



**Boston
Children's
Hospital**

What the Heck is an Ileoanal J-Pouch?

GO

A guide to surgical treatments for
Ulcerative Colitis (UC) and Familial Adenomatous Polyposis (FAP)

Contents



Introduction.....	3
Understanding How Your Digestive System Works	4
Overview & Procedure.....	5
Preparing for Surgery.....	11
After Surgery.....	12
Follow-Up Appointments	18
Support.....	20
Glossary	21

Introduction

IF YOU HAVE ULCERATIVE COLITIS (UC) OR FAMILIAL ADENOMATOUS POLYPOSIS (FAP) and are considering surgery, you probably have many questions and concerns. This guide has been prepared to help answer many of your questions and prepare you for the hospital experience.

In this guide, we explain:

- reasons for surgery and who may be a good fit
- surgical procedure
- steps to prepare for surgery
- what you can expect after surgery, including living with a temporary ostomy and possible complications

A glossary of technical terms appears at the end of the guide; many of these terms are also explained in the body of the text.

We have done our best to give current and practical information in this guide. Every person and every situation is different. Please talk to your nurse practitioners, nurses and surgeons whenever you have any questions or concerns.

There are several different surgical ways to treat people with ulcerative colitis or familial adenomatous polyposis. The surgical procedure offered at Boston Children's Hospital is the Ileoanal procedure with J-Pouch. It is also known as the Ileoanal Pull-Through (IAP) procedure.

During your outpatient visit, you will meet many staff members from the general surgery department including:

- pediatric surgeons
- nurse practitioners (NPs) and/or nurses, who will teach you about an ostomy and show you what an ostomy pouch looks like
- administrative assistants and surgical schedulers who will schedule your surgery, post-operative appointments and arrange any testing that may be needed

You may experience many emotions when you come for a surgical consult. It is not uncommon to feel sad, afraid, angry, depressed or nervous. You might even feel relieved and hopeful that surgery will make you better! These are all normal emotions.

You may have been ill for some time. It is sometimes hard to believe that surgery will help you achieve a new outlook on life. As you become more comfortable and confident with the care and management of your ostomy, we hope you will find that it gets easier to deal with.

We have a program where you can talk to someone who has already been through this surgery. Most patients and families find this to be an excellent resource. They can help answer your questions about the surgery, help ease concerns and talk about recovery and life after a pull-through.

In addition to this guide you will also be given the following Family Education Sheets:

- *Home Care Instructions for Changing an Ostomy Pouch*
- *Ostomy Diet Guidelines*
- *Ostomies: A Patient Guide to Ileostomies and Colostomies*

Understanding How Your Digestive System Works

1. The human digestive system (“food tube”) begins with food entering the mouth and traveling down the **esophagus** into the **stomach**.

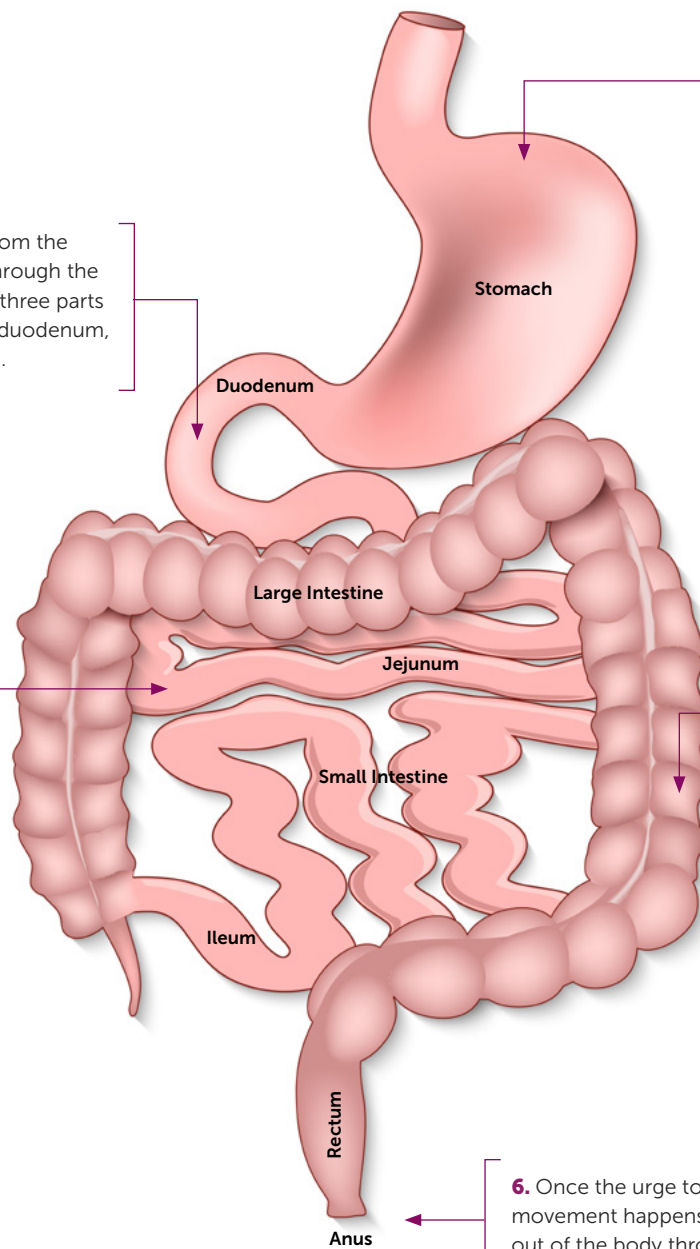
2. In the **stomach**, digestive enzymes break down the food into smaller parts so the body can use them to give nutrition to the cells and provide energy.

3. The food then moves from the stomach into the bowel through the **small intestine**. There are three parts of the small intestine: the duodenum, the jejunum and the ileum.

4. In the **small intestine**, food is broken down even more, fats are digested and nutrients are absorbed into the body through its lining.

5. Finally, food moves into the **large intestine**, also called the colon. This is where water and minerals are absorbed from the digested foods. This becomes the brownish, semi-solid waste called feces (stool or “poop”), which is stored in the **rectum**.

6. Once the urge to have a bowel movement happens, the stool is passed out of the body through the **anus**.



Overview & Procedure

What is Ulcerative Colitis (UC)?

Ulcerative colitis is an inflammatory bowel disease in which the inner lining of the large intestine (colon) and rectum become inflamed. Inflammation usually begins in the rectum and lower large intestine and spreads upward, potentially involving the entire colon. The inflammation causes diarrhea and frequent emptying of the colon. As cells on the surface of the colon die and fall off, ulcers (open sores) form, causing pus, mucus and bleeding. You may notice pus, mucus and blood in your stool.

What is Familial Adenomatous Polyposis (FAP)?

Familial adenomatous polyposis is an inherited familial disorder in which polyps gradually form throughout the colon and rectum. Colorectal cancer will develop if left untreated. Most people who have FAP have a family member with FAP.

Ileoanal J-Pouch Overview

The procedure was developed in the late 1970s to help people who had been diagnosed with ulcerative colitis or FAP. The procedure involves removing the entire colon. The colon is replaced with an internal pouch that your surgeon will create using your own small intestine. The pouch is then attached to your anus (the opening where your stool comes out). Many people prefer this procedure to other alternatives because after all the surgeries you are able to go to the bathroom the "normal way."

This procedure will involve two or three surgeries, based on your particular situation. Your surgeon will create a temporary ostomy, which is a surgically created opening in your abdominal wall where the end of your intestine will be placed. This opening is called a stoma or an ostomy.

When you have an ostomy created, your stool (poop) now comes out of your stoma into a bag or pouch that you will wear. Your stool will not come out your anus. This is only temporary until your body has healed from the surgery and your clinical condition improves. Once you have healed, you will have another operation to connect the intestine to allow you be able to go to the bathroom the "normal way."

Who may be a good fit for this procedure?

