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HEALTH CARE

How you want to be treated.

A Patient's Guide to

The Pelvic Pouch Procedure

Please bring this booklet to all your appointments

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The information in this document is intended solely for the person to whom it was given by the health care team. If you have questions, please talk to a member of your team.

The Pelvic Pouch Procedure

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our thanks to all.
References available upon request.

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This material has been reviewed and approved by patients, families and staff.

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Introduction

What you need to know about a Pelvic Pouch Procedure

This booklet was written to help you understand all the ins and outs of having a pelvic pouch procedure. This includes understanding the surgery and then what happens in the hospital and beyond. There are different names for this procedure but they all refer to the same thing. We call it the "pelvic pouch procedure" or the "pelvic pouch." It is also called ileal pouch anal anastomosis, IPAA, "S", "J" or pelvic pouch procedure.

This booklet also includes information you need after your operation. Bring it to the hospital so you can look at it after your operation. Write your questions in the blank pages in the back of the booklet. There is also a list of definitions to help you understand unfamiliar words.

What is the Pelvic Pouch Procedure?

During pelvic pouch surgery, the large intestine is removed and then the small intestine is connected directly to the anus. Because you no longer have a large intestine, many people find certain diseases get better after the surgery.

After this surgery your body works differently. It is a big change. You have to learn how to control your bowels again. It takes time to get used to having a pelvic pouch.

There are some very important things only you can do to get ready for surgery and have the best possible results from it. Pelvic floor exercises (or Kegels) are very important for both women and men, both before the surgery and afterwards. See page 8 for more information."

Conditions that can benefit from a Pelvic Pouch Procedure

Ulcerative Colitis

An inflammatory disease of the lining of the large intestine (large bowel or colon), including the rectum. Symptoms of this disease include crampy abdominal pain and bloody diarrhea with frequency and urgency. People with ulcerative colitis are at a higher than average risk for cancer.

Familial Adenomatous Polyposis

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 large bowel. If the disease is untreated people with this condition have a 100% risk of developing cancer.

In both of these diseases only the mucosal (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 you to maintain control of your bowel movements.

Who should not have a Pelvic Pouch Procedure?

There are some medical conditions that mean you should not have a pelvic pouch procedure.

Crohn's Disease:

Because the disease affects the small and large intestine, we cannot use the small intestine to make an internal pelvic pouch.

Anal Incontinence:

Individuals who have serious problems with rectal control will not benefit from this procedure. This will be evaluated by your surgeon.

Although not absolute contraindications, the following factors affect the risks and success of this procedure.

- Age: Some older adults (over 65 years of age) are at greater risk of dehydration and electrolyte loss. It may also take longer for their body to adapt and the pouch to start working, compared to younger patients.
- Obesity: The operation is more difficult in people who are overweight. This is because their body fat makes the abdominal wall thick.

What to Expect after Surgery

It takes time for your body to adjust after pelvic pouch surgery. A pouch can take from 1 to 5 years to truly settle down. During this time you may have more frequent bowel movements than expected. You may also have incontinence episodes that require you to wear incontinence pads. In general, a year after surgery, people with a pelvic pouch have:

- An average of 4 to 8 bowel movements every day, with one at night.
- Each bowel movement will take at least 10 to 15 minutes
- You will be able to hold your bowel movements for up to an hour or longer
- Very little or no stool leakage. If this does occur, it is usually at night.
- Difficulty telling the difference between gas and stool. Because of this you may or may not pass both at the same time.
- The ability to eat a varied diet

Pros (Benefits)

- No permanent ileostomy.
- Fecal continence usually good.
- Good function in more than 90% of patients.
- Risk of cancer is extremely low, but regular checks are needed.
- Low risk of sexual problems.

Cons (Potential Challenges)

- Often needs more than one operation
- It may be more difficult to become pregnant
- Frequent bowel movements (usually 4 to 8 per day)
- About 10% of patients have fecal incontinence, especially at night. Possible skin irritation around the anus due to many bowel movements.
- Up to 30% of people with a pouch report an occurrence or recurrence of bowel inflammation of the pouch (pouchitis).
- You will have to make some changes to what you eat.
- You may need anti-diarrheal medicines such as Imodium
- About 5% of patients have their pouch fail and may choose to have a permanent ileostomy with possible removal of the internal pouch

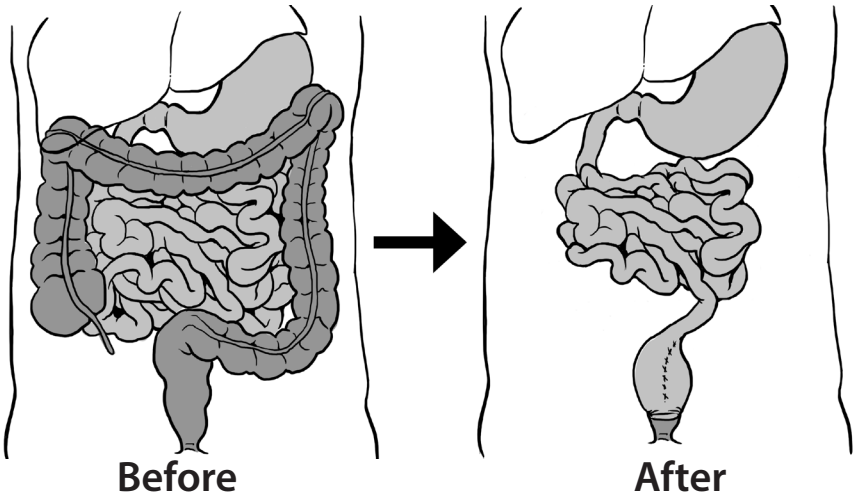
Talk to your ostomy nurse after your final surgery. They will be able to help you through your journey. You will have difficult times while you recover from surgery and your body adapts. You must be able to continue taking care of your new pelvic pouch even when you are not happy with the way your body is behaving. It takes motivation to persevere when things are difficult. To achieve this, you must be well informed and be willing to follow the necessary routines.

Support is available from your surgeon or ostomy nurse. Many communities also have support groups. We have listed some of these in the 'Resources' section on page 22.

