervention may be needed. |

| | | | | |
|-----------------------------|----------------------------|---|--|---|
| Pouch fistula | 2.6%–14%. ^{8, 11} | Can happen soon after ileal pouch surgery or years after surgery. | This is an abnormal connection or path between the pouch and another part of the body (e.g., pouch-vagina, pouch-anus). | Drainage and occasionally further operations to repair the fistula |
| Pelvic sepsis | 5–20%. ¹² | Usually happens soon after surgery but can occur in the long-term after surgery | This is an infective process in or near the ileal pouch. Symptoms include fever, perineal pain, discharge of pus, and increased white blood cells. ⁸ | Antibiotics and drainage |
| Perianal abscess or fistula | 7.4%. ¹³ | Can happen soon after surgery but more common in the long-term after surgery. | A collection of pus near the anus that can coincide with being a fistula (i.e. abnormal connection between pouch and anus). Symptoms include pain when sitting or moving bowels, skin irritation, discharge of pus, fever, chills, and malaise. | For abscess, drainage followed by antibiotics. For fistula, fistulotomy (i.e. surgical opening of the tract), seton drain insertion, or a transanal mucosal advancement flap can be used. ⁸ |
| Wound infection | 7.2%. ¹⁴ | Will only happen immediately post-surgery; not long-term. | This is an infection of where the surgeon has put incisions. Symptoms include pain and redness around the area, drainage of pus, and fever. | Antibiotics +/- drainage. |
| Haemorrhage | 3.6%. ¹⁴ | Happens immediately following surgery. | This is severe bleeding. | Blood transfusion or further surgery is very occasionally necessary. |

| Name of complication | How common is it | When can it happen | Description and Symptoms * | Treatment or prevention options |
|--------------------------------|----------------------------|---|--|---------------------------------|
| Death | Less than 1%. ⁸ | Happens during or immediately following surgery | Please note this complication is very rare and will often be because the patient has more problems than just the ulcerative colitis. | Not Applicable. |
| Major Heart/Lung Complications | Less than 1% | Happens during or immediately following surgery | Problems such as blood clots in the lungs, pneumonia and heart attacks can occur after surgery but with adequate prevention are very rare events in ulcerative colitis patients. | Not Applicable. |

*sources include www.mayoclinic.org and www.webmd.com

Table 3: Detailed descriptions of complications that can happen a long time after ileal pouch surgery (in no particular order)

| Name of Complication | How common is it | When can it happen | Description and Symptoms * | Treatment or prevention options |
|------------------------------|---|--|---|--|
| Pouchitis | 23 to 46% 10 years after IPAA surgery. ¹² | Can happen years after ileal pouch is made. | Inflammation of the pouch causing symptoms like diarrhoea, abdominal pain and joint pain, cramps, fever, increased number of bowel movements, night-time faecal seepage, faecal incontinence, and a strong feeling of the need to have a bowel movement. Pouchitis can be acute (i.e. short term) or chronic (i.e. needing long-term treatment with anti- or pro-biotics) | The antibiotics metronidazole and ciprofloxacin are most useful for gaining remission. There is some evidence a probiotic called VSL3 can be used to keep the pouchitis in remission. ¹² |
| Reduced fertility in females | Female infertility increases from 15-20% before surgery to 50-63% after surgery. ^{6,7} | Will be caused during surgery but will be a lifelong complication. | This is the inability to bear children. It is probably caused by pelvic adhesions and scarring affecting the fallopian tubes. | Your ileal pouch may be put off until after you have completed your family but also note that fertility treatment post-IPAA is associated with good success rates. ⁵ Having the ileal pouch procedure performed laparoscopically may reduce the risk of infertility. ^{3,4} |
| Erectile dysfunction (men) | 0-14%. ¹⁵ | Can happen years after ileal pouch is made. | This is the inability to get and keep an erection firm enough for sex. Symptoms include trouble getting or keeping an erection and reduced sexual desire. | Responds well to standard treatments for impotence (e.g., sildenafil). |