You may be a good fit for this procedure if you have ulcerative colitis and feel it is affecting your quality of life. Examples include:

- missing multiple days of school or work
- side effects from the long-term use of medications
- failure to grow or are poorly nourished
- missing out on sports and other extracurricular activities due to frequent "flare-ups"
- ineffective medications, or the inability to be taken off steroids
- an urgent or emergency situation in which, without the operation, you may suffer serious consequences such as:
 - » abscesses
 - » perforation (tear)
 - » severe bleeding
 - » toxic megacolon (widening of the large intestine; this is the most severe and the least common)

You may be a good fit for this procedure if you have FAP and want to decrease the risk of developing colorectal cancer when there is a family history of abnormal polyps growing in the colon.

Surgical Procedures

Ulcerative colitis and FAP affect only the lining of the large bowel. Surgical treatment includes removal of the colon (“colectomy”) including creation of a temporary ileostomy stoma. We have found there are fewer complications when we create a temporary ileostomy stoma.

Surgery for creation of an internal pouch or reservoir can be done in either two or three operations referred to as “stages”. The decision on how many operations you need will depend upon your specific clinical condition. Your surgeon and your gastroenterologist (GI doctor) will discuss this with you. This guide explains the two and three stages of the surgical procedure.

You and your family may find it helpful to talk about these procedures with someone else who has already experienced them. Your surgeon, outpatient nurse practitioner or social worker will make every effort to match you up with someone of similar age and gender to speak with — by phone, in person, email or text — with your parents’ permission, as appropriate.

Please Note: If you have Familial Adenomatous Polyposis, skip the Three-Stage Procedure section.

The Three-Stage Procedure

The three-stage procedure is generally done when a patient is:

- Too sick to safely undergo a two-stage procedure.
- On a high dose corticosteroids.
- When the colon and rectum are severely inflamed. Severe inflammation, ulceration, or breakage in the lining of the rectum make successful removal of the rectal lining more difficult.



A temporary ileostomy stoma is shown above. Pictured at right is a patient who has completed all stages of the procedure, showing her healed surgical scar.



Overview of Surgical Procedures

Three-Stage Procedure

First Stage

- Colectomy (removal of colon/large bowel)
- Temporary ileostomy created

Second Stage

- Ileoanal J-pouch created
- New ileostomy created

Third Stage

- Ileostomy closure

Two-Stage Procedure

First Stage

- Colectomy (removal of colon)
- Ileoanal J-pouch created
- Ileostomy created

Second Stage

- Ileostomy closure

THE THREE-STAGE PROCEDURE

First Stage

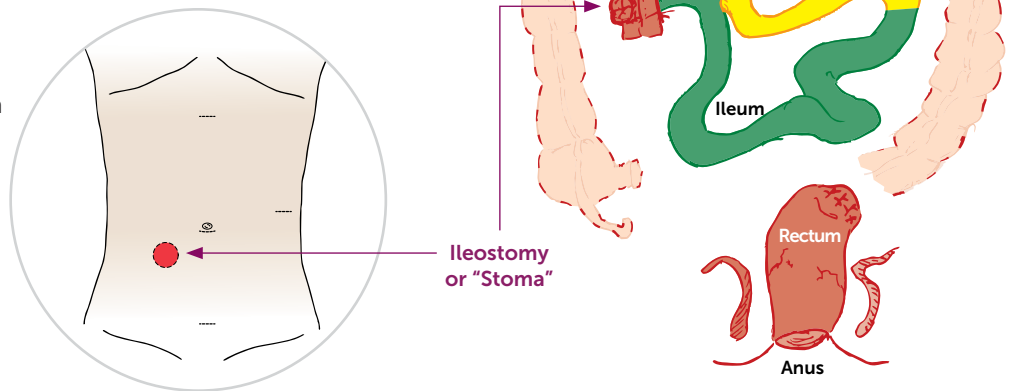
The entire colon (large bowel) is removed using **laparoscopic surgery** (also called minimally invasive surgery).

Your doctor will give you medication that makes you sleepy.

Once you are asleep, a nasogastric (NG) tube is placed into your nose and down to your stomach to drain the fluid from the stomach. It will stay in place after the surgery. A small tube is also placed into your bladder to drain the urine (pee). These tubes stay in place for the first couple of days after surgery.

Laparoscopic Colectomy

- Four small incisions are made on your abdomen (belly) and a larger incision is made on the site of the new ileostomy stoma (opening). A camera is placed in the abdomen and the colon is removed, but the rectum is left in place. The rectum will still have disease and you may pass small amounts of blood after the surgery. When your health has improved you will undergo the second stage of the surgery, where the rectum will be removed and the J-pouch created.
- The ileostomy is created. A surgically created opening at the end of the small intestine (bowel) is brought through the skin of the abdominal wall to form a stoma or ostomy. This is a temporary (not permanent) ostomy needed until the J-pouch is created and has healed, which usually takes six to nine months or sometimes longer based on your clinical condition. The stoma empties stool into a pouch that is worn on the abdomen (belly) over the stoma.
- At the end of the procedure, the incisions are closed with dissolvable stitches that you cannot see. Small white bandage strips and gauze with a clear plastic bandage will be placed on the incisions. The operation usually takes about four to six hours depending on your condition.



Home Care After the First Stage

You will be taught how to take care of the stoma while you are in the hospital recovering from surgery. You'll be taught how to care for your skin, empty your pouch and put on a new pouch before you go home.

The nursing staff and discharge planner (called a Patient Care Coordinator) will arrange for a visiting nurse to come to your home to review teaching. They also will order your ostomy supplies for you from a medical supply company that will deliver directly to your home. Please refer to *Home Care Instructions for Changing an Ostomy Pouch*.

One important job of the colon is to absorb water. With the colon removed, it is important that you drink plenty of fluids to prevent dehydration.

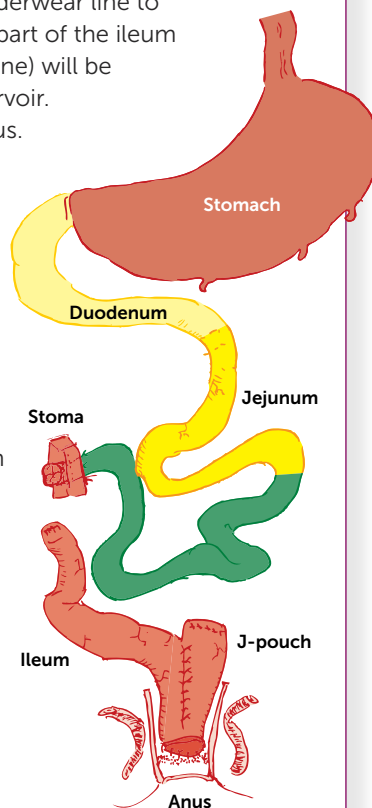
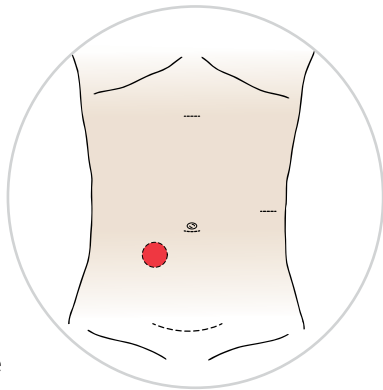
Most patients are discharged from the hospital within five to seven days. After healing, regaining strength and weaning off medications, the next stage of the operation is scheduled at least three months after the first procedure. This time frame may vary depending on the healing of the lining of your rectum.

THE THREE-STAGE PROCEDURE

Second Stage

The pouch is created using laparoscopic surgery (also called minimally invasive surgery).