The Final Result: Pelvic Pouch Procedure

- The entire large bowel and rectum are removed but the nerves, muscles and sphincters that are needed to control bowel movements are left in place.
- 20 to 30 cm (up to 12 inches) inches of the small intestine are used to build a pouch inside the pelvis. This is called an ileal pouch or pelvic pouch.
- The pelvic pouch is attached to the top of the anal canal above the sphincters.
- Many patients have a temporary stoma (ileostomy) on the outside on their abdomen (which will need a pouching system) for a time to allow the pelvic pouch to heal after surgery. This stoma will be a "loop" or "diverting" ileostomy. (see Ileostomy management on page 4 for more information)

Types of Pelvic PouchSurgeries



Depending on the patient, their medical condition and their health the surgeon may need to do more than 1 surgery. (2 to 3 surgeries are the most common). This decision will be made between you and your surgeon. The choice of procedure will depend on how healthy you are, whether you have been on certain medications (like steroids) that may increase your risk for problems, and your underlying disease. Typically, elective patients undergo a 2 stage procedure (2 surgeries). For people who have been ill, a three stage procedure may be the best choice. Please see Appendix A on page 18 for more detailed information on the surgical procedures

Please see Appendix B on page 20 if you currently have an "end" ileostomy and will be getting a "loop" or "diverting" ileostomy during the surgery when your pelvic pouch is created.

How to get ready for your surgeries

What to expect when you are in hospital after your surgeries

Although there are many kinds of bowel surgeries, the preparation and recovery for these surgeries is often very similar. Please refer to the following for general information.

Bowel Surgery: Preparation and Recovery

Please refer to the patient information booklet titled "Bowel Surgery: Your Guide to Recovery"

OR

go to the following website for more information

http://colorectal.providencehealthcare.org/patient-info/enhanced-recovery-after-surgery

For a new or existing ileostomy, please refer to the following:

Ileostomy Management

For two and three Stage procedures, please read these patient information booklets:

Caring for Your Ostomy

Ileostomy Diet

These booklets are online at: http://colorectal.providencehealthcare.org/patient-info

If you will be having an ileostomy created, you will see an Ostomy Nurse in the preadmission clinic prior to your surgery. This nurse will provide a general overview about your surgery and recovery, answer your questions and place a mark on your abdomen to assist the surgeons with creating your ileostomy in a location that will work with your body type, clothing and lifestyle.

If this is your last surgery, your ileostomy is closed and your new pouch is starting to work, refer to the "Bowel Surgery: Your Guide to Recovery" booklet, and the information below.

What to expect when your new pouch starts to work

As your pouch starts to work, your hard work begins as you start to adapt. Essentially, you will need to learn how to use your bowels again.

Here is what you can expect when your pouch starts to work:

- On the first or second day after surgery, you will start passing gas and having frequent loose bowel movements. This is normal as your bowels start to work again. Most people have 12 to 15 bowel movements a day at this early stage. Over time your bowel movements will eventually average 4 to 8 per day.
- Keep track of your bowel movements. Staying hydrated is very important. See section "Getting Enough Liquid" on page 11.
- Sometimes the first bowel movements are uncontrollable. They may be painful until your body heals. You may experience soreness around your anus due to the frequent bowel movements. Use barrier wipes and protective creams (like zinc) as soon as possible. They prevent soreness around your anus. You may also choose to use pads or incontinence liners in case of incontinence at night.
- You will be given some incontinence pads and protective creams while in the hospital and instructions about what types you may want to buy when you get home. We give more instructions on page 7, "Perianal Skin Care."
- As you gradually start eating normal foods, you may take medication to reduce diarrhea and add bulk to your stool. These medicines will help reduce the number of bowel movements you have. They also help your body use the liquid in your stool so that you don't lose too much water in your stool. If you continue to have diarrhea speak to your surgeon.
- You will meet with a dietitian before you go home.

Strengthen your pelvic floor muscles

The most important thing you can do to get ready for your surgeries is to strengthen the muscles of your 'pelvic floor' (the muscles that are inside your pelvis and work like a 'sling' to support the organs inside your abdomen). If these muscles are strong you will have better control of your bowels after your surgeries. To strengthen these muscles, you can do 'pelvic floor exercises' (also called Kegel exercises) starting 3 or 4 months before your surgeries.

Pelvic Floor Muscle Exercises will:

- Strengthen your anal sphincter (valve) muscles. These are the muscles that control your bowel function once the ileostomy is closed.
- Strengthen pelvic floor muscles that may have been stretched and weakened with surgery.
- Help improve continence by strengthening the muscles around the sphincters and help learn how to relax these muscles when it's time to have a bowel movement

To find out more, read the section called "Improve Control of Your Bowels" on page 8.

What to Expect After You Go Home

The first few weeks and months

- To have bowel movements less often, you need to stretch the pelvic pouch and make it bigger. To do this, try to "hold on" to your bowel movements as long as you can. This builds up pressure and causes the pouch to stretch. Deep breathing, tightening the sphincter muscle (valve) and allowing the sensation to disappear may help. Some people find holding on to be very uncomfortable but this shouldn't be painful.
- If you have pain, talk with your surgeon. If you have severe pains please go to your nearest emergency room.
- Allow yourself 10-15 minutes for each bowel movement for your pouch to empty completely.
- Take care of that peri-anal skin to avoid 'Butt Burn' (redness and pain of the skin around your anus)!
- As you start to eat a normal diet, your stool will become thicker. This can take a few days or a few weeks. Your stool should be soft, but you may notice times when it is more liquid due to certain foods or drinks. Some patients may always have more liquid stools. You will never have fully formed, solid stool.
- As you feel better, you can slowly go back to your normal activities. For example: running, weight lifting, sex, etc.

Be patient. This can be a frustrating time. It takes time to get used to the pouch and learn your body's new signals.

Having a Bowel Movement (Emptying Your Pelvic Pouch)

Allowing 10 to 15 minutes for your pouch to empty is normal for each successful bowel movement. The rectum normally contracts to squeeze stool out like you would squeeze toothpaste from a tube. A pelvic pouch works differently. It empties by using gravity and this takes time. If you spend only a few seconds on the toilet you may only empty stool from the bottom quarter of your pouch. Then, ten minutes later stool in the upper part of the pouch falls into the lower part and another trip to the toilet is required. Instead, sit and rest to let the pouch empty more completely. This way, you need fewer trips to the toilet.

Here are some ways to help your pouch empty:

- Stand up once you feel you have emptied completely. If you have any more stool, this helps it drop down into the pouch.
- Position on the toilet: Lean forward while keeping your back straight. It may be helpful to have a footstool to support your feet so that your knees are higher than your hips.
- Using your breath: Take a deep breath in with your hands resting on your belly and hold so you can feel your belly expand into your hand gently. Exhale a little bit of air and try this sequence three times. Exhale all the way out then inhale again and hold. Exhale all the way out and relax your pelvic floor muscles and sphincter. It may help to visualize your tailbone unfolding to allow the stool to come out.

