LIVING WITH A J-POUCH

United Ostomy Associations of America, Inc.

A publication of
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UOAA would like to acknowledge the following individuals who developed the first edition and subsequent revisions of our Continent Ileoanal Diversions guide book.

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Glossary

See the Glossary Section at the back of this publication for the definition of blue highlighted words.

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Introduction

When faced with the possibility of an operation for the treatment of **inflammatory bowel disease (IBD)**, it is only natural to have many questions and concerns.

Our goal is that after reading this guide, you will have answers to the most common questions and the knowledge necessary to have a successful outcome.

Not everyone is a candidate for Ileoanal J-Pouch surgery. If you have any of the below conditions, this booklet may not be right for you. United Ostomy Associations of America's (UOAA's) website has many other resources that may be able to help you: https://www.ostomy.org/what-is-crohns-disease/.

You are likely NOT a candidate if you have:

- **Crohn's disease:** Crohn's disease is an inflammatory condition that can affect the entire digestive tract, involving all layers of the bowel. Because of the high risk of recurring disease, the small intestine must not be used to construct the reservoir.
- **Fecal incontinence:** Individuals who have serious problems with fecal incontinence are not candidates for this procedure.
- **Advanced age:** Optimal outcomes from this surgery occur in the 20- to 50-year age group. These individuals usually have the best anal sphincter control. Age is a relative contraindication. Selected patients up to 70 years old have had the procedure completed with favorable results. The most important factor is the actual function of the anal sphincter and the J pouch rather than age. Anal sphincter function will be assessed by your surgeon at the time of your initial assessment.
- **Obesity:** The operative procedure is more difficult in persons with obesity or in those who have a thick abdominal wall.

You ARE a candidate if you have:

- **Ulcerative colitis:** Ulcerative colitis is an inflammatory disease of the lining of the large intestine, including the rectum. Symptoms of this disease may include crampy abdominal pain and bloody diarrhea with frequency and urgency. Frequency of diarrhea may be as often as 25 movements per day. The disease may be chronic or acute, and persons with ulcerative colitis may be at a higher-than-average risk for cancer.
- **Familial polyposis coli (familial adenomatous polyposis):** Familial adenomatous polyposis coli is an inherited disease in which the individual develops an unusually large number of **polyps** in the large intestine. Polyps are small projections which grow from the inner lining of the bowel into the **lumen**. These persons show few symptoms, and the disease is found during routine check-ups or by following individuals known to be at risk. If the disease is left untreated, these people have a 100% risk of developing cancer.

In both these diseases, only the **mucosal** or inner lining of the intestine is affected. Since the underlying layers (including the muscles) are not affected, the sphincter, the nerves, and the anus can be saved. This allows the individual to maintain control of their bowel movements.

History

The J-pouch procedure has become widely accepted as the procedure of choice for certain patients who require surgical treatment for ulcerative colitis (UC) and familial adenomatous polyposis (FAP). Removal of the colon and rectum is curative for these diseases. The creation of an intestinal pouch allows the individual to regain health and a relatively normal lifestyle without a permanent ileostomy.

Prior to the development of the **ileoanal pouch** procedure, treatment of choice for patients with ulcerative colitis was complete removal of the **colon**, **rectum**, and **anus**, with the formation of an **ileostomy**. Over the years, however, alternative surgical procedures have been developed. These include total colon and rectum removal with straight **ileoanal anastomosis**, total colon removal with preservation of the rectum and **ileorectal anastomosis**, and the continent ileostomy or **Kock pouch/K-pouch**. Many of these approaches are seldom-performed today.

In 1978 Sir Alan Parks and Mr. John Nicholls combined the idea of a three-limbed **ileal reservoir with ileo-anal anastomosis**. With this advance, they were the first to describe the Ileal pouch anal anastomosis (IPAA), having fashioned the S-pouch for patients with ulcerative colitis (UC) after proctocolectomy. Since then, much has progressed and surgeons today prefer a J-shaped pouch as it has demonstrated to have superior function over the S and W shaped pouches. (1)

To start, it is important to know the basic normal function of the digestive system. This will help you understand the changes you will experience after your surgery.

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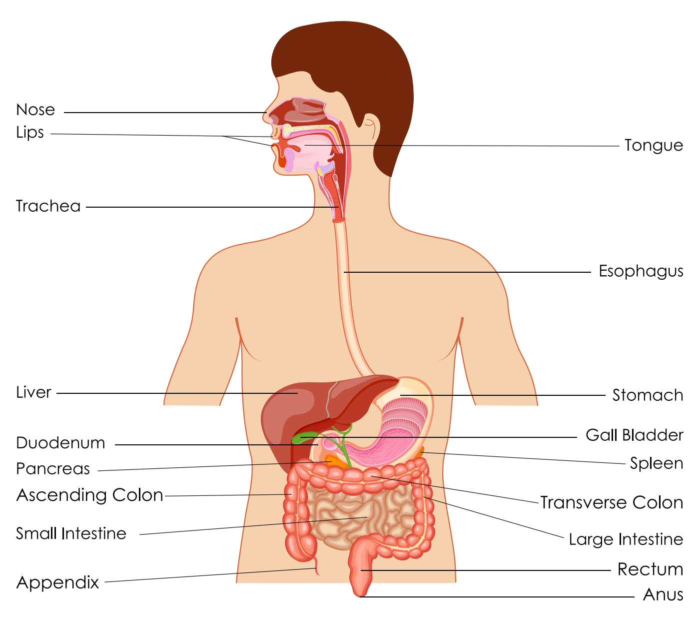
(1) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6710180/ # World J Gastroenterol. 2019 Aug 21; 25(31): 4320–4342. Published online 2019 Aug 21. doi: 10.3748/wjg.v25.i31.4320
Ileal-anal pouches: A review of its history, indications, and complications Kheng-Seong Ng, Simon Joseph Gonsalves, and Peter Michael Sagar



The Digestive System

The Digestive System

Mouth

1

- Starts the process of digestion.
- Breaks down food as it is chewed and mixed with saliva.
- Saliva contains digestive enzymes and moistens food to aid in swallowing.
- Food is swallowed and moves down the esophagus until it enters the stomach.