- Once you are asleep, a tube (NG tube) is placed into your nose and down to your stomach to drain the fluid from the stomach as in the **first stage**. A small tube is also placed into your bladder to drain the urine (pee). These tubes stay in place for the first few days after surgery similar to the first stage.
- The remaining rectum is taken out through the same small incisions from the first stage. The mucosa, or the inner lining of the rectum, is separated from the muscular wall through the anus. The muscle wall of the end of the rectum is left in place, but the diseased rectum is removed.
- Once the rectum is removed laparoscopically, an incision is made under your underwear line to create the ileoanal J-pouch. A part of the ileum (the last part of the small intestine) will be used to create a J-shaped reservoir. The J-pouch is sewn to the anus.
- There will be several additional drains placed during this procedure. Two Jackson Pratt (JP) drains are placed around the pouch, and will come out through one of the side incisions on the abdomen. Additionally a small drain will be placed in your anus into the pouch. These drains will remain for 4–5 days after surgery and will be removed at the bedside.
- A new temporary ileostomy is brought out onto the abdominal surface in the same place as the first stoma. This allows the J-pouch, along with the area where the pouch is sewn to the anus, to heal properly.



Post Discharge

After you are sent home (discharged), you will have outpatient visits with the surgeon and nurse practitioner.

During each of your surgical office visits, you will have a rectal examination done by your surgeon to check how the pouch is healing. The examination may be uncomfortable, but should not be painful. The surgeon will insert a lubricated gloved index finger, press the finger against the outer edge of the anus, and then slide the finger into the anal canal. At this point, the anal tone will also be checked by asking you to squeeze the finger with your anal muscles.

To prevent the connection of the pouch to the anus (anastomosis) from narrowing and making it difficult to poop, it may be necessary to stretch the anus (anal dilations, see page 9). If this is necessary, part of your visit will be dedicated to teaching you to insert a Hegar dilator into the anus to help slowly stretch the area where the new pouch has been made so that stool can pass. Your surgeon and/or nurse practitioner will explain and demonstrate how often and for how long these dilations will need to be done.

In about six weeks, after healing and regaining your strength, you will be scheduled for an x-ray study (Pouchagram) to look at how the J-pouch is healing.

The following will take place:

- A catheter is put into the anus to instill a small amount of contrast solution into the pouch, while taking pictures of the pouch in order to make certain it has completely healed.
- You will then be seen in the surgical clinic, where the nurse practitioner will teach you how to begin fluid “challenges” once a day. Some call these “irrigations” or “instillations.” You will be instructed to place a soft, flexible catheter into the anus and reservoir and put water in once a day. This will help exercise your sphincter muscles to improve how well you will be able to hold the stool and avoid accidents once the ileostomy is surgically closed and the stool passes through the anus. This will also potentially help decrease the amount of times you need to go to the bathroom once the ileostomy is surgically closed.

The amount of water and time to hold the water will be increased every week to let the reservoir slowly stretch and increase the amount of fluid it can hold. You will be encouraged to hold the water for 10 to 45 minutes, if possible, then sit on the toilet and empty it out.

THE THREE-STAGE PROCEDURE

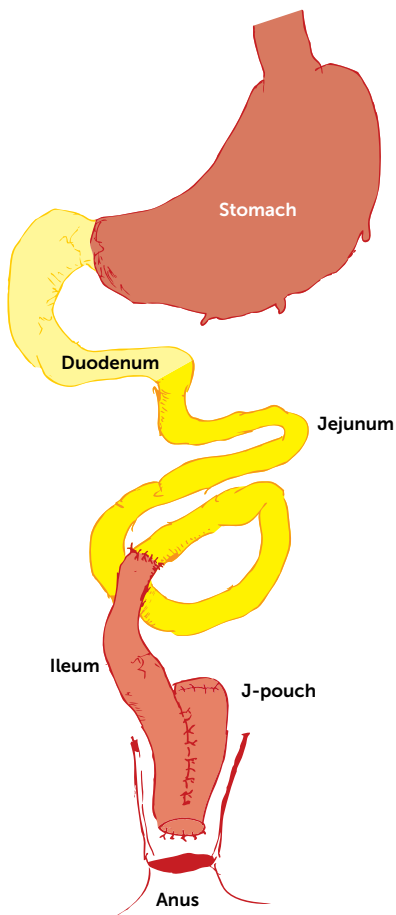
Third Stage

The ileostomy is closed.

This stage is often called the “takedown” because the end of the ileum, which made the ileostomy, is taken down from the abdominal wall and connected to the ileoanal reservoir (J-pouch). The operation is done through the same incision as the previous surgery.

The ostomy site will be closed with sutures and then covered with gauze and tape.

Stool can now flow directly into the internal J-pouch and come out of the body through the anus. The surgical procedure usually takes three to four hours.



Post Discharge

You will go through a period of adjustment with your new ileoanal J-pouch after the ostomy is closed. It will begin to stretch slowly and the frequency of bowel movements will slow down after the first few months from the ileostomy takedown. Each week, you will feel better and better, and be able to return to your previous activities, school-work and sports.

During each of your surgical office visits, you will have a rectal examination done by your surgeon to check how the pouch is healing. The examination may be uncomfortable, but should not be painful. You may have a feeling of rectal fullness and the desire to poop. The surgeon will insert a lubricated gloved index finger, press the finger against the outer edge of the anus, and then slide the finger into the anal canal. At this point, the anal tone will also be checked by asking you to squeeze the finger with your anal muscles.

To prevent the J-pouch from narrowing and making it difficult to poop, it may be necessary to stretch the anus (anal dilations) daily. If this is necessary, during your visit you will be taught how to insert a Hegar dilator into the anus to help slowly stretch the area where the new pouch has been made so that stool can pass. Your surgeon and or nurse practitioner will explain and demonstrate how often and for how long these dilations will need to be done.

The first six to eight weeks: It is not uncommon to have 8–12 watery-like stools per day in the first few weeks after surgery. It’s important to drink plenty of fluids even when the stoma is taken down to prevent dehydration (refer to importance of hydration on page 13).

The first six to twelve months: You may have occasional “accidents” in your underwear during this early time of adjustment. This is most common during the night when you are sleeping. Most people are able to sense whether they have to pass gas (fart) or stools (poop). This will get easier as you eat more regularly and your stools begin to thicken and have a pasty or semi-formed consistency. Once fully recovered, most people have between four to six bowel movements per day and can successfully pass gas without having an “accident.” Some people may need to get up during the night the first few weeks or months after surgery. This may also happen if you eat late at night.

How to Do Anal Dilations

- Run Hegar dilator under warm water, then lubricate its end with a water-soluble lubricant (such as K-Y jelly).
- Get into the position you need to put in the dilator. (You will have been shown a few positions by your doctor.)
- Apply gentle pressure until dilator passes up into the anal reservoir as instructed by your surgeon or nurse practitioner (NP) and move it back and forth while you slowly count to 10.
- Some bleeding is normal following anal dilations; however, this should not be more than a few drops and right after dilation is done. If bleeding continues, call your surgeon’s office.
- Remove dilator and clean it with soap and water and store for next use.