Perianal Skin Care

The stool from your pelvic pouch can damage the skin around your anus. This is often due to enzymes that are moving through your body and out of the anus.

After your surgery, start protecting the skin around your anus as soon as you have your first bowel movement. Barrier creams stop the stool from touching and irritating the skin. Do not wait for itching or soreness to start. Protecting the skin is important to keep your skin healthy and preventing skin irritation and breakdown. Once your skin "toughens" up, you can use less cream. Each person has a different tolerance so gradually decrease. If you notice skin irritation, see below:

Prevent Irritation:

- Ensure proper hygiene with every bowel movement. Soft toilet paper, wet wipes or a bidet are a gentle way of cleansing for each bowel movement.
- Cleanse and dry skin at least once a day. Be very gentle. Pat the area. Do not wipe or rub. Moistened cotton balls or soft facial tissue are softer than toilet paper. Some people find using a bidet or squirt bottle provides gentle but effective cleansing.
- Warm water or no-rinse cleansers are good for everyday use. Soap can irritate the area. Do not clean with alcohol.
- Use skin protectants to protect perianal skin. Skin barrier creams soothe the skin and add a layer of protection. Some examples: Medline Remedy Hydraguard, Critic Aid Clear, Penaten, or ProShield Plus. Provide skin hygiene and use a barrier after every bowel movement. Use these until you have fewer bowel movements and your stool consistency is thicker.
- Do not use Vaseline or other products that contain petroleum jelly (petrolatum). This ingredient can trap harmful bacteria and harm the skin.
- Change incontinence pads/liners when soiled. If they are not soiled, change at least twice a day or more often to keep skin clean and dry.
- Wear natural fiber underwear that wicks moisture and allows skin to breathe. Do not wear synthetic fabrics (nylon or polyester) – cotton is best.
- Keep a pack of non-scented wet wipes with you to use in public washrooms. These are softer than toilet paper. Do not flush them; wipes go in the garbage.

Treat Irritation:

- You may take Sitz baths or regular baths if your skin is irritated. A Sitz bath uses a special basin on top of your toilet seat, so that you can bathe the perianal area. Use warm or cool water. Hot water can increase irritation. If you have access to a bidet it is an excellent choice. For travelling, you can use a squirt bottle.
- Change your diet, especially if your skin is irritated. See page 11.
- If you have stopped using barrier creams start again.
- If the problem continues, talk with your family doctor or ostomy nurse. They will reassess the problem and suggest further care.

Improve Control of Your Bowels

You need strong pelvic floor muscles to control your bowels. These are the muscles that will help you to hold your stool inside and also help you to empty your new pouch. Many people do have strong pelvic floor muscles; however, exercising these muscles before and after surgery will help you learn how to use these muscles properly and keep them strong. See below for instructions. If you are concerned about whether or not to do these exercises, talk to your surgeon or a pelvic floor physiotherapist.

If you continue to experience leaking or have difficulty locating and exercising these muscles, see a pelvic floor physiotherapist for assessment and treatment. There is a listing of physiotherapists at www.bcphysio.org under "Find a Physio." Select 'Advanced search' and type in your preferred location and choose "Incontinence (urinary/bowel)" as the 'AREA OF PRACTICE'.

Pelvic Floor Exercises (Kegel Exercises)

What are pelvic floor exercises?

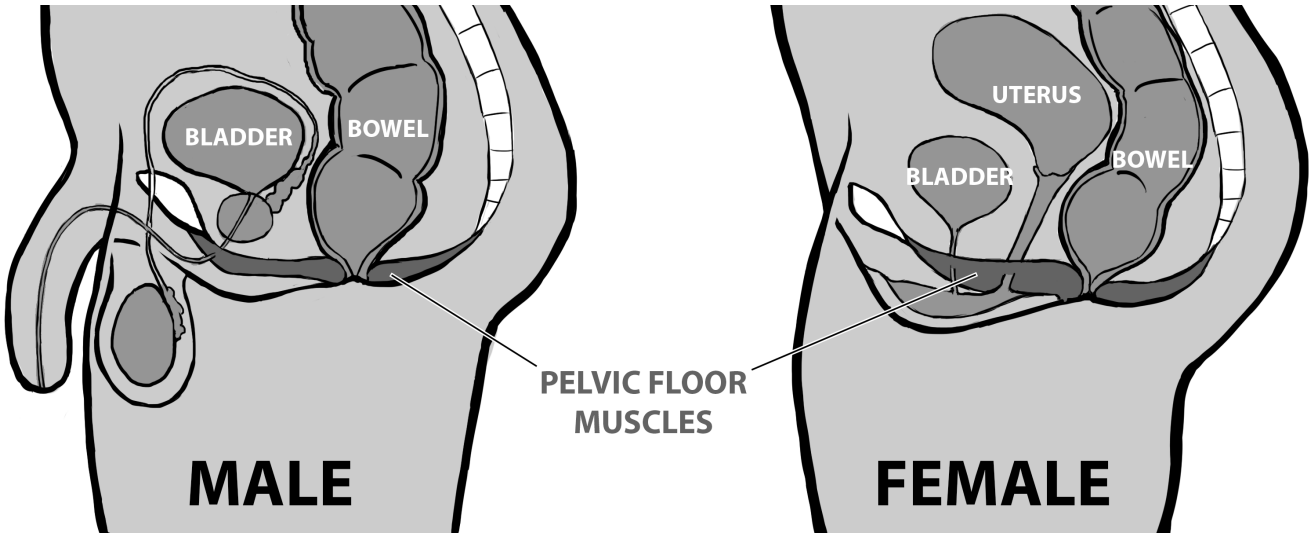
Pelvic floor exercises help strengthen the pelvic floor muscles and they help men and women. It is important to strengthen these muscles before surgery so that you will have better control of continence after your final surgery. It is easier to empty your pouch and maintain continence when these muscles are strong.

Where is my pelvic floor?

The pelvic floor is a sling of muscles and ligaments that stretch across the bottom of your pelvis. It is attached to the pubic bone in front, and to the tail bone behind.

The openings that pass through the pelvic floor are:

- Your urethra, the tube that your urine (pee) passes through
- Your anus
- The vagina (women only)



What does my pelvic floor do?