Stomach

2

- Secretes acids and enzymes that further break down and digests food into smaller particles and nutrients that the body can use.
- Stores and churns the food.
- Slowly releases the processed food to the small intestine.

Small Intestine (approximately 20 feet long)

3

Responsible for the absorption of nutrients, which are sent to the liver for processing and allows the nutrients to be used by the rest of the body. Made up of 3 sections:

- The **duodenum** helps neutralize the food as it enters the small intestine.
- The **jejunum** is where most of the absorption of nutrients takes place.
- The **ileum** is essential for the absorption of certain nutrients, such as vitamin B12 and bile salts.
- From the ileum the intestinal contents pass through the ileocecal valve that separates the small and large intestine.

Large Intestine (Colon) (approximately 5 to 7 feet long)

4

Collects, concentrates, transports, and eliminates waste in the form of stool from the body. As the intestinal contents move through the colon, fluids and electrolytes are being absorbed.

Anus

5

The opening where the gastrointestinal tract ends.

- Connected to the rectum.
- Where stool exits the body.

Surgical Options

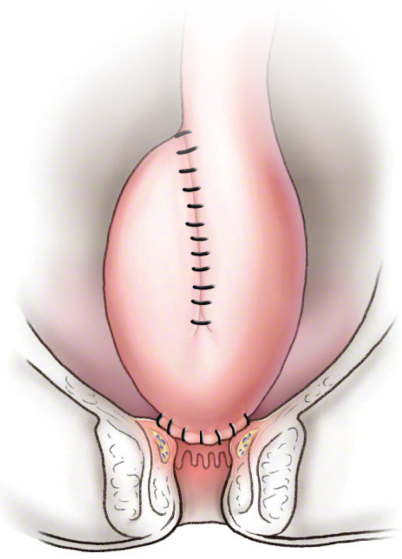
As we mentioned in the history of continent bowel surgery, there have been different surgical options over the years to create continent bowel diversions.

The J-pouch is considered the gold standard for management of ulcerative colitis today. There are other configurations like the S-pouch, as illustrated on the following page.

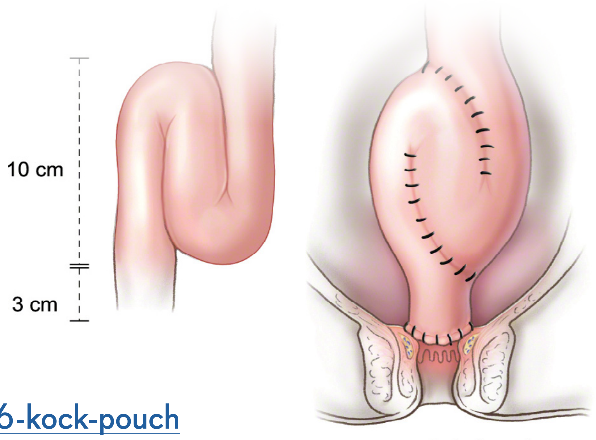
If you are not a candidate for a J or S-Pouch, you may be a candidate for a Kock or K-Pouch, described on the following page.

This guide will only address in more detail the J-pouch surgery.

J-Pouch



S-Pouch



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There is a second and less common procedure used which is the **Proctocolectomy** with end ileostomy ileal reservoir, also known as the Kock Pouch / K-Pouch.

We will briefly touch on what Kock/K-Pouch surgery entails. If your surgeon recommends this procedure for you, you can find more information on K-pouch surgery on the Cleveland Clinic website.

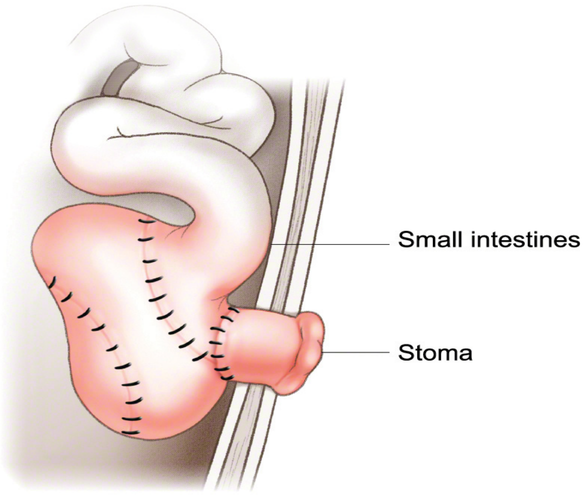
https://my.clevelandclinic.org/health/treatments/24996-kock-pouch

You may also want to go to UOAA's website and read the article in the 2024 New Ostomy Patient Guide on pages 62-65 titled "Continent Bowel Diversions – Innovative surgical procedures designed to achieve continence".

https://www.ostomy.org/new-ostomy-patient-guide/

K-Pouch Surgery - Continent Ileostomy

Kock pouch



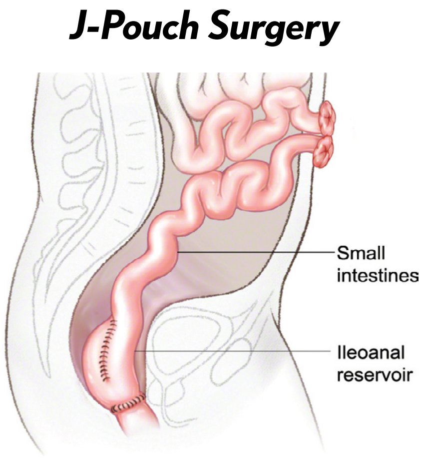
- This surgery involves the complete removal of the large intestine, rectum, and anal sphincter.
- An internal reservoir is created by using the end of your small intestine (about 18 inches) and the surgeon will fold this end up against the upper part of the intestine in a long "U" shape.
- Then they open the intestine in the middle of the "U" and stitch the edges of the lining together, leaving the last few inches unconnected. This creates a pouch with a "tail" at the end.
- The tail is used to create a one-way valve at the opening of the pouch. This valve/flap closes when the pouch is full. The "tail" with the valve is attached to the inside of your stoma.
- They'll test the valve to make sure that fluids, solids and gasses don't leak through the opening.