THE TWO-STAGE PROCEDURE

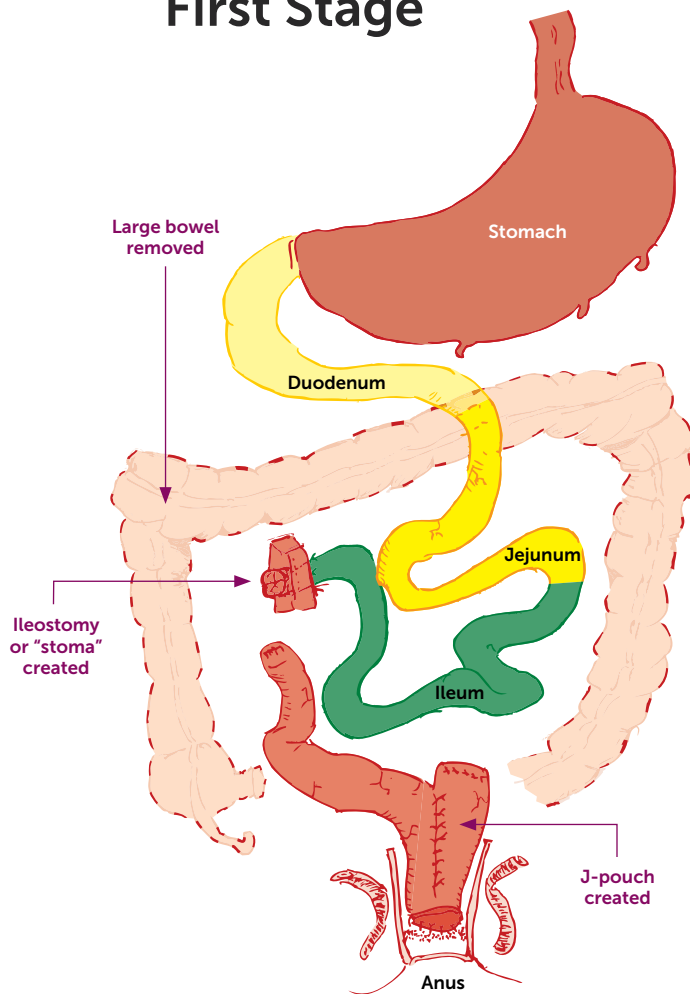
The two-stage procedure can be done for those with ulcerative colitis if:

- you have been off corticosteroids or are on a low dose,
- medical treatment so far has helped you, and
- your rectal lining is intact with minimal inflammation (swelling).

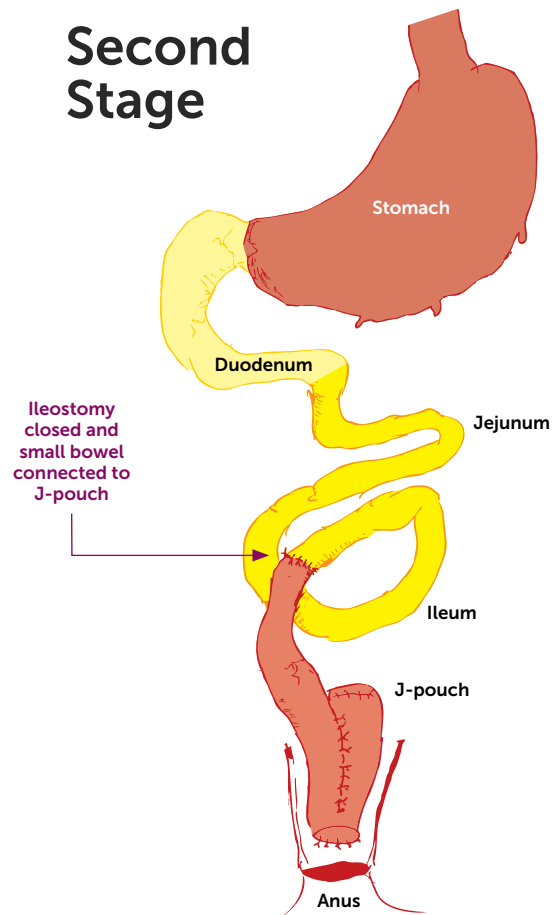
The two-stage procedure is done for all people with FAP.

The two-stage procedure combines the first and second stages as described on pages 6–9 into one longer operation (about seven to eight hours). The second surgery is the “ostomy takedown” as described on page 9. It is the same surgery as the third stage of the three-stage procedure.

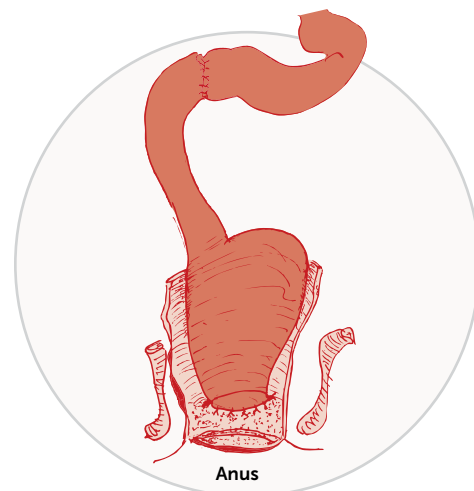
First Stage



Second Stage



Healed J-Pouch



Preparing for Surgery

Before Surgery

You will need to come in for a pre-op appointment approximately one week before your scheduled operation to have a history and physical exam done. At that time, you will meet with nurses and/or nurse practitioners and a member of the Anesthesia Department to talk about medicine that will be used to put you asleep during your surgery.

The day before you are scheduled to come to the hospital you will get a call from the Admitting/Pre-Op Clinic. They will tell you what time to come to the hospital.

How should I clean my bowel out to prepare for surgery?

Before the surgical procedure, it is very important that your bowel be cleaned out to minimize the risk of an infection. A surgical nurse practitioner will contact you during the week before surgery to discuss your bowel preparation instructions (which may vary) and answer any questions or concerns you may have. You can only drink clear liquids the day before you're admitted for surgery. You will not be able to eat or drink after midnight in preparation for surgery and anesthesia the next day.

What should I bring to the hospital?

- comfortable sleepwear
- underwear
- slippers and/or flip-flops
- books, e-readers, magazines
- handheld electronic devices you use, and headphones if desired
- favorite objects such as a stuffed animal or blanket
- toiletries

Day of Surgery

When you arrive the day of surgery, you will go to the Pre-Op area on the third floor of the Main Building. You will meet with your surgeon who will review with you and your family about the surgery and answer any questions you have. You (if you're over the age of 18) or your parent will sign a consent form for the surgical procedure.

A member of the Anesthesia Department will meet with you and your family to review the plan for anesthesia and answer any remaining questions. While asleep during the procedure, your vital signs (such as pulse, temperature and blood pressure) will be fully monitored throughout the surgery. The surgery requires intravenous lines (IVs) and the insertion of a breathing tube while you are asleep.

Should I keep taking all of my medications?

Tell your surgeon or nurse practitioner about all of the over-the-counter medications and prescription medications that you are taking regularly or occasionally. Your surgeon will discuss whether you need to reduce or stop taking any medications before your operation.



After Surgery

What happens after the operation?

After the operation, you will go directly to the Recovery Room (also called the "PACU"). You will feel groggy and sleepy. Some patients are so sleepy they don't really remember the PACU. A nurse will be checking your blood pressure, heart rate and breathing. The nurse will ask you to take deep breaths while listening to your lungs. Some oxygen will be gently blowing a cool mist near your face or through a small mask.

Your IV, NG tube and urinary catheter that were put in during the operation will still be in place. You may have other tubes or drains based upon which surgical procedure "stage" you are in. In the PACU, if you are having pain, a nurse will give you pain medicine.

Your parents/guardians may come in to visit you in the PACU. After one to two hours in the PACU, you will be moved to your room in the surgical inpatient area.

After the Operation (Post-Operative Care)

Though many of our rooms are for one patient and a parent or guardian, you may have a roommate. If you have a roommate, each of you will have a TV, and a DVD player. A child life specialist is available on the unit to provide videos, arts and crafts, games and other activities.

Your nurse will meet with you and get you settled into your room. You will be somewhat sleepy for the first day. Your temperature, heart rate, breathing and blood pressure will be checked. You will be shown how to use something called an incentive spirometer ("blow bottle") which helps show you how big your breaths are. Your nurse and parents will remind you to do 10 breaths with the incentive spirometer every hour. This helps to inflate your lungs fully until you are up and moving around more often. This prevents you from developing pneumonia.

During the next few days, you will do many tasks to help in your recovery. One of the most important ones will be learning how to take care of your ostomy. You will not go home until you and a family member are comfortable and able to care for your ostomy and change your pouch. A discharge planning nurse will speak with you and your family about arranging for a visiting nurse, who will help you learn about and care for your ostomy, and order ostomy supplies for you.