Your pelvic floor:

- Supports the uterus (women only), rectum, bladder, and abdominal contents
- Helps control the bladder and bowels by holding urine and stool
- Works together with the muscles of the back and abdominal wall to support the back
- Plays an important role in sexual function and pleasure

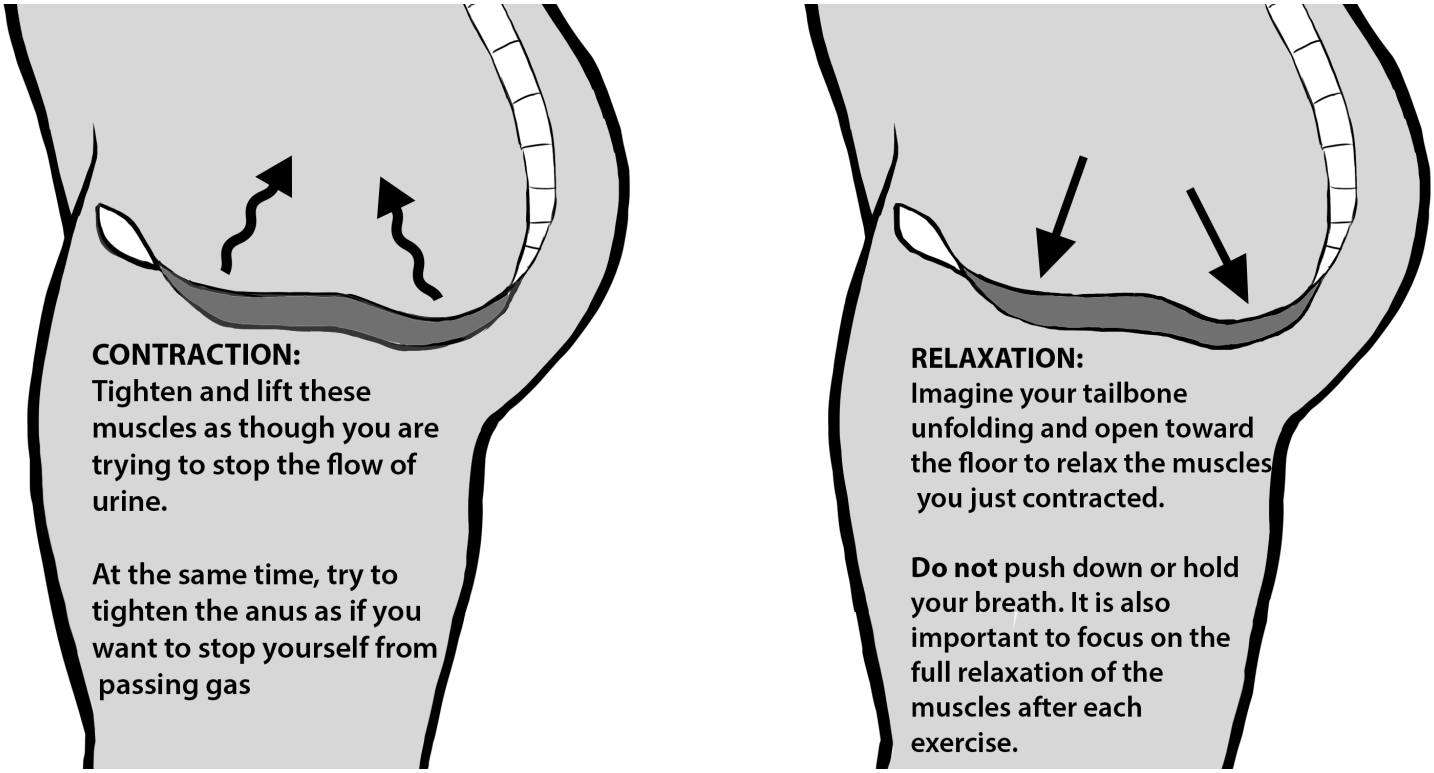
Like all muscles, the pelvic floor can weaken. This may happen after pregnancy, childbirth, bladder, prostate surgery or recent temporary ileostomy. When your pelvic floor muscles are weak, you have less control of your bladder and bowels and you may leak urine when you cough, sneeze, laugh or exercise. This is why it is important to strengthen your muscles with pelvic floor exercises.

When should I start doing pelvic floor muscle exercises?

Start pelvic floor muscle exercises 3-4 months before surgery. Directly after surgery, stop for 2 or 3 weeks to allow for your tissues to heal and talk to your surgeon before you start again. Pilates and yoga can also help increase your pelvic floor strength.

Learning how to find your pelvic floor muscles:

Start by imagining the sling of pelvic floor muscles. The follow the diagram bellow:

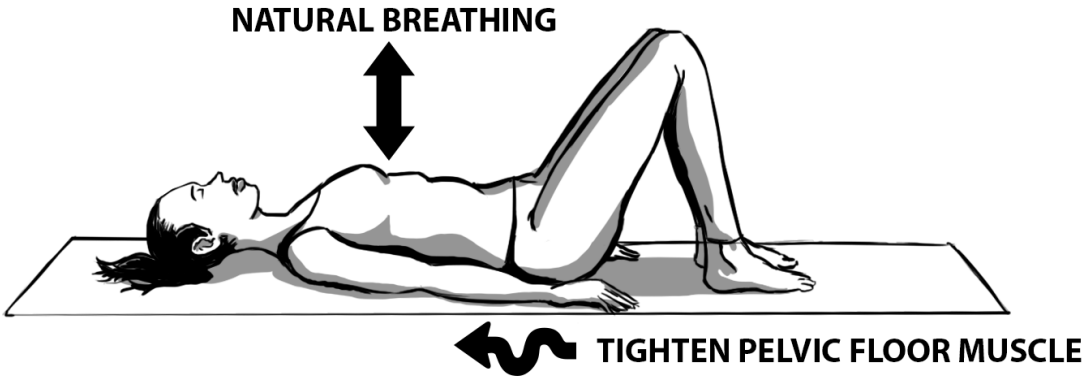


* If you are having trouble finding your pelvic floor muscles, consult a pelvic floor physiotherapist.

It is incorrect to pull in the belly button towards the backbone and hold your breath which can cause bearing- down on the pelvic floor.

How to beginning your exercises:

Once you find your pelvic floor start doing the exercises (listed below) while lying down. This way your muscles do not have to work against gravity. As your strength starts to increase, you can start doing the exercises while you sit or stand. As you tighten the pelvic floor muscles, do not tighten your legs, bum or tummy. Do not push down or hold your breath. It is also important to focus on the full relaxation of the muscles after the contraction.
Try to complete both of following exercises daily.