J-Pouch Surgery

The type of surgery you have (i.e. a two or three-stage procedure), will be made by your surgeon and discussed with you. Be sure to ask your surgeon if you have any questions at that time.

Two Stage:

The most commonly performed procedure is the two-stage operation in which the large intestine and rectum are removed, which is called a proctocolectomy.



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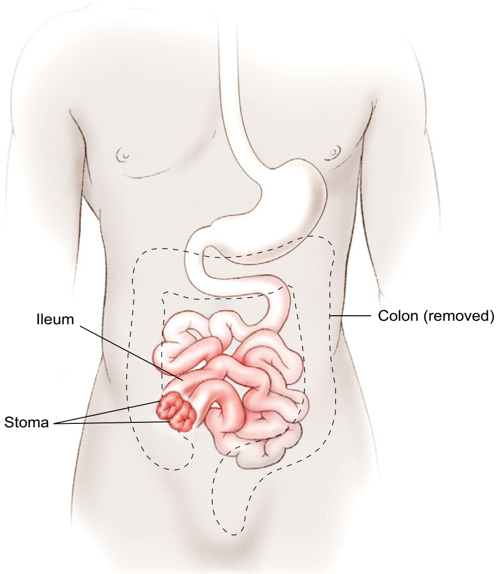
Stage 1: A reservoir is created from the terminal end of the small intestine and joined to the top of the anal canal.

A temporary **loop ileostomy** is created above the newly created internal pouch. To create the ileostomy, the surgeon uses another loop of small intestine that is brought out through an opening on the abdomen, which creates a stoma.



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A loop ileostomy is formed when small intestine is brought through the abdominal wall and two openings (stomas) are made.

Stage 2: The second stage of the operation is performed when the internal pouch is found to be leak proof and healthy, after approximately 8 to 12 weeks. The ileostomy is taken down/closed and the continuity of the bowel is reestablished. The stool now passes through the small intestine into the reservoir and out through the anus.

Three Stage:

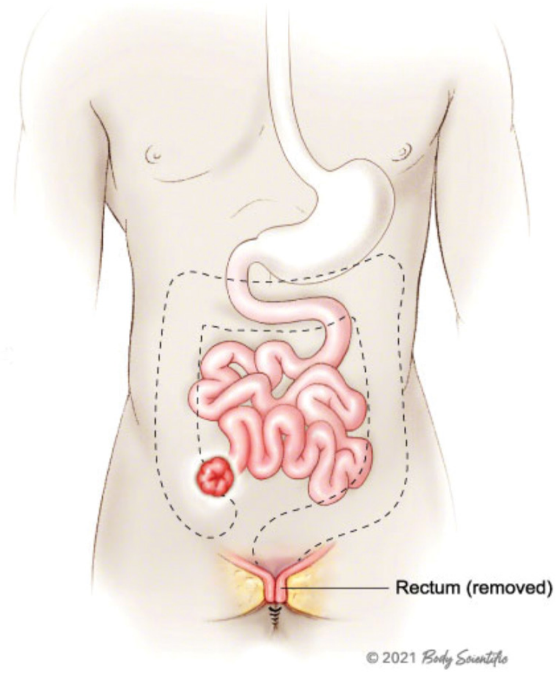
The surgeon may prefer to operate in three stages in some cases of severe disease, poor physical health due to prolonged illness, other health problems, or use of high doses of steroids or other immunosuppressant medications.

Stage 1: The large intestine is removed leaving the rectum intact. This is called a **partial colectomy**. The **end ileostomy** is created. The recovery period for this stage of the surgery is two to three-months.

Stage 2: The rectum is removed. A reservoir is then created from the terminal end of the small intestine and joined to the top of the anal canal. This procedure is called an ileoanal pouch anastomosis. The surgeon next creates a loop ileostomy. This ileostomy is temporary but is necessary in order to allow the pouch anastomosis time to heal. The healing time is two to three-months. The location of the loop ileostomy is usually at the same site where the end ileostomy was located.

Stage 3: The ileostomy is taken down or closed and the patient will begin to use the reservoir.

An end ileostomy is formed when the last portion of the small intestine (the ileum) is brought through the abdominal wall.



For more information on J-pouch surgery, go to the link below from the Crohn's & Colitis Foundation:
https://www.crohnscolitisfoundation.org/what-is-ulcerative-colitis/surgery/j-pouch-surgery

Preoperative Planning

What Should Occur?

You should be scheduled for an initial visit with your **ostomy nurse**. This is usually done before your admission to the hospital.

The goal of the visit is to provide education that may help decrease any anxiety you and your family/significant others may have regarding your upcoming surgery.

The nurse will provide you with a lot of information. It may be helpful to bring a family member, significant other, or friend to this appointment. Some people find it beneficial to speak with others who have undergone the same type of surgery. If this is something you, your family, significant other/s feel would be beneficial, make sure to ask your ostomy nurse to arrange it.

Before admission to the hospital, you may

- have a chest X-ray and an electrocardiogram (ECG or EKG) ordered,
- have blood drawn for laboratory tests,
- be asked to give a urine specimen,
- be given a bowel prep to cleanse the bowel of stool. The specific bowel prep will be ordered by your physician. Be sure to drink all of the prep as directed so that your bowel is as clean as possible at the time of surgery.

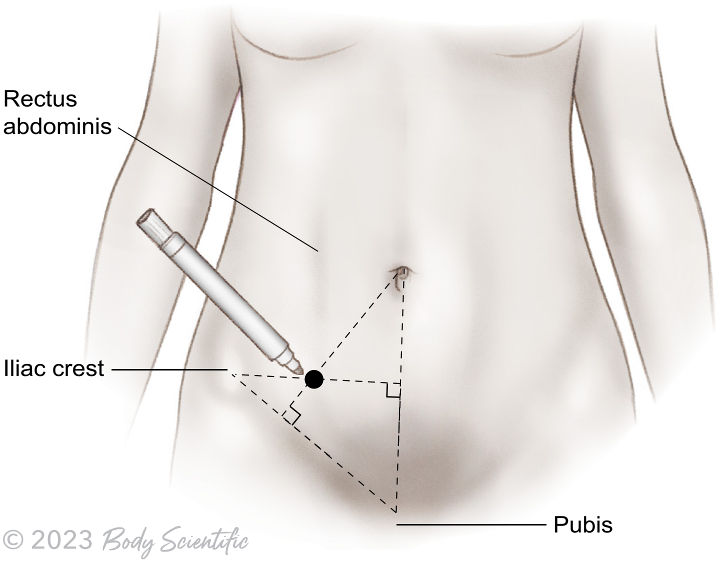
Your physician may recommend a specific preoperative diet, which often include protein drinks 1 week before surgery to help optimize your nutrition. Usually, these instructions include 1 to 2 days of a clear liquid diet before the day of surgery. As with most surgery, you will be asked to not have anything to eat or drink after midnight. You may also be asked to shower with a special antibacterial soap beforehand.