Pain Management

Controlling post-operative discomfort or pain is very important to your recovery. When your pain is controlled, you will sleep better, feel more relaxed and be able to move around more easily. Before your surgery, your surgeon and anesthesiologist will talk with you about options to control your discomfort after the surgery. Your nurses will ask you about your level of pain to determine when you need pain medicine.

Pain control is managed by giving pain medicine either through an IV, pain catheter or an epidural catheter. (Please refer to Family Education Sheets: "Patient Controlled Analgesia for Pain Relief" and "Epidural Catheter for Pain Relief.")

IV pain management uses a **patient controlled analgesia (PCA) pump**. By pushing a button, you can give yourself a dose of pain medicine directly into your IV catheter. This technique requires you to be an active participant and allows you to use as much medicine as necessary. Several safety mechanisms prevent accidental administration of too much medicine.

A second option for pain management is to have an **epidural catheter** (a thin flexible tube) placed during the operation by an anesthesiologist. The catheter attaches to a syringe filled with pain medicine. A pump delivers a continuous flow of pain medication, giving you more continuous pain relief. A doctor orders the amount of medicine delivered by the pump. Since a local anesthetic (like numbing medicine at the dentist) is used, you may notice that you have some temporary numbness or weakness in your legs after the surgery. Occasionally, people report itching as a result of epidural pain medications.

Another type of regional anesthesia that has been helpful for patients instead of an epidural catheter is a **transversus abdominis plane (TAP) block**. The anesthesiologists use ultrasound to help them place a dose of pain medication in the muscles of the abdomen, or place a tube that can provide continuous medication to the area after you wake up from surgery. This type of pain control helps numb the area around the incisions. The anesthesiologist will talk to you more about this before surgery.

All these techniques of pain control are supervised by the Pain Treatment Service (PTS). PTS nurses and doctors check on you every day and are available 24 hours a

day. They can make adjustments at any time to help control your pain. Usually you will need an epidural, TAP catheter, or PCA pump for three to five days until you can drink fluids by mouth. Then you will be changed to taking pain medication by mouth.

Eating and Drinking

The operation, anesthesia and medications make your stomach and intestine slow down for several days. You will be given fluids and nutrients through your IV during this time. A nasogastric (NG) tube is used to help keep your stomach empty, rest the bowel while it heals, and prevent nausea and vomiting. The NG tube is passed through the nose down into the stomach during surgery. It will stay taped in place near your nose until your stomach and intestine start to pass air (gas) and poop into your ostomy pouch. This means that the bowel has begun to function after surgery. You may hear noise from the stoma as it begins to work and air passes from it. Many patients say their stoma is "burping." The amount of air passing from the stoma will decrease over time. Your doctor and nurses will decide when it's time to remove the NG tube. It takes a few moments to untape and remove the tube.

After removing your NG tube, your nurse will let you know when you can start having a small amount of water and ice chips. Go slowly at first! Usually the next day, you are gradually introduced to more clear liquid choices (like Jell-O®, ginger ale and apple juice). You will gradually be able to eat regular foods in small amounts. It may take one to two weeks for your appetite to return to normal. In general, eat small frequent meals for the first two to three weeks. During this time:

- chew food well
- introduce new foods gradually, one at a time
- avoid foods that may cause a blockage of the bowel (such as corn, seeds, nuts, celery, popcorn and raw vegetables like carrots)

Your nurse will review the Family Education Sheet *Ostomy Diet Guidelines* with you before you go home. These guidelines will help decrease your risk of obstruction. There is no need to follow a highly restricted diet. This is a benefit of the surgery for many patients who have had to follow restricted diets before surgery.

The Importance of Hydration

Once you go home, be sure to drink plenty of fluids to avoid getting dehydrated. Good choices are water, milk or lactose-free milk substitute. Limit your amounts of sports drinks and soda as they have lots of sugar.

During digestion, the colon absorbs fluids and some electrolytes, which are chemicals important to the function of many processes in the body. You no longer have the large bowel or colon to absorb water so you must increase the amount of fluid you drink. The stool that comes out of the ileostomy has a lot of fluid in it, which increases the risk of dehydration and problems with the normal chemicals of the body.

If you do become dehydrated, you may need to be brought to the hospital and possibly have to stay in the hospital again.

Blockages or Obstructions

A possible complication of ileostomy and bowel surgery is a blockage or obstruction. Typically, you may have some or all of these signs of obstruction:

- feelings of fullness
- cramping
- vomiting (throwing up)
- a significant increase or decrease in stool coming from the stoma

Activity

You will be on bed rest after you return from the PACU. The nursing staff will help you to turn and adjust your position every few hours so that you do not develop sore skin or any pressure areas. The next day (post-operative day #1), your nurse will help to get you sitting up in a chair. By the second or third day after the operation, the nurses will help you start to walk. This may be a little scary with all the tubes you have in place. You may also be a little weak. Each day you will feel stronger and need less help getting out of bed and moving about.

Assume you will be in the hospital for five to seven days.

When you get home, you may not do any strenuous activity or heavy lifting for the first several weeks. This means no:

- contact sports
- bike riding, roller blading or skiing
- any activity that may involve heavy lifting for three to four weeks

You should not drive a car until you are off all narcotic pain medications and have been instructed by your surgeon that it is safe to do so.

You will probably not be attending school the first week you are home. You may want to think about returning to school the second week but maybe for only half-day sessions. Speak with your doctor about this before you go home.

Bathing

You can shower within a few days after the operation as long as the clear dressing covering the incision is still on. You should not sit in a tub until after the seventh day after surgery.

Ileostomy Care and Management

Your nurses will help you start to feel comfortable taking care of your stoma so that you can get back to doing the things you enjoy doing. Once you have healed from surgery, having an ostomy will not stop you from doing activities, such as swimming, playing sports or riding a bike, to name a few.

The stoma is moist and bright pink or red and looks like the tissue on the inside of your cheek. There are no nerve endings in the bowel so the stoma does not hurt if bumped. Stool drains from the stoma into a pouch that you wear on your abdominal surface. The stoma doesn't have a muscle to control when stool or gas is released, so you must wear a pouch to cover it all the time. The pouch sticks to your abdominal surface and is fitted over and around the stoma.

Gas passing from the stoma is one of the first signs that the bowel has started to "wake up" and work after surgery. Some kids say it's "farting" or "burping!" It can be somewhat noisy the first one to two weeks after surgery, but will be less noticeable as you eat a regular diet again.

The first stool from the stoma usually begins within one to three days after surgery and is a watery green liquid. As you begin to drink fluids and start to eat, the consistency of ostomy output will vary from semi-liquid to a thick, pasty consistency. The stool from the ileostomy contains enzymes (proteins that help digest the food) that are part of the normal digestive process, but can be irritating to the skin around the stoma. It is important to empty your pouch frequently as instructed and to regularly change it about every two to three days as the nurse teaches you, to help you avoid skin irritation.

Your nurse will teach you how to:

- empty the ostomy pouch whenever it has air or is one-third full
- put on a new pouch — which should be done every two to three days
- care for the skin around your stoma

After approximately four to six weeks, the swelling goes down and the stoma usually shrinks. (Please refer to the Family Education Sheet: *Home Care Instructions for Changing an Ostomy Pouch*.)

A discharge-planning nurse from Boston Children's will arrange for ostomy supplies and a visiting nurse to come to your home to continue teaching and answer any questions you may have. Do not hesitate to call the surgical outpatient nurse practitioners if you receive different information and instructions that may be confusing.



Supplies needed for ostomy care



Patient with non-see-through ostomy pouch

Tubes and Drains

The abdominal incisions have dissolvable stitches and small white bandages-like strips across them. These will be covered with gauze and a clear plastic dressing. The first dressing put on in the operating room will be changed at least once before going home from the hospital. The small white bandages begin to peel off usually about 10 days after surgery. You should take them off if they are still in place two weeks after surgery.

You will have many tubes and drains. Remember that each one has a purpose and will be removed as soon as possible.