| Name of Complication | How common is it | When can it happen | Description and Symptoms * | Treatment or prevention options |
|--------------------------------------|--|--|--|--|
| Retrograde ejaculation | 0-19%. ¹⁵ | Will be caused during surgery but will be a lifelong complication. | This is when your semen goes into your bladder instead of out of your penis when you ejaculate. Symptoms include dry orgasms, cloudy urine after sex, and infertility. | With the help of fertility specialists it is still very possible to father children in the presence of this complication |
| (Occasional) night-time incontinence | 25% to 47%. ¹⁴ | Can happen years after ileal pouch is made. | Night-time incontinence is relatively common in people with ileal pouches. However, this does not happen all the time and is usually only occasional. In addition, the incontinence is usually not large amounts of stool but small amounts. | Pelvic floor exercises to strengthen the anal sphincter muscles. Loperamide tablets. |
| (Occasional) daytime incontinence | 20 to 30%. ¹⁴ | Can happen years after ileal pouch is made. | Daytime incontinence is far less likely to occur than night-time incontinence because it is less likely to occur when the person is awake. Once again, the incontinence is usually not large amounts of stool but small amounts. | Pelvic floor exercises to strengthen the anal sphincter muscles. Loperamide tablets. |
| Small bowel obstruction | 15 to 44% overall and 5 to 20% requiring surgical intervention. ⁸ | Half of small bowel obstructions will occur in the first 30 days after surgery and half will happen in the long-term. ⁹ | Small bowel obstruction is the term used to describe when there is a blockage in the small intestine that is keeping food or liquid from passing through. The symptoms include abdominal pain or cramping, nausea, vomiting, diarrhoea, constipation, inability to have a bowel movement or pass gas, and swelling of the abdomen. | Depending on the severity, treatment options include conservative management (most commonly) or further surgery (rarely) |

| | | | | |
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| Cuffitis | 15% have symptomatic anal canal inflammation. ¹⁶ | Can happen years after ileal pouch is made. | Cuffitis is inflammation of the remaining 1-2cm of the large bowel (i.e. inflammation at the anus). Despite being such a small piece of inflammation, the symptoms can be significant and tend to mimic those of pouchitis (described above). | Cuffitis can be treated with 5-ASA suppositories (e.g., asacol) or topical steroids. More stubborn cases may require oral treatment. |
| Pouch failure | 5.3% ¹⁴ to 16.1%. ¹⁷ | Can happen years after ileal pouch is made. | Pouch failure occurs when the pouch is removed because it does not work well enough for the patient. Common causes of pouch failure are the diagnosis of ulcerative colitis being changed to Crohn's disease, fistula, and pelvic sepsis. | Usually the person will have a permanent stoma although can have a second ileal pouch performed on some occasions. The latter option is high risk because it uses up more small intestine. |
| Anal stricture | 7.8 to 14%. ⁸ | Can happen soon after surgery but more common in the long-term after surgery. | This is a narrowing of the anus often caused by scar tissue from the surgery. Symptoms include pain with bowel movements, bleeding, difficulty evacuating stool, constipation, and a feeling of anal discomfort. | Sometimes a finger dilation is all that is required and other times the patient can be given something called a Hegar dilator to take home and gradually dilate mild strictures. In more severe cases of stricture, surgical intervention may be needed. |

| Name of Complication | How common is it | When can it happen | Description and Symptoms * | Treatment or prevention options |
|---|---------------------------|---|---|--|
| Pouch fistula | 2.6%-14%. ^{8,11} | Can happen soon after ileal pouch surgery or years after surgery. | This is an abnormal connection or path between the pouch and another part of the body (e.g., pouch-vagina, pouch-anus). | Drainage and occasionally further operations to repair the fistula |
| Ulcerative colitis diagnosis changed to Crohn's disease | 5-10%. ¹⁸ | Can happen years after ileal pouch is made. | Sometimes a person can seem to have ulcerative colitis before surgery but end up having Crohn's disease diagnosed some time after surgery. This could be caused by the initial diagnosis being wrong or the ulcerative colitis somehow becoming Crohn's disease; it is unknown which of these two scenarios is more likely. Symptoms include abdominal pain, nausea, anaemia, weight loss, inability to gain weight, fever, and fistula drainage. ¹² | If the diagnosis is changed to Crohn's disease, the patient can try to use immunosuppressants or biologicals to treat the Crohn's disease. Unfortunately, many patients who get Crohn's disease of the ileal pouch need the pouch removed. |
| Perianal abscess or fistula | 7.4%. ¹³ | Can happen soon after surgery but more common in the long-term after surgery. | A collection of pus near the anus that can coincide with being a fistula (i.e. abnormal connection between pouch and anus). Symptoms include pain when sitting or moving bowels, skin irritation, discharge of pus, fever, chills, and malaise. | For abscess, drainage followed by antibiotics. For fistula, fistulotomy (i.e. surgical opening of the tract), seton drain insertion, or a transanal mucosal advancement flap can be used. ⁸ |

* sources include www.mayoclinic.org and www.webmd.com

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Supporter

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Dr Andrew McCombie is a Postdoctoral Fellow at the University of Otago in New Zealand. He completed his PhD in the psychological aspects of inflammatory bowel disease and has since continued doing research in inflammatory bowel disease and bowel cancer. He wrote this booklet with the expert advice of Associate Professor Tim Eglinton (Colorectal Surgeon) and Professor Richard Geary (Gastroenterologist) so future ulcerative colitis patients can understand the risks and benefits of surgery better than he did.