What Will the Nurse Review?

- Review of preoperative preparation
- Review of the anatomy and physiology of the digestive tract
- Discussion defining a stoma and an ostomy
- General description of ostomy pouches, their application, insurance coverage, sources to obtain supplies, and cost
- Living with an ileostomy, including diet, medication, hygiene, sexuality, and clothing
  - Be sure to bring up any particular concerns or issues you may have.
  - You may be given some written material to take home with you.
- Preview of what types of tubes, catheters, and pouches you may have when you wake up from surgery

The ostomy nurse will mark a place on your abdomen where the stoma will be. It is called siting the stoma. The goal is to place the stoma in a location that will be convenient and visible to care for and as non-interfering as possible with your activities of daily living.

- You will be asked to lie down, sit, and stand so that changes that occur with natural body movement can be observed.
- A site is chosen that is away from bony areas, skin folds, and scars.
- The lower right quadrant of your abdomen, an area that you can readily see, is usually selected.
- The site is usually below the waist so that the waist lines and belts of clothing will not interfere with the stoma or pouch.
- The location will be marked with a small tattoo or indelible marker that will not wash off during the preoperative skin preparation and can easily be identified by the surgeon in the operating room.



Bowel Continence

What Can You Do?

Pelvic Floor Therapy

The purpose of pelvic floor therapy/exercise is to strengthen the tone of your pelvic floor muscles. These include the anal sphincter muscles, which allow you to control your bowel function/**continence** and play an important part in the success of your J-Pouch surgery.

Pelvic floor therapy may include Kegel exercises, electrical stimulation, and biofeedback.

There are physical and occupational therapists who are specially trained in pelvic floor therapy. You can speak with your surgeon about a referral to someone in your area.

When to Start

Pelvic muscle exercises should be initiated before surgery. *It is important to check with your surgeon as to when you can resume pelvic floor exercises after surgery. You can expect not being able to resume any of these exercises for at least 4 weeks.*

Can be done lying down, sitting, or standing.

1. Squeeze your sphincter muscle as if you want to prevent the passing of gas or a bowel movement. Do not squeeze your buttock together. You want to isolate the sphincter muscle.
2. Hold this position for as long as you can. You may start out only being able to hold it for a few seconds but, as your muscles get stronger, you will be able to increase the time you hold it. Try to build up to a hold time of 10 seconds.
3. Then, relax the muscle for 10 seconds. Repeat 10 times in a row, which is considered 1 set.

   You should aim to complete 4 to 6 sets per day. You do not want to do them all at once because the muscle will become fatigued.

Post Operatively

What to expect:

Stage One: This is the term that refers to your first operation.

You will likely be in the hospital for 5 to 7 days.

Your overall recovery will be longer than for those who have a conventional ileostomy because you require two stages of surgery. During this time period, while you are recovering from your initial surgery, your new pouch is allowed to heal and you will care for your ileostomy.

The Ileostomy

In an effort to streamline this guide and to stay consistent with UOAA's education on Ileostomies, we have provided you with a link to our *Living with an Ileostomy Guide* below. You may also obtain a hard copy by requesting one from UOAA.

We strongly suggest reviewing this guide and keeping a copy easily accessible as it will be a valuable resource to you in caring for your ileostomy.

For more information, visit: https://www.ostomy.org/wp-content/uploads/2022/10/UOAA_Living_with_an_Ileostomy_Guide-2022-10.pdf

The Pouch (Reservoir) Adaptation:

Generally, over the course of 1 year, the size of the pouch increases and the number of bowel movements per 24 hours decreases. This is a pouch adaptation. There will also be another period of adaptation of your reservoir/pouch after your ileostomy is closed.

It is important to remember that the time that elapses from your surgery to complete pouch adaptation can be 6 months and up to 1 year. During this time period, you will likely be able to return to your previous activities and work.

Initially:

You can expect that there could be up to 15 bowel movements a day. There may be some problems with control and you may need to get up several times at night. This all improves with time as the pouch capacity gradually increases in size.

In order to begin increasing the size of the reservoir and decreasing the number of trips to the bathroom, you should avoid responding to every urge to evacuate the pouch. You can also help with pouch adaptation by learning to control pouch function with diet and, if necessary, medication.

The majority of people do not have any major problems with control. However, some nighttime seepage or incontinence may be experienced. This may initially improve with time but can become worse with advancing age. You may wish to wear a pad to prevent soiling of your clothing. You will also want to pay special attention to your **perianal** skin care.

Eventually:

Most patients experience 4 to 6 bowel movements daily, have good control, and are not troubled by nighttime incontinence.

It is very important to practice perseverance, tolerance, and patience with a liberal dash of good humor during this period of personal adjustment and pouch adaptation.

Stage Two: This is the term that refers to your second operation.

You will likely be in the hospital for 3 to 5 days. Before admission to the hospital, a **pouchogram** (contrast enema) will be ordered by your surgeon.

A pouchogram is performed to ensure that the pelvic pouch has healed and there are no leaks. This is a special X-ray and is done by instilling fluid into your pouch from below, via your anus, and taking an X-ray. The procedure takes about 10 to 15 minutes and is usually well-tolerated.

Note: Be sure to empty your ostomy pouch prior to the procedure and have a spare appliance with you in case a change is needed.