When your surgeon creates your ileoanal pouch a **Jackson Pratt (JP) drain**, or drains, may be inserted through your skin and into your abdomen. They will help drain any fluid from your pelvis and from around your pouch. These clear thin drainage tubes will be attached to a soft squeezable bulb about the size and shape of a lemon that has a plug-type closure (like a beach ball cap). The squeeze bulb on the end of the drain tube creates a gentle suction that helps to get the fluid out of your abdomen faster. Your nurse will open this cap a few times a day to empty and measure the drainage into a measuring cup. The drainage in the beginning will be red, and should change to pink then colorless as you heal. A JP drain is usually taken out four to five days after surgery. There is a gauze dressing around the tube site, which your nurse will change once a day and whenever it becomes wet with drainage.



A soft, flexible drain called a **Penrose drain** is also placed during surgery. It is placed when your ileoanal reservoir is made. The drain comes out from your anus. It looks like the neck of a balloon. It helps empty any mucus or bloody drainage from the ileal pouch to prevent it from becoming too full. It is usually removed five days after surgery. The pouch will continue to produce small amounts of mucus daily or every few days. For the first few weeks after surgery, it may be tinged with blood. At some point, you may have an urge to have a bowel movement. You may need to sit on the toilet and gently push mucus from the anus. The amount of mucus and frequency of discharge varies. The drainage usually does not have an odor.

The skin around your anus may become irritated after any of the surgical procedures, but the irritation is most common after the final stage when the ileostomy is closed and you are passing stool through the anus again.

The mucosa (or lining of the bowel) secretes slippery mucus to lubricate the passage of stool. Before the ileostomy is closed, mucus from the unused lower portion of the colon (i.e. the rectal remnant) or the J-pouch — depending upon which stage of surgery you have had — may seep from the anus and be hard to control. This is temporary; once the ileostomy is closed, the mucus mixes with the stool and is easier to control.

Using soft toilet paper and keeping the area clean and dry is very important. Initially, some people feel more comfortable wearing an absorbent pad in their underwear to avoid moisture. The treatment for rectal drainage is to protect the surrounding skin. Your nurses/nurse practitioners will recommend skin care powders, creams or ointments that will help.

An **epidural catheter** is a small tube, which the doctor may place in your back, in which pain medicine is sometimes given.

A **PCA pump**, or patient controlled analgesia pump, is a device that has a button you can push to give yourself pain medication.

A **TAP block**, or transversus abdominal plane, describes the location of the anesthesia. This block is placed in the muscles of the outside of the abdomen, and pain medication is either given during your operation or given continuously through a catheter (tube) to the area after you wake up from surgery.

A **Foley catheter** is placed into your bladder while you are in surgery. This thin tube drains urine (pee) and empties your bladder. While the epidural or PCA pump is in place, you may not feel the sensation of a full bladder and your bladder will not empty normally. This is usually removed six to eight hours after you begin taking pain medication by mouth.

An **intravenous (IV) catheter** is inserted into a blood vessel in your arm to give you fluids and medicines until you are able to drink and eat.

Sequential compression devices (SCDs), sometimes called “pneumoboots,” are Velcro®-wrapped sleeves that are placed around your legs during the operation. These sleeves are attached to a pump that gently squeezes and then relaxes. These are to help with the blood circulation and prevent any blood clots from forming in your leg veins. They will be removed several times a day to wash your legs and check your skin.

You will be shown how to use an **incentive spirometer** (“blow bottle”). This will help keep your lungs healthy after surgery by teaching you how to take slow, deep breaths and inflate your lungs fully. Using the incentive spirometer every few hours will decrease the risk of pneumonia.

Medications

If you took steroids before your surgery, you may be on what is called a “steroid taper” after your surgery. This is when the dose of the steroids is slowly decreased over the first few weeks after surgery.

Review of Potential Complications

Before surgery, your doctor and nurses will have reviewed possible complications related to the surgery. Several of them will be mentioned here again.

Small Bowel Obstruction (SBO)

Small bowel obstruction is a blockage of flow of food, fluid and gas through the small bowel in a normal way. Symptoms may include cramping or severe belly pain, vomiting (throwing up) and swelling of your belly. Your doctor will check your belly for swelling and tenderness and may do an abdominal x-ray. Small bowel obstruction is often treated with medicine and fluids through an IV for a few days to provide enough fluid in your body. A nasogastric (NG) tube is also placed to empty the stomach of fluid and gas, relieve pain and pressure and rest the bowel. Most bowel obstructions get better on their own. If the blockage does not get better, or if there is a complete blockage and you have a lot of pain, surgery may be needed.

Dehydration

During digestion, the colon absorbs fluids and some electrolytes (which are important chemicals in the body).

After the surgery, you no longer have the large bowel or colon to absorb water. The stool that comes out of the ileostomy has more water in it than the stool that usually comes out of the anus. Therefore, you must increase the amount of fluid you drink to prevent dehydration. If you become dehydrated, you may need to be brought into the hospital for IV fluids. To prevent dehydration, you need to increase the amount of fluids you are drinking when:

- the weather is hot and humid
- you are playing sports
- you are increasing activity like hiking, biking, skiing
- may occur when you become sick, are unable to drink

Stenosis

After surgery there may be narrowing of the anal canal where the J-pouch is surgically sewn and connected to the rectum. While the ileostomy is in place, scar tissue forms where the J-pouch connects to the anus. The surgeon will need to feel this area every time you come in for routine office visits or if you are having symptoms of an obstruction or blockage. These symptoms may include: straining, anal pain, frequent watery stools, urgency (feeling like you need to go right away), feeling like the stool doesn't come completely out, and leakage. The stenosis will need to be stretched to allow proper healing and easy passage of stool. Sometimes your doctor can stretch the area by using a lubricated gloved finger. More likely, you will require daily dilations with a special dilator to slowly stretch (dilate) the anal area (see How to Do Anal Dilations, page 9).

Pouchitis

Pouchitis is an inflammation (swelling) of the internal reservoir or J-pouch. This takes place in about 30 percent of patients with an ileoanal J-pouch. No one knows what causes pouchitis. Symptoms may include:

- an increase in the number of stools and going to bathroom more often
- bloody diarrhea
- urgency (feeling like you have to have a bowel movement immediately)
- abdominal cramping or pain
- runny (more liquid) stools
- incontinence or “accidents” (unable to hold stool inside)
- fever
- feeling more tired than usual

If you have any of these symptoms, your gastroenterologist (GI doctor) or surgeon should evaluate you. There is no single test that diagnoses pouchitis. It is often diagnosed based on the symptoms you are having. An examination of the pouch by your GI doctor using endoscopy may be needed to confirm the diagnosis and show the degree of inflammation. Pouchitis may resolve with a short course of antibiotics and sometimes with probiotics (“good” bacteria that normally live in the digestive tract) such as Lactobacillus, Bifidobacterium and Thermophilus. Pouchitis rarely becomes chronic, but may require long-term antibiotic therapy or steroids.

Pelvic Infections

In some cases, the rectal stump or ileoanal J-pouch does not heal properly and an infection in the pelvis can occur. This is different than pouchitis. Antibiotics and/or drainage (if a collection of fluid, called an abscess, is present) may manage the infection. To help confirm the diagnosis and create the right treatment plan, your doctor may do an ultrasound scan or computerized tomography (CT) scan. Sometimes, surgery is required.

Perianal Skin Care

After the ileostomy stoma is closed and stool is passing through the ileoanal J-pouch out the anus, it is important to care for the skin around the anus, called perianal skin, to prevent irritation. This is very important for the first few weeks after surgery. Since the irritation can become severe, it's important to rinse and clean the area each time you go to the bathroom. Irritation can also occur if you develop gastroenteritis or pouchitis and have an increased number of stools. If perianal skin irritation develops, it is usually temporary. Cleaning the skin well and using ointments that the nurse practitioner has recommended to protect your skin will help it to heal. You may need to wear a pad or liner to absorb any stool that may leak onto the skin.