Slow and sustained

Squeeze and lift your pelvic floor slowly. Hold the contraction for 3 seconds and relax the muscles for 3 full seconds. Gradually work up to holding for 10 seconds and relax for 10 seconds. Repeat 10 times to make one set. Do 6 to 8 sets every day.

How long does it take to work?

It can take months for these muscles to get stronger. Don't give up. Keep working on strengthening your pelvic floor. This is an exercise you should continue throughout your life. If you want help or you think your symptoms are not getting better, you can see a pelvic floor physiotherapist. You do not need a referral from a doctor.

If your pelvic floor muscles are very weak, you may need to see a pelvic floor physiotherapist for biofeedback training and possibly electrical stimulation of your pelvic floor muscle. This will help to strengthen the muscle enough so you can do the exercises correctly on your own.

Finding a pelvic floor physiotherapist

If you continue to experience leaking or have difficulty locating and exercising these muscles, see a pelvic floor physiotherapist for assessment and treatment. This may include biofeedback training and possibly electrical stimulation of your pelvic floor to strengthen the muscle enough so you can do the exercises correctly on your own.

There is a listing of physiotherapists at www.bcphysio.org under "Find a Phyisio". Select "Advanced Search" and type in your preferred location and choose "Incontinence (uriany/bowel/pelvic floor" as the "Area of Practice".

The fees changed by physiotherapists vary- ask the therapist about their fee structure and payment options. You may have coverage (full or partial) through your private insurance provider.

Diet

What you eat with a pelvic pouch

Most people adjust the way they eat once they have a pelvic pouch. Some people find they can eat a greater variety of food. Other people find their diet does not change much. Everyone has a different "usual" diet before a pelvic pouch procedure, and everyone's diet is a bit different after surgery.

Certain ways of eating are helpful for everyone with a pelvic pouch. To stay well-nourished and well-hydrated be sure to:

- Eat at regular times. Smaller, more frequent meals may be easier with the pouch.
- Chew food thoroughly to help with digestion.
- Don't skip meals. This can lead to to malnutrition and dehydration, and also increase gas.

Start with a low fibre diet

When you start passing stool through your pelvic pouch, we recommend a low fibre diet for the first 4 to 6 weeks. Low fibre foods that are easily digested and absorbed. Limit foods that are harder to digest. For example, eat small amounts of whole grains and fruits and vegetables with tough skins and seeds. Eating less fibre to start helps decrease stool frequency, anal irritation and stress on the pouch.

Long-term Diet

It may take a year for your pouch to heal and adapt. During this time, you can gradually try new foods and progress towards a regular diet. As your pelvic pouch adapts, it is important to add fibre and a variety of foods back into your diet. In time most people eat a regular diet with only a few modifications.

Get Enough Liquid

Pay extra attention to how much liquid you drink. More frequent and watery stools indicate that you may need more fluid. Drink at least 8 cups (2 liters) of non-caffeinated fluids every day.

Is your stool too thin?

When you have a pelvic pouch, you do not want your stool to be too thick.

If you do need thicker stool, you can take Lomotil or Imodium. Talk to your family doctor or surgeon first. These medicines slow down the movement of the bowel. Your body has more time to absorb the liquid in the stool causing the stool to be thicker. Take these medicines 30 to 45 minutes before a meal to help with absorption

Gas and stool

Sometimes it is difficult to tell the difference between gas and stool in your pelvic pouch. This usually improves over time as the pelvic pouch adapts. Some people find that lying down on their side allows them to release gas without releasing stool.

Using Diet Strategies to Manage your Stool

You can manage changes to your digestive system by changing your diet. You can help change your stool by choosing certain foods, when you eat, and how you eat. Adjusting your diet can help to:

- Manage how often you have a bowel movement
- Thicken your stool
- Reduce anal irritation
- Reduce gas

A dietitian will talk with you about the strategies that are right for you after surgery.

Night Time Incontinence and Sleep

When you have a pelvic pouch, incontinence at night is common. During deep sleep your sphincter muscles relax and small amounts of stool or mucous may escape. For most people there is less incontinence as you heal. Some people choose to wear an incontinence pad at night until it gets better. Protect the skin around your anus (using wipes and cream) at all times and especially during the night.

You may find it hard to sleep because you need to use the bathroom more often. We recommend allowing more time at night to sleep or try to nap during the day.

To decrease nighttime bowel movements, stop eating four to six hours before bedtime. Do not drink large quantities of liquids (especially carbonated beverages) in the evening. Do not have an evening snack. Eat your largest meal at lunchtime instead of dinner.

Taking medications such as Lomotil or Imodium before your evening meal and/or at bedtime may also be helpful. Consult with your family doctor or surgeon before taking this medication.

Getting Back to Life

After this surgery, many people are uncertain about going back to their previous activities, including work and school. Start with what is most comfortable. There is plenty of research showing that being physically active is important for your general health, your gut health and your mental health. We encourage you to gradually become more active as you feel better. Walking and swimming are excellent choices but feel free to choose activities that make you feel happy and have a low risk of physical contact. You can talk with a physiotherapist about which activities may be best for you and how much is the 'right' amount (not too little and not too much).

You may feel worried about having an accident (e.g. leakage) or be concerned about using the bathroom outside your home. This is a normal fear and it gets better with time. As you gain more control you will feel more confident. Some people wear a pad until they have more control of their bowel movements.

If you have any questions or concerns, talk with your ostomy nurse. The United Ostomy Association has regional chapters and support groups. It is also possible to meet people who have had the same surgeries. See the resource section at the end of this booklet. It may also be helpful to speak to a social worker or counsellor to help you work through these concerns.

Post-Operative Concerns

Pouchitis

An inflammation (swelling and irritation) of the pelvic pouch. The symptoms are similar to a mini-attack of colitis. If you notice these symptoms, call your surgeons office for help in how to manage this situation.

About 30% of people who have a pelvic pouch sometimes have pouchitis. The exact cause of pouchitis isn't definitely known. Some possible causes are changes to the immune system, too many bacteria, changes how your body handles your bile salts, reduced blood flow to the pouch, and sometimes unrecognized Crohn's disease or indeterminate (unclassified) colitis.

Symptoms:

- Significant increase in stool frequency with watery diarrhea
- Feeling of urgency or pressure in the pouch
- Cramping
- Bleeding
- Low grade fever
- Malaise (general unwell feeling)
- Dull pain and pressure in the area of your pelvis

As long as you have a pelvic pouch, you are at risk for developing pouchitis. For most people pouchitis does not happen often. A small number of people have multiple episodes or even continuous "chronic pouchitis".