Every surgeon has a slightly different preoperative protocol. Make sure you understand the instructions your surgeon has given to you. Usually, an individual is placed on a clear liquid diet for 1 to 2 days before surgery. A mild laxative may be prescribed for you by your surgeon; some do not do this. Laboratory work may be ordered. You will be NPO (nothing by mouth) starting at midnight the night before your surgery. Upon arrival at the hospital, an intravenous line (IV) will be started.

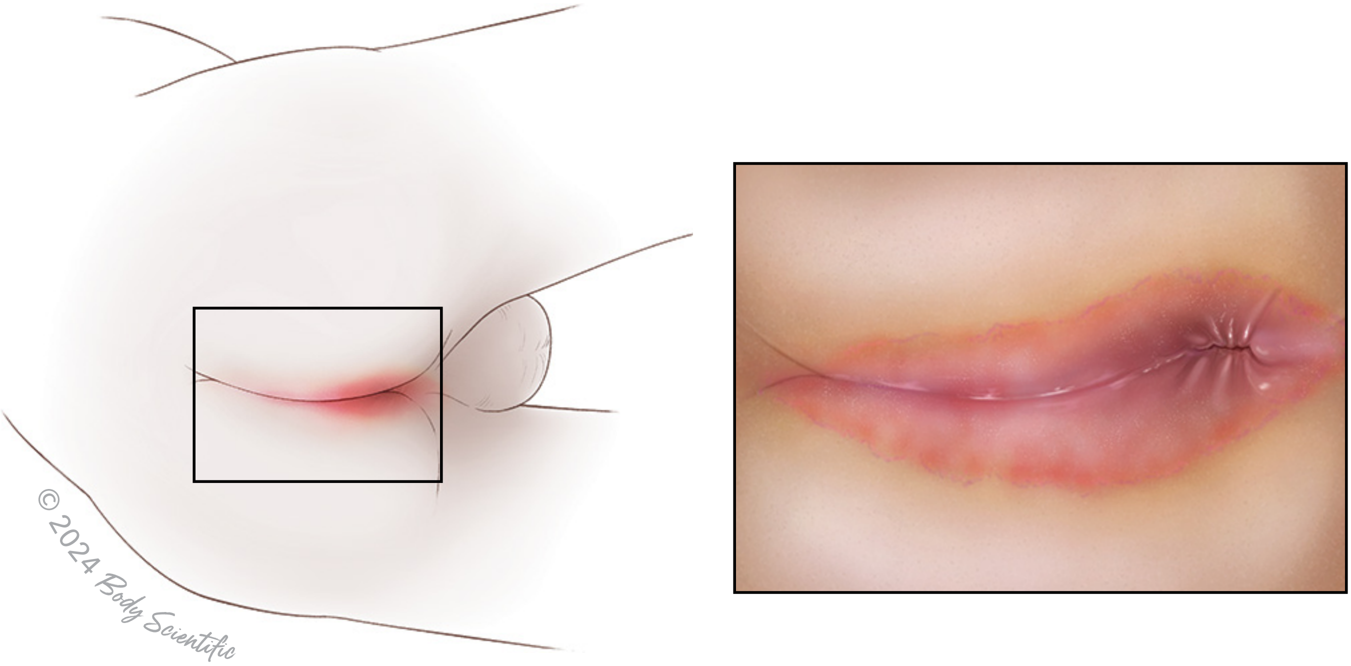
Self-Care

Perianal Skin Care

As initial ileoanal pouch function begins, aggressive perianal (around the anus) skin care is started to prevent perianal skin irritation. This irritation can become severe and there are specific times when you are at greater risk of developing perianal skin irritation or breakdown, including:

- When **mucus** is discharged with temporary incontinence following the first surgery
- Immediately following ileostomy takedown
- During bouts of **gastroenteritis**
- During bouts of **pouchitis**
- After indiscriminate eating

The risk of developing skin irritation is directly related to an increase in bowel action. Decreased transit time results in increased skin irritation due to the presence of digestive enzymes in the stool and on the perianal skin. If perianal skin irritation develops, it is usually temporary. However, certain foods such as spicy foods, tomatoes, onions, coffee, and tea cause irritation and should be avoided until the irritation improves.



Final Procedure

Ileostomy Takedown

This final operation is the ileostomy takedown or closure of the ileostomy. It is a much shorter procedure and includes the following steps:

1. In most instances the ileostomy is closed by making an incision around the stoma and freeing it down to the abdominal cavity. Closure of the ileostomy usually does not require an abdominal midline incision.
2. The two ends of the bowel, one leading from the upper intestine and one leading to the ileoanal pouch, are rejoined so that the stool will pass through the small bowel, the ileoanal pouch, and out through the anus.
3. The former stoma site may be closed or the muscle layer may be closed. The skin and subcutaneous tissue layer may be left open to allow the area to heal from the bottom up. This depends on surgeon preference.

Postoperative Period

Your post operative care will be similar to what you received after your first operation, except that you are less likely to have any tubes. Following the closure of the ileostomy, passing gas and intestinal function generally begin around the second or third day after surgery and frequent loose movements are to be expected.

As diet is advanced, bulk forming agents or antidiarrheal medications may be given to decrease bowel frequency and to avoid dehydration. You will be asked to keep track of your bowel movements. At first you may have as many as 12 to 15 bowel movements a day. This number is likely to decrease by the time you leave the hospital and often settles at an averageof four to six bowel movements per day.

Possible Complications and Considerations

Perianal Skin Irritation

Perianal skin irritation is an uncomfortable and frequently painful problem. Fortunately, it can be controlled and generally becomes less of a problem with time.

There are steps you can take to help prevent this:

- Control bowel frequency.
- Perform good perianal hygiene.
    - Cleanse and dry skin thoroughly once a day. Gentleness is key. Pat the area rather than rubbing or wiping.
    - Ideally, use a moistened soft cloth or soft tissue for cleansing, which are less abrasive than toilet tissue.
    - Warm water is generally all that is needed. Soap and scented tissue may be irritating to the skin and leave a residue resulting in itching. Skin care cleansers can be used as an alternative to soap. Skin cleansers contain surfactants, substances that help to gently remove stool and other irritants from the skin.
- Apply occlusive **skin protectants** such as ointments, pastes, and liquid skin sealants without alcohol. Examples include zinc-based pastes/ointments. Your ostomy nurse can give you some recommendations on the types of products to try.
    - It is not necessary or advised to cleanse to skin level after each bowel action. Remove any soiled layers of ointment or paste and apply a fresh coat on top.