Special Considerations with Medications

People who have their colon removed when they have the J-pouch surgery digest food more quickly and must take special precautions when taking some forms of GI medications.

Be aware of different forms of medications you are prescribed. For example, time-release or enteric-coated pills will no longer be effective. Consult with your GI doctor or surgeon. Delayed-release or time-release medicines will not be effective because it takes a shorter period of time to pass through your GI system. Antibiotics can cause diarrhea, so be aware that this may occur and let the prescribing physician know if you have diarrhea.



NEVER TAKE AN ENEMA OR LAXATIVE!

These are often given to clean out the large bowel, which you will no longer have. If you have any questions or concerns, contact your general surgeon or GI doctor.

Exercises

Pelvic exercises called Kegels may be started a few weeks before your last surgery for ileostomy closure. The purpose is to strengthen the tone of your anal sphincter muscle. These muscles help you control your bowel function, and keep the stool (poop) inside your body and prevent "accidents."

How to Do Kegels

Tighten your anal muscle as if you are trying to stop a bowel movement. It should feel like the same sensation when you stop your urine stream when voiding (peeing). Do not just squeeze the buttock ("bottom") muscles.

Hold to the count of ten while squeezing tightly then relax for a count of ten.

Repeat these exercises 10 times for one full set.

Try to do four to five sets a day. You can do them anytime in any position. Most people remember to do them whenever they go to the bathroom or when watching TV. Kegels can be done at any time and in any position.

Follow-Up Appointments

You will see your surgeon frequently in the first year after surgery. During the appointments, the surgeon and nurse practitioner will make sure that you are healing properly and help address any concerns that you may have.

You will have your first appointment with your surgeon approximately two weeks after surgery. During each appointment, the surgeon and nurse practitioner will review your health and do a physical exam. At that time, they will talk with you about your activity level and what you can and cannot do.

Once the ileoanal J-pouch is created, the surgeon does a digital rectal exam. A digital rectal exam is done during every visit after the J-pouch creation to make sure that the connection is healing properly and there is no stenosis (narrowing) of the ileoanal connection. During the visit, if a stenosis is present you will be taught how to do dilations in order to stretch the connection of the J-pouch and the anus.

Follow-Up Schedule for the Three-Stage Procedure

After the 1st Stage

FIRST MONTH AFTER THE 1st STAGE

- The team will check to see if you are ready to start planning for the 2nd Stage.
- Endoscopy of the pouch and ileostomy is scheduled with your gastroenterologist approximately two weeks prior to the 2nd Stage. You may also start cortifoam enemas to prepare the remaining rectum for the 2nd Stage operation.
- 2nd Stage is scheduled at least 3 months after the 1st Stage. Your team will discuss the surgical plan.

After the 2nd Stage

2 WEEKS AFTER THE 2nd STAGE

- The surgeon will do the first digital rectal exam. You may be taught to do dilations to be performed at home at least daily.

6 WEEKS AFTER THE 2nd STAGE

- Pouch study will be done in Radiology.
- Surgeon will do another digital rectal exam and possible dilations.
- You will get supplies along with instructions for pouch irrigations (see instructions below).

3–6 MONTHS AFTER THE 2nd STAGE

- 3rd stage will be scheduled.
- Your team will discuss the surgical plan.

After the 3rd Stage

2 WEEKS, 2 MONTHS AND 6 MONTHS AFTER THE 3rd STAGE

- Rectal exam and/or dilations (if necessary) will be performed at each clinic visit.

WITHIN 1 OR 2 MONTHS AFTER DISCHARGE

- You will also need an appointment with your GI doctor.

You can call your nurse practitioner at any time with questions or concerns at **617-355-7716**, Mon.–Fri., 8 a.m.–6 p.m. A surgeon is available at **617-355-7800**, 24 hours a day. To schedule an appointment with your GI doctor, call **617-355-6058**, Mon.–Fri., 7 a.m.–8 p.m.

Pouch Irrigations or “Fluid Challenges”

These are started six weeks after your pouch has been created (and at least six weeks before your final surgery for ileostomy closure). The purpose is to slowly increase the volume of water (fluid) that the pouch can hold. It also strengthens the anal sphincter muscles so they can hold stool or gas and helps your pelvic muscles “learn” the sensation of ileal pouch fullness for when your ostomy is closed. Your surgeon and/or outpatient nurse practitioner will give you detailed instructions on when to begin these “fluid challenges” and how much water to instill. You will start by using a catheter and water.

The Pouch Irrigation Procedure

1. Fill a catheter tipped syringe with prescribed amount of water.
2. Carefully insert the catheter about two to three inches into the anus and hold in place.
3. Gently push the water from the syringe into the catheter, which should then enter the pouch. If the water drains out from the anus, gently move the catheter in a little more and then continue to instill the water gently.
4. After water has been put in, take out the catheter.
5. Try to hold the water in for as long as possible while doing pelvic floor muscle exercises, then empty it out by sitting on the toilet.

Each week increase the amount by 1 ounce.

Week 1 1 ounce total, hold for 10–15 min.

Week 2 2 ounces total, hold for 15–20 min.

Week 3 3 ounces total, hold for 20–25 min.

Week 4 4 ounces total, hold for 25–30 min.

Week 5 5 ounces total, hold for 30–35 min.

Week 6 6 ounces total, hold for 35–40 min.

If you have any discomfort while doing the procedure, stop and call your surgeon or outpatient nurse practitioner to discuss if you should continue the irrigations.



Support

Home Care Agencies

A nurse from a Visiting Nurse Agency (VNA) may come to your home to help review ostomy care and watch for any possible complications.

A Durable Medical Equipment (DME) supply company will deliver ostomy supplies to your home that have been ordered by the hospital. Your nurse will provide you with the name and phone number of your supply company who you contact directly for supply refills.

Coping: A Note for Parents

Learning how to cope is easier when parents, children and health care professionals work together as a team. While in the hospital, child life specialists are available to help reduce any fears surrounding this experience, especially for younger children. Adolescents may not want to ask many questions or admit their concerns and fears. They may prefer not to speak with the entire team present on morning rounds, for example, and may need a private, confidential environment to bring up their questions.

If your son or daughter has questions, always answer them honestly so they will be prepared for what will happen. Children often sense when their parents, doctors, nurse practitioners or nurses are hiding something from them. Providing honest information about what to expect may promote positive self-esteem and coping ability during hospitalization and outpatient doctor's visits.

Decide appropriate "advance notice" time. Some children prefer to know well ahead of time what's coming, and some do better knowing closer to the time of the event (for example, when a tube is going to be removed). You know your child better than anyone. In our experience, it's helpful for children to have information about what is going to happen to them. Our team can support you in this.

If your child is an adolescent and would like to speak privately with their health care team providers, please respect their wishes.

Some children and youth like to have comfort objects like stuffed animals or music during procedures.

Emotional support for you and your child is available during the hospitalization. There are nurses, child life specialists, social workers and psychologists available to provide support. Parents often feel sad, fearful or helpless even if your doctor assures you that your child's prognosis is good. Some may feel guilty thinking they may have done something to cause the disease or should have been able to do something to prevent it. Although these kinds of questions are both common and normal, try to remember you are not to blame for your child's illness.

Please don't hesitate to ask to meet with a social worker to discuss any concerns you may have.