Treatment

90% of pouchitis cases are temporary and respond to antibiotics. The most commonly used antibiotic is Metronidazole (Flagyl). Once you start the antibiotics, you usually start to feel better in about 48 hours. You can help prevent pouchitis. Drink lots of liquids and always go to the bathroom before bed. This way stool does not sit in the pouch for a long time.

Irritation of the Pelvic Pouch Lining

Bleeding is caused by irritation of the pelvic pouch lining. Most often the cause is due to 'straining' or pushing too hard when doing a bowel movement. This can irritate the sensitive lining of the small bowel. If you notice blood in your bowel movements, report it to your surgeon.

Narrowing at the Anus

A narrowing or "stricture" may occur between your anus and the pelvic pouch. Scar tissue builds up and makes the passage narrower. You will notice that it is more difficult to empty your pouch: it takes longer and you must use more force (or bear down more) to empty the reservoir. If you notice these symptoms, call your surgeon. The narrowing can be stretched (dilated) to open the connection.

Skin Tags

Some people may develop small skin-tag like small growths around their anus. These can be uncomfortable. If you notice this, talk with your surgeon. Sometimes they can be removed.

Pouch Failure

About 5% of people who have pelvic pouch surgery will find that their pouch does not work like expected. (Called a pouch failure) Most failures are due to misdiagnosis (Crohn's disease), persistent disease in the pouch (pouchitis), or complications from the operation. For those with problems after pouch construction, the first step is usually a trial period of medication, resting the pelvic pouch (with a temporary ileostomy), or both. If this trial period fails, surgery may be needed to repair the pouch, remove the pouch and create a new pouch, or convert to a permanent ileostomy.

Sex and Sexuality after Pelvic Pouch Surgery

If you have concerns about sex and sexuality after surgery, speak with your surgeon or ostomy nurse. You can also self-refer to a therapist, or have your surgeon or family doctor refer you to a therapist who specializes in sexual health counseling.

For Women

You can start sexual relations as soon as you are ready. Many women find that sharing their worries with their partner is helpful.

After pelvic pouch surgery, some women notice vaginal dryness and pain during intercourse. These usually get better with time. Vaginal dryness can be due to hormonal changes following surgery or sometimes nerve damage during the surgery. If it occurs it is usually temporary and can be remedied through use of vaginal lubricants or trying other position for sex.

The pouch sits very close to the vagina. If the pouch is full, it can put uncomfortable pressure on the vagina. If you notice this, make sure your pouch is empty. Try different positions to find one that is comfortable.

When you have a pouch your stool moves quickly through your body and medications may not be absorbed well. Medications that are extended/ sustained release or enteric coated should be absorbed. Birth control pills may also not be absorbed. We strongly recommend using condoms for birth control.

For Men

For men, there is some risk of nerve damage during surgery. This can interfere with erections, ejaculation, or both. For 98% of patients this gets better in a year or less. 1 to 2% of all cases are permanent. Medications (such as Viagra) may assist with this issue.

Very rarely, complications of this surgery include impotence and retrograde ejaculation (the sperm going into the bladder instead of out the end of the penis.)Ask your surgeon about these complications.

Anal Intercourse

Anal intercourse is not safe. It will damage the pelvic pouch, the sphincters, or both.

Pregnancy

This surgery can affect your reproductive system. Some women are more likely to become pregnant if they have an inflamed colon removed. However, women who develop adhesions or scar tissue often have difficulty getting pregnant.

When you deliver a baby, there is always a risk of damaging the anal sphincter. If this happens, you cannot control your stool. If you have (or are considering) a pelvic pouch, talk to your obstetrician. They will work with you to find the best way to safely deliver your baby and protect your pouch.

Glossery

Anal sphincter – the muscles surrounding the anus that contract or close the opening. They work like a valve or gate.

Anastomosis – a surgical connection between two parts of the intestine.

Anus – the opening in the rectum through which stool is eliminated from the body.

Appliance – the device used to collect discharge such as stool, mucous, gas, or urine; it consists of a pouch, skin barrier, etc. Also called a pouching system.

Bowel – another word for intestine.

Colon – the last 4 to 5 feet (1.5 meters) of the digestive tract; the large bowel or large intestine.

Colostomy – a surgical opening into the colon or large bowel.

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

Crohn's Disease – an inflammatory disease that can involve the entire digestive tract but that usually occurs in the small bowel, colon, or rectum and/or anus. It is characterized by diarrhea, fever, weight loss and pain. The cause is unknown.

Familial Adenomatous Polyposis – an inherited disease characterized by a tendency to develop masses or lumps (polyps) in the colon.

Frequency – the number of bowel movements that occurs over a given time.

Gastrointestinal – related to the digestive system.

Incontinence – lack of voluntary control over feces or urine
Ileostomy – a surgically created opening from the ileum to the skin.

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, cut half way 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 (4 meters) feet of small bowel.

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

Kegel exercises – pelvic floor muscle exercises which is the contraction and relaxation of the floor of the pelvis.

Large Bowel – the last 4 to 5 feet (1.5 meters) of bowel that extends from the small bowel to the anus, also referred to as large intestine or colon.

Lumen – the space in the center of a tubular structure i.e. the intestine.

Mucus – a lubricating substance produced by the digestive tract.

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

Ostomy – a surgical opening, usually on the abdominal wall, for the drainage of body wastes.
Pelvic pouch – an ileoanal reservoir created from the ileum. Also known as J-Pouch.

Perianal – located around the anus.

Peristalsis – the pulsing movement of the intestine by which the contents are pushed toward the anus.

Peristomal – located around a stoma.

Polyp – small growth inside the bowel may be flat or mushroom shaped, usually not cancerous.

Pouchitis – Inflammation of the pouch that occurs when it becomes irritated and inflamed.

Proctocolectomy – removal of the colon, rectum, and anus with the creation of a permanent ileostomy.

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

Small bowel – the 22 to 25 feet (7 meters) of intestine betweenW the stomach and the large bowel. Also referred to as the small intestine.

Stoma – an end of the ileum or colon which is brought through the skin as a site for stool or urine to exit the body. (Note that even urinary stomas are built from a segment of ileum or colon.) The stoma often protrudes like a nipple and may be around 3/4" to 1-3/4" in diameter. It is usually pink to red in color. Stomas do not include nerves sensitive to pain, so it is possible to cut or burn a stoma without feeling anything. Stomas do, however, include nerves sensitive to other stimuli such as stretching.