Unless skin protectants are applied to protect the skin from contact with bowel content, the skin remains unprotected and WILL become irritated.

- Change pads or panty liners frequently to keep skin clean and dry.
- Wear cotton underwear rather than nylon or polyester because cotton absorbs perspiration and allows air to circulate.
- Sitz baths may be advised and are a gentle and thorough way to cleanse and soothe irritated skin.

- To protect the skin from small amounts of seepage, consider using an absorbent bandage, which is made for rectal drainage and may be helpful when placed over the anal opening.

If you experience continual perianal skin irritation even after taking special precautions, you should consult your physician or ostomy nurse who will reassess the problem and suggest further care.

Pouchitis

Pouchitis is an inflammation of the ileoanal reservoir.

Pouchitis has been reported with an incidence rate of 15% to 44% among patients with ostomies. The exact cause of pouchitis is unknown, but it is attributed to unrecognized Crohn's disease, indeterminate **colitis**, bacterial overgrowth, alteration in bile salt metabolism, immunologic changes, and pouch ischemia.

Symptoms:

- Significant increase in stool frequency with watery diarrhea
- Urgency or a pressure sensation in the pouch
- Cramping
- Bleeding
- Low grade fever
- Malaise (general unwell feeling)
- Dull pelvic pain and pressure

Treatment:

- 90% of cases are temporary and respond to antibiotics.
- If there is little or no response to antibiotics, anti-inflammatory medications may be used.
- In rare instances, diversion with an ileostomy or pouch excision may become necessary for cases of pouchitis with intolerable symptoms not responsive to medical therapy.

Medications

You should discuss any medications you are taking with your doctor or pharmacist to be sure they are not absorbed in the small intestine (e.g., coated tablets or sustained release capsules). Medication adjustments may be needed.

Diet Guidelines

- Follow a low fiber diet for approximately 4 weeks following closure of the temporary ileostomy. After this, gradually increase fiber as tolerated until you are eating a regular diet.
- Emphasis is placed on good eating habits: eat meals at regular time intervals in a relaxed atmosphere and chew thoroughly. Skipping meals will not stop pouch output. In fact, this practice may result in greater production of gas and increase the risk of dehydration.
- Eat moderate amounts and chew your food well.
- Some individuals find pouch output to be high in the afternoon, increasing toward the evening. You may wish to try experimenting with the timing of your meals. Consider eating your larger meals earlier in the day or limit the amount of food and fluid intake toward the end of the day.
- If a particular food is not tolerated, try it again at a later date.
- Drink at least 6 to 8 glasses of fluid each day. Consumption of fluids is recommended between meals rather than drinking large volumes only with meals.
- There may be an increased requirement for sodium; use salt with meals unless otherwise instructed.
- High potassium foods will be required in the presence of diarrhea. Good sources of potassium include meat, fish, poultry, dried fruits, bananas, oranges, tomatoes, fruit juices, milk, potatoes, and sweet potatoes.
- Limit intake of foods that are high in simple sugars because these can aggravate diarrhea (e.g., sugar, honey, candy, jam, jellies, pastries, and sweetened beverages such as soda).

Dietary modifications may help relieve problems with high pouch output, anal irritation, and gas. The following food lists have been compiled based on the individual experiences of others with an ileoanal pouch. The temporary exclusion of certain foods may or may not be effective in helping to control these problems. Experiment and find out what works for you.

Foods That Increase Pouch Output

- Raw fruits and vegetables (especially broccoli, beans, and spinach)
- Leafy green vegetables
- Spicy foods
- Beer
- Chocolate
- Wine
- Caffeinated beverages

Foods That May Decrease Pouch Output

- Bananas
- Cheese
- Boiled white rice and rice dishes (e.g., rice pudding)
- Tapioca pudding
- Creamy peanut butter
- Applesauce

Foods That May Contribute to Anal Irritation

- Certain raw fruits and vegetables (e.g., oranges, apples, coleslaw, celery, and corn)
- Popcorn
- Vegetables
- Nuts
- Coconut
- Dried fruits (e.g., raisins, figs)
- Foods with seeds
- Spicy foods
- Coffee and tea

Foods That May Cause Gas

- Onions
- Vegetables from the cabbage family
- Dried beans and peas
- Baked beans
- Cucumbers and radishes
- Beer
- Carbonated beverages
- Milk and milk products

Sexual Adjustment

Concerns about sexual activity are common after these surgeries. The removal of the diseased colon and rectum quickly restores the feeling of well-being. Check with your surgeon about when it is safe for you to resume sexual activity after surgery.

Women

Menstrual cycles are often disrupted following any operation. Your menses may be irregular for up to 1 year following surgery.

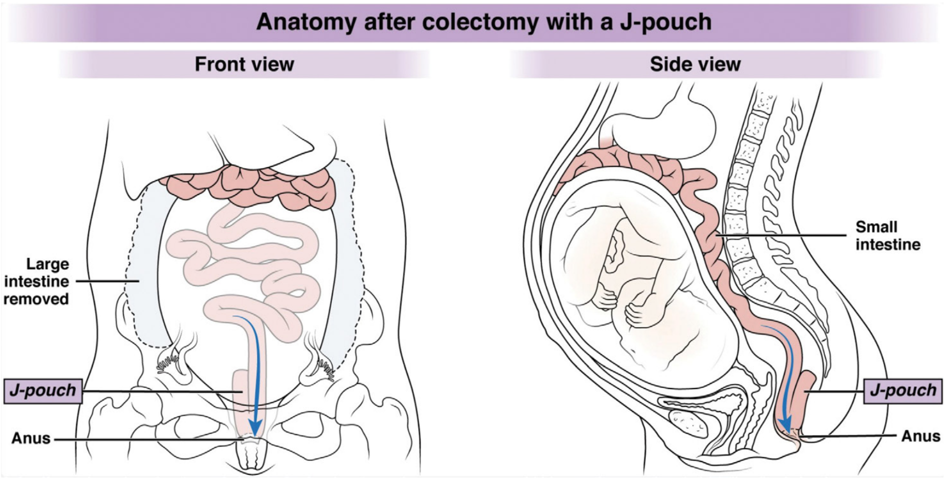
Discuss with your surgeon your desire to become pregnant after pelvic pouch surgery. Techniques can be used during the operation to help prevent the ovaries and tubes from becoming trapped in the scar tissue that forms after abdominal surgery.