Resources

Boston Children's Inflammatory Bowel Disease (IBD) Center

617-355-6058

bostonchildrens.org/IBD

Crohn's & Colitis Foundation of America (CCFA)

800-932-2423

ccfa.org

International Foundation for Functional GI Disorders (IFFGD)

888-964-2001

aboutkidsgi.org

National Digestive Diseases Information Clearing House (NIDDK)

800-891-5389

Ostomy Surgery of the Bowel

niddk.nih.gov/health-information/health-topics/digestive-diseases/ostomy-surgery-bowel/Pages/ez.aspx

United Ostomy Association of America (UOAA)

800-826-0826

ostomy.org

U.S. National Library of Medicine

888-346-3656

Genetics Home Reference:

Familial Adenomatous Polyposis

ghr.nlm.nih.gov/condition/familial-adenomatous-polyposis

Wound, Ostomy and Continence Nurses Society (WOCN)

888-224-9626

wocn.org

Youth Rally

An overnight 5-day camp for kids ages 11–17 who have a variety of conditions affecting their bowel and/or bladder systems.

youthrally.org

Glossary

Please note: Some of these terms below may be used in other medical situations. Here, we are giving the definitions that apply to the bowel and this surgical procedure.

Anal dilations A procedure to stretch the anus with a plastic or metal dilator after surgery if it is narrowed or scarred.

Anal sphincters Muscles that surround the anus, which are used to close the anal opening.

Anastomosis The joining (sewing) together of two parts of the bowel.

Anesthesiologist Doctor who gives medication to make you comfortable and prevent pain during the operation.

Anus The opening at the end of the rectum, where poop is emptied from the body.

Blockage An obstruction that keeps digested food or fluid from passing through your bowel. May be caused by swelling that causes narrowing of bowel, an ileus when your intestine slows down or stops contracting, or fibrous bands of tissue (adhesions) in the abdomen which can form after surgery.

Bowel Another word for the intestine. It is the part of the digestive tract that begins at the outlet of the stomach and extends to the anus.

Colectomy Removal of part or all of the entire large bowel or intestine (colon). This is done in the 1st Stage.

Colitis Inflammation of the colon (large bowel).

Colon The lower part of the digestive system, also called the large bowel or large intestine. It is approximately four to five feet long.

Colostomy A surgically created opening on the abdomen or "belly." The end of the colon (large intestine) is brought through this opening to form a stoma.

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

Crohn's disease A chronic, inflammatory process that may affect any part of the digestive tract but that most frequently affects the small bowel, colon, or rectum and/or anus. It often produces diarrhea, fever, weight loss and pain. The cause is unknown.

Dehydration A condition that occurs when someone doesn't replace the fluid they lose through sweat, urination (pee), diarrhea or vomit.

Distention To become bloated or swollen. The abdomen may become distended or enlarged if the intestine is not functioning normally or if there is an obstruction of the intestine.

Electrolytes Chemicals that are part of the fluid of your body and that are crucial for normal function of the body.

Enema A procedure in which liquid is put into the rectum to help empty its contents.

Epidural A small catheter placed during surgery to help deliver pain medication.

Familial adenomatous polyposis (FAP) An inherited disorder characterized by multiple polyps, which are most commonly located in the colon and rectum. People show few symptoms; the disease is often found during a routine check-up or by following individuals known to be at risk. The number of polyps increases with age; hundreds to thousands of polyps can develop in the colon. If untreated, the polyps in the large intestine almost always become cancerous.

Foley catheter A thin, sterile tube inserted into the bladder to drain urine.

Frequency The number of bowel movements in a given time period.

Gastrointestinal Referring to the digestive system.

Ileoanal anastomosis surgery Commonly called the "J-pouch," is the joining of the ileum to the anus after removal of the colon and the rectum. It allows elimination of body waste normally through the anus after removal of the lining of the rectum and large intestine (colon).

Ileostomy A surgically created opening on the abdomen or "belly." The end of the small intestine is brought through this opening to form a stoma.

Ileostomy closure or "takedown" Surgical closure of the temporary ileostomy stoma and reconnect the intestine.

Ileum The last part of the small intestine consisting of about half the length of the small bowel and ending at the ileocecal valve. It is approximately 12 to 15 feet long.

Ileus Absence of the normal contraction and movement of the intestines that helps move food and fluid through the digestive system. An ileus can occur after an abdominal operation. It can also be a side effect of certain pain medications such as morphine and oxycodone.

Incontinence The inability to control the passage of urine and/or stool.

Glossary

Intestine The digestive tract extending from the end of the stomach to the anus. It is divided in the small and large intestine (colon). Most absorption of nutrients and water happen in the intestines.

IV (Intravenous) line A small tube inserted in a small vein in the arm or hand to run fluids, medications and nutrients into your body.

Kegel exercises Pelvic floor exercises (tighten/relax) that strengthen the anal muscles.

Laparoscopy Use of a thin, lighted tube connected to a camera placed through a small incision in the abdomen to look at the internal organs. It allows the surgeon to do surgeries such as removal of the colon with only small incisions. The benefits are less post-op discomfort, quicker recovery time, smaller scars and often a shorter hospital stay.

Large bowel/intestine The lower part of the digestive system, also called the large intestine or colon. It extends from the ileum to the anus. The large intestine absorbs fluid from the intestinal contents. It is approximately 4 to 5 feet long.

Mucus A slippery substance produced by the lining of the bowel to lubricate the passage of stool.

Nasogastric (NG) tube A tube inserted through the nose and extending into the stomach. It may be used to decompress and empty the stomach of gas and liquids or to give liquids, such as the bowel prep solution. After surgery, it is used to prevent nausea until bowel function begins to return.

Ostomy A surgically created opening in the intestine (bowel) through the abdomen (belly) for the drainage of body waste. This opening is also called a stoma.

Ostomy Nurse A registered nurse specially educated to care for patients with ostomies.

Pelvic pouch An ileoanal reservoir created from the ileum. Also known as "J-pouch."

Perianal Area surrounding the anus.

Peristomal Area surrounding the stoma.

Polyp Small growths on the lining of the colon or rectum, which may be flat or bulging, and are usually non-cancerous benign growths that may become malignant.

Pouching system An ostomy pouch or bag which collects body waste such as stool or gas. It can be a one- or two-piece pouching system.

Pouchitis An inflammation of the lining of the ileoanal reservoir pouch (IAP).

Pouch study A rectal x-ray contrast study done around 6 weeks after J-pouch created to look at healing of the new ileoanal reservoir. Fluid is put in your anus and fills the J-pouch. It takes about 15 minutes and you may feel pressure or crampy discomfort when they instill the contrast. This is also called a pouchagram.

Rectum Lower part of the large intestine that is located in the pelvis, between the sigmoid flexure and the anal canal.

Reservoir The surgically created J-pouch that collects or holds stool.

Small bowel Also called the small intestine. It begins just below the stomach with the duodenum, connecting to the jejunum and ending with the ileum. It is approximately 22 to 25 feet long. All nutrients from foods and fluids are digested and absorbed there.

Stoma An opening that is brought through the abdominal skin, usually the right lower abdominal area for stool to exit the body. It is usually pink or red in color.

Stool Solid waste from the body that is passed in a bowel movement. Also commonly called "poop" or "feces."

Stricture A narrowing or constriction. This may occur at the connection of the J-pouch to the anus. Anal dilations can stretch and open this up.

Ulcerative colitis An inflammatory disease of the large intestine (colon) and the rectum in which open sores or ulcers form (in the intestinal lining) that produce pus and mucous. Bleeding, cramping, abdominal pain and diarrhea are the primary symptoms of the disease.

Urgency Sudden need to have a bowel movement without much warning.



AUTHORS



Ellen A. O'Donnell,
MSN, RN, CPNP-PC



Sandy Quigley,
MSN, RN, CPNP-PC, CWOCN

ACKNOWLEDGEMENTS

Special thanks must be extended to our patients and their families for their involvement in the creation of this guide. We'd also like to thank Drs. Robert Shamberger and Jill Zalieckas for their support and guidance, Dr. Neil Feins for his medical illustrations, Dianne Arnold, MSN, RN and Melissa Howard, Administrative Associate for their contributions to the original guide.



Then and Now

When this guide was first published in 2007 it featured Kim, who had undergone the ileoanal J-pouch procedure, on the cover. Today she is a nurse in the Boston Children's Hospital Emergency Department.