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

Ulcerative colitis – an inflammatory disease of the colon and rectum in which ulcers form in the intestinal lining. Bleeding, cramping and diarrhea are the primary symptoms of the disease.

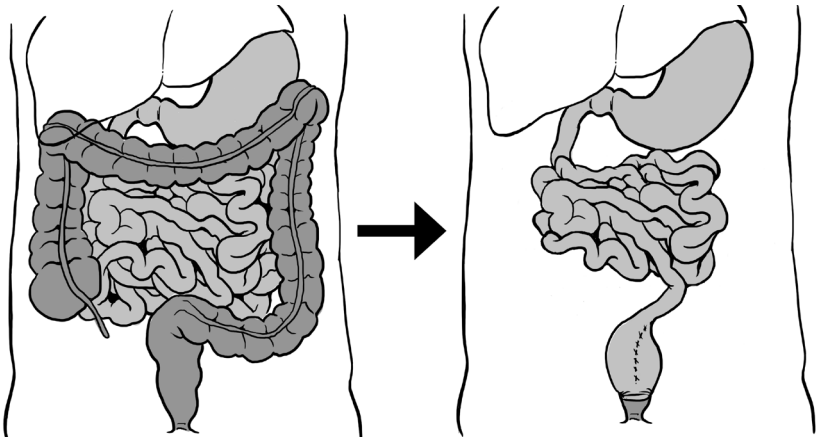
Appendix A: Types of Pelvic Pouch Surgeries

1 STAGE PROCEDURE (1 Surgery)

The 1 stage procedure to make a pelvic pouch is not often carried out. Having this surgery done completely at one time is very hard on the body and patients usually need much longer to recover. Patients who have a one-stage procedure are at a higher risk for pelvic infection due to surgery

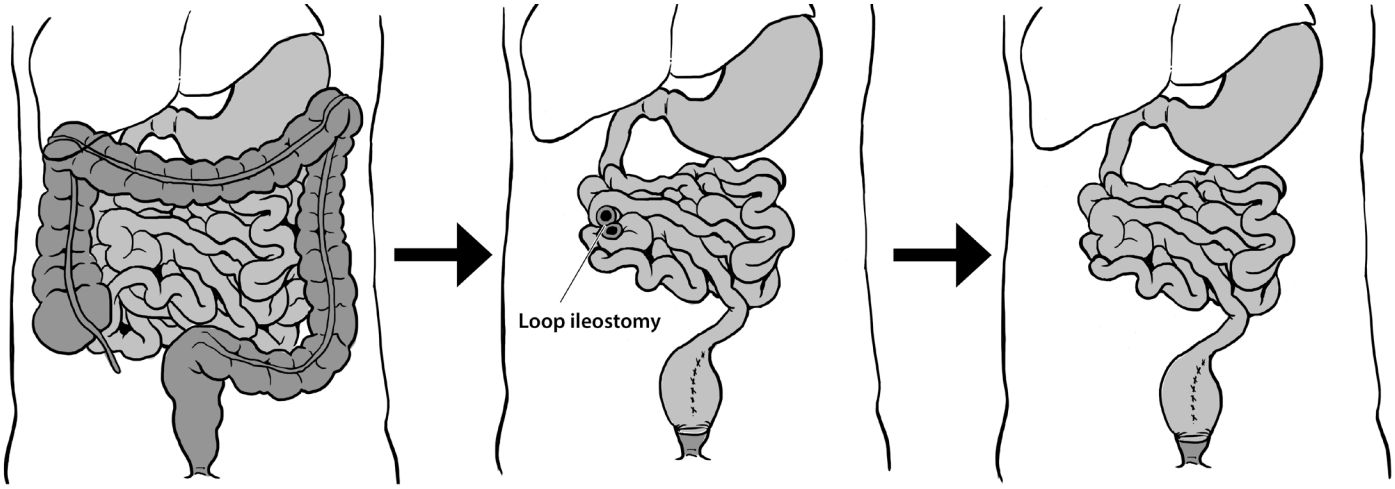
What is the 1 stage surgery?

1. Take out the large bowel and rectum
2. Make the pelvic pouch from the last 20 to 30 centimeters (12 inches) of the small intestine and joined to the top of the anal canal.
3. No ostomy is created



2 STAGE PROCEDURE (2 Surgeries)

The 2 stage procedure is often used for people who are relatively healthy, not actively bleeding and not taking high doses of steroids.



Before Surgery | After 1st Surgery | After 2nd Surgery

Loop ileostomy

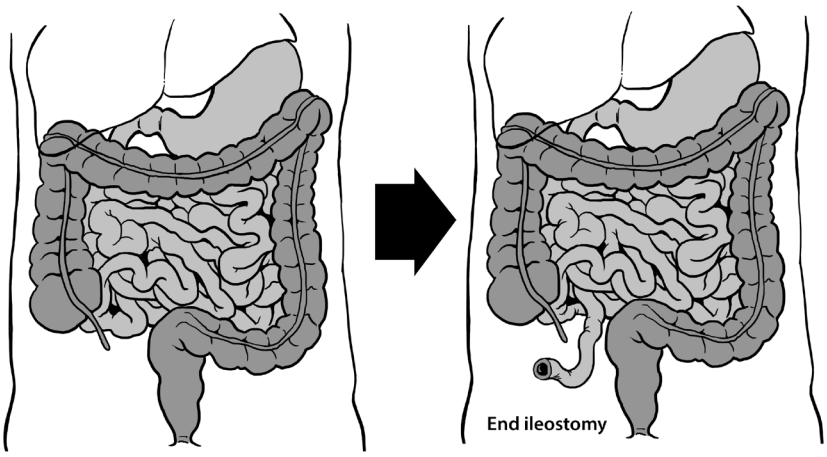
1. Take out the large bowel and rectum.
2. Create the pelvic pouch from the last 20 to 30 centimeters (12 inches) of the small intestine. Join the pouch to the top of the anal canal.
3. Create a temporary loop ileostomy to protect the pelvic pouch while it heals.
4. Close the ileostomy.

3 STAGE PROCEDURE (3 Surgeries)

The 3 Stage Procedure is for people who have already had an ileostomy, have been on high dose steroids or have active bleeding.