Pregnancy following ileoanal pouch surgery is certainly possible but it is advisable to wait for at least 6 months after surgery to become pregnant.

Colorectal surgeons may recommend that your baby be delivered by cesarean section to avoid any possibility of injury to the anal muscles and nerves, which can occur during a vaginal delivery. However, women have had vaginal deliveries without adverse outcomes. Talk with your surgeon about the best delivery method for you.

For more information on pregnancy with an ostomy, please visit:

https://www.ostomy.org/pregnancy



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Men

- Men who have had J-pouch surgery have been able to have children.
- In males, there is a reported 1.5% sexual dysfunction resulting in impotence or infertility due to retrograde ejaculation.
- Some men report it taking longer to get an erection and the erection is not as firm.
- Speak with your doctor if you are experiencing any sexual dysfunction. They can make a referral to a specialist. There are new and effective treatments for sexual dysfunction.
- Anal sex is not recommended.

Birth Control

In the initial postoperative period, the transit time of the digestive tract is usually very rapid. For this reason, ***birth control pills will probably not be completely absorbed***. If you do not wish to become pregnant, be sure to discuss with your doctor which birth control options may be best for you.

Travel

Some form of identification stating you have had J-Pouch surgery is advised. There are many companies that provide bracelets or necklaces that can have this information imprinted on them. At the very least, carry an identification card in your wallet. The card should note the contact information for your surgeon and the type of surgery (e.g., J pouch, Kock Pouch) you received.

You can also download and print the Transportation Security Administration (TSA) Notification Card and Restroom Access Communication Card from UOAA's website. These tools may be helpful when traveling.

For more information, visit: https://www.ostomy.org/ostomy-travel-and-tsa-communication-card

Resources

American Gastroenterological Association

https://gastro.org/news/first-comprehensive-guideline-pouchitis/

American Society of Colon & Rectal Surgeons:

https://fascrs.org/patients/diseases-and-conditions/a-z/j-pouch

https://fascrs.org/patients/diseases-and-conditions/a-z/ulcerative-colitis

https://fascrs.org/patients/diseases-and-conditions/a-z/ostomy-expanded-version

Crohn's & Colitis Foundation:

https://www.crohnscolitisfoundation.org/what-is-ulcerative-colitis/surgery/j-pouch-surgery

https://www.crohnscolitiscommunity.org/crohns-colitis-resource-center

Centers for Disease Control and Prevention

https://www.cdc.gov/ibd/resources.htm

Cleveland Clinic

https://my.clevelandclinic.org/health/treatments/24996-kock-pouch

HealthCentral

https://www.healthcentral.com/condition/ulcerative-colitis/ostomy-or-j-pouch-weighing-your-uc-surgery-options

Glossary of Terms

Ostomy A to Z
Getting to Know the Ileoanal Lingo

Anal sphincter - The muscles surrounding the anus that contract or close the opening.

Anastomosis – The union of one structure to another.

Anus – The opening at the end of the rectum through which stool is eliminated from the body.

Appliance – Also known as an ostomy pouch system, ostomy pouch, or ostomy bag. A prosthetic medical device consisting of a wafer (barrier) and a pouch that is worn over the stoma to contain body waste (i.e., urine, stool).

Blockage - When something obstructs the stoma preventing stool from coming out. The blockage can be partial (a small amount of stool is able to come out) or complete (no stool is able to come out).

Bowel - The intestine; the part of the digestive system between the stomach and the anus.

Colectomy – A surgical procedure in which part or all of the colon is removed.

Colitis – Inflammation of the colon (large bowel). See IBD.

Colon – The last 4 to 5 feet of the digestive tract; the large bowel or large intestines.

Colostomy – A section of the large intestine (most commonly the descending or sigmoid colon, less commonly the ascending or transverse colon) is brought to the surface of the body and a stoma is formed from that part of the intestine.

Continence – The ability to keep stool, gas, or urine inside the body voluntarily.

Continent Diversion (CD) - A fecal (stool) or urinary diversion where control is made possible through the creation of an internal reservoir (a surgically made pouch inside your body). The reservoir is emptied by either manually inserting a catheter (a small tube) into a stoma or by going to the bathroom in the "normal" way through the anus for stool or through the urethra for urine.

Crohn's Disease – A chronic inflammatory bowel disease (IBD) that can affect any part of the gastrointestinal tract from the mouth to the anus but is more commonly found at the end of the small intestine (ileum).

Familial adenomatous polyposis coli - An inherited disease characterized by a tendency to develop masses of polyps in the colon.

Frequency - The number of bowel movements that occurs in a given period.

Gastroenteritis – Inflammation of the stomach and intestines/gastrointestinal tract, which can cause vomiting or diarrhea.

Gastrointestinal (GI) system - Pertaining to the digestive system.

Ileal reservoir – Also known as a Kock pouch; involves construction of a reservoir/pouch and a continence mechanism from 40 to 45 cm of the terminal ileum. This type of continent diversion requires the patient to insert a catheter into the reservoir at regular intervals to drain the pouch.

Ileoanal anastomosis – Joining the ileum to the anus following removal of the colon and the rectum.

Ileoanal pouch - The ileoanal pouch procedure has become widely accepted as the procedure of choice for certain patients requiring surgical treatment for ulcerative colitis (UC) and familial adenomatous polyposis (FAP). The surgical procedure to create the ileoanal pouch is a total colectomy with ileoanal reservoir or ileal pouch anal anastomosis (IPAA).

Ileorectal anastomosis - Joining the ileum to the rectum following removal of the colon.