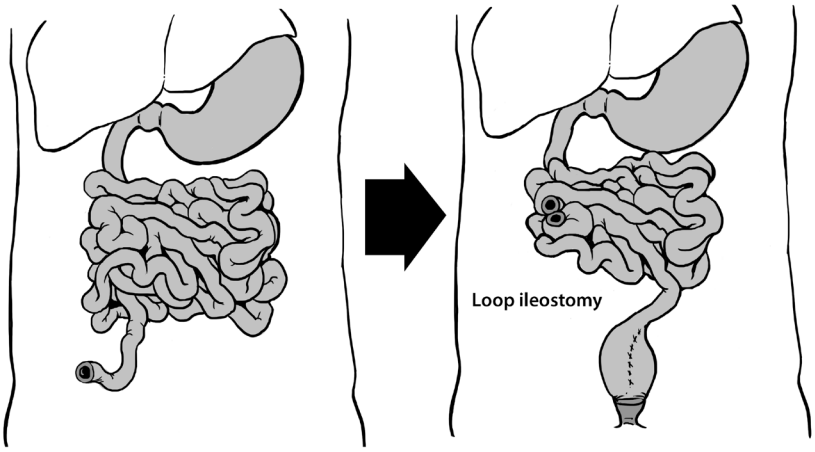
Stage 1:

1. Take out the large bowel
2. Create an end ileostomy. An "end" ileostomy is where your small bowel is disconnected your rectum/ anus and is made into a stoma (with one opening) on your abdomen. This will be exit for stool into an external appliance (pouch or bag).



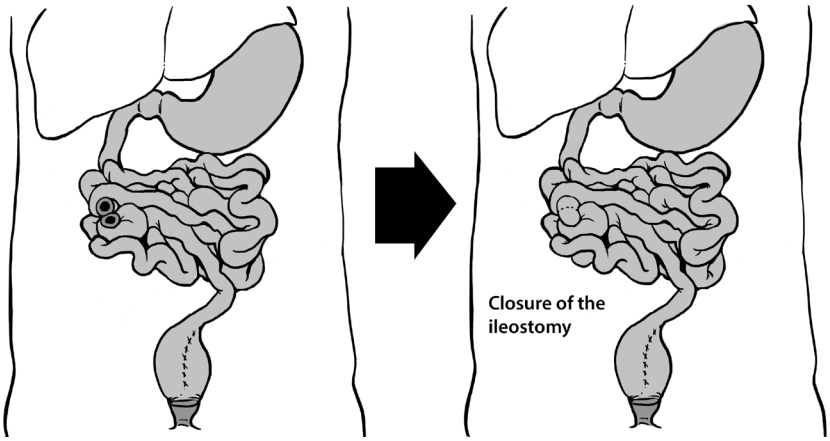
Stage 2:

3. Remove the rectum.
4. Remove the "end" ileostomy and create the pelvic pouch from the last 20 to 30 centimeters (12 inches) of the small intestine. Join it to the top of the anal canal.
5. Create a temporary loop ileostomy to protect the pelvic pouch while it heals. The new loop ileostomy keeps the stool away from your internal pouch to allow it to heal. See Appendix B to see the differences between an end and a loop ileostomy.
6. Bowel Surgery: Preparation and Recovery" & "Caring for your Ostomy"



Stage 3:

7. Join the two openings in the stoma. Stool passes through the small bowel, into the pelvic pouch, and out the anus.
8. The surgeon closes the stoma.
9. The stoma may be closed completely or closed only at the muscle layer. This allows it to heal from the inside.

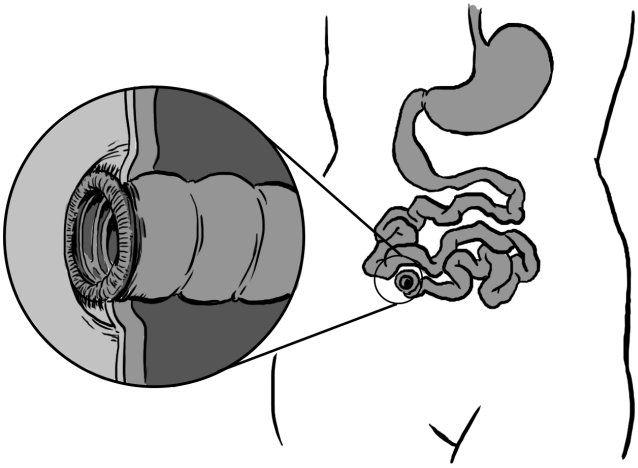


Appendix B: End Ileostomy versus Loop Ileostomy

Some people may already have an end ileostomy due to previous illness/ choices and then choose to have surgery to create a pelvic pouch. There are a few key differences between these types of ileostomies that are important to understand.

End Ileostomy

An end ileostomy is where the bowel is completely cut off and the "end" of it comes out to the abdomen. The stoma is usually round.



Loop (or "diverting") Ileostomy

After the pelvic pouch has been created it needs time to heal. The surgeon will create a "loop" ileostomy to protect your new pouch. The new loop ileostomy will (most likely) be placed into the same opening in your abdomen where your previous stoma was placed.

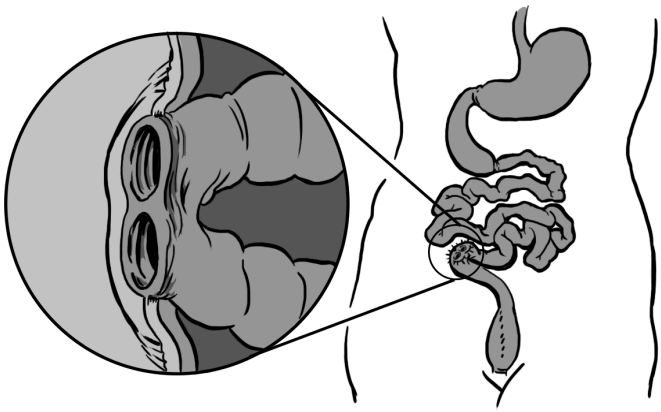
Instead of one opening, your stoma will now have two. Stool will exit from the top opening. The bottom opening connects to your pelvic pouch and will only secrete mucous while the pouch heals. The new stoma is usually oval shaped.

Once the pelvic pouch has healed, the surgeon closes the opening in your abdomen. Your pelvic pouch starts to work.

Pouching System after Surgery:

Your new stoma may be a different size, shape or height therefore you may need to use a different pouching system after surgery than before surgery.

- Try to use up your old supplies in case you can no longer use them after surgery
- **DO NOT** buy more supplies before surgery believing that you will use the same pouch after surgery
- After surgery your stoma will be swollen and then change shape as the swelling decreases over the next 4-6 weeks. The hospital ostomy nurse will assist you finding the right pouch for your new ileostomy and assist with setting up your supplies and any resources you may require after discharge.



Resources

Badgut
www.badgut.