Ileostomy - The entire colon, rectum, and anus are removed or bypassed. A part of the small intestine (ileum) is brought through the abdominal wall, creating a stoma.

- **End ileostomy** - The cut end of the small bowel is brought out to the surface of the skin, turned back on itself like a small cuff, and stitched to the skin.
- **Loop ileostomy** - A loop of small bowel is brought out to the surface of the skin and cut halfway through, leaving the ileum otherwise intact but with two openings. As with an end ileostomy the bowel is turned back on itself like a small cuff and stitched to the skin.

Ileostomy takedown - Removal of an ileostomy by rejoining the bowel and placing it back in the abdomen.

Ileum - The last 12 to 15 feet of small intestine.

Ileus – Intestinal slowing due to failure of peristalsis.

Incontinence – The inability to control the elimination of urine, stool, or gas.

Inflammatory bowel disease (IBD) – A group of chronic intestinal disorders of unknown etiology (cause) that most commonly affects adolescents or young adults, but can arise at any age. Usually refers to Crohn's disease and ulcerative colitis (UC).

J-pouch - A surgically created (J-shaped) internal reservoir made from an individual's own small intestine as an alternate way to store and pass stool.

Kock/K-pouch - See Ileal reservoir.

Large intestine/bowel - The last 4 to 5 feet of bowel that extends from the small intestines to the anus, also referred to as the colon.

Lumen - The space in the center of a tubular structure like the intestine.

Mucosa – The lining of the digestive tract and of other organs of the body.

Mucus – A lubricating substance produced by the digestive tract.

Ostomy – Surgery in which an opening is created (called a stoma) where urine or stool exits the body. Bodily waste is rerouted from its usual path because of malfunctioning or diseased parts of the urinary or digestive system. An ostomy can be temporary or permanent. Ileostomy, colostomy, and urostomy are different types of ostomies.

Ostomy Management Specialist (OMS) – A health care professional who is certified in all aspects of ostomy care and management. A special training course is required for certification.

Partial colectomy – Removal of the diseased portion of the colon and a small portion of surrounding tissue (also known as subtotal colectomy).

Pelvic pouch (ileoanal reservoir) - A pouch created from the ileum. Also known as a J pouch.

Perianal - Located around the anus.

Peristalsis – The progressive movement of the intestine by which the contents are pushed toward the outlet.

Polyp – Small projection inside the bowel, may be flat or mushroom shaped, usually benign but may be malignant.

Pouchitis – Most prevalent long-term complication of proctocolectomy with an ileoanal anastomosis. It is an inflammation of the lining of the pouch.

Pouchogram – A special X-ray that is done by instilling fluid into the pouch from below, via the anus, and taking an X-ray. Also known as a contrast or barium enema.

Proctocolectomy - A surgical procedure that involves removal of the entire colon/large intestine and more or all of the rectum.

Rectal cuff – A small portion of the rectum, including the sphincter muscle that may be retained after proctocolectomy.

Rectum – The last part of the large intestine/bowel which joins the colon to the anus.

Reservoir (pouch) – An anatomic structure that serves as a place to collect or retain fluid.

Skin protectants – Includes ointments, pastes, and liquid skin sealants without alcohol such as zinc-based pastes/ointments.

Small intestine/bowel – The 22 to -25 feet of intestine between the stomach and the large bowel. Also referred to as the small bowel.

Stoma – A portion of the large or small intestine that has been brought through the surface of the abdomen (belly) and then folded back like a sock cuff. A stoma provides an alternative path for urine (in the case of a urostomy) or stool (in the case of a colostomy or ileostomy) to leave the body.

Transit time – The minutes and hours that elapse between the eating of food until the time that waste is passed, either through the anus or the stoma.

Ulcerative colitis – A form of inflammatory bowel disease that targets the colon (large intestine) and affects its innermost lining. Symptoms can include abdominal pain, fatigue, weight loss, and bloody diarrhea. Surgery for this condition may result in one having an ostomy.

Urinary Tract – The system in the body composed of the kidneys, ureters, bladder, and urethra. Urine is made in the kidneys, passes down the ureters, accumulates in the bladder, and passes to the outside through the urethra.

Urostomy (ileal conduit) – A type of ostomy surgery in which a passageway for urine (conduit) is made by attaching the ureters to an isolated piece of the small intestine (ileum), which is brought outside of the abdomen to form a stoma.

Wound, Ostomy, and Continence Nursing Certification Board (WOCNCB®)

Certifies registered nurses who have a bachelor's degree or higher and who have completed formal and experiential learning in ostomy education and passed a certification exam(s). These nurses are certified as CWOCN (Certified Wound Ostomy Continence Nurse), CWON (Certified Wound Ostomy Nurse) or COCN (Certified Ostomy Care Nurse). Certifications must be renewed every 5 years by exam or the creation of a professional growth portfolio (PGP).

Wound, Ostomy, and Continence Nurses Society™ (WOCN® Society)

A professional international nursing society of healthcare professionals who are specialists in the care of patients with wound, ostomy and continence needs.

- They support members by promoting educational, clinical and research opportunities.
- They have developed the Ostomy Care Associate (OCA) Program as a continuing education program. It empowers WOC specialty nurses to prepare LPN, RNs and other licensed clinicians to provide optimal care for ostomies, fistulas and feeding tubes. They function as an extension of the WOC nurse team.

Wound Care Education Institute (WCEI)

The Institute provides wound and ostomy care education based on current standards of practice guidelines and evidence-based research. It is for healthcare professionals, including all levels of nurses, registered dietitians, physical therapists, occupational therapists, and physicians.

- They offer a 1-week educational program for ostomy management specialists (OMS). Candidates who complete this program can sit for the examination offered by the National Alliance of Wound Care and Ostomy Member Association (NAWCO).
- Recertification by NAWCO is every 5 years and can be done through an online or onsite refresher course at WCEI.

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- Colwell JC, Goldberg MT, Carmel JE. Fecal & Urinary Diversions: Management Principles. Mosby; 2024.

Notes/Recommendations

UOAA

United Ostomy
Associations
of America, Inc.

www.ostomy.org

UOAA promotes quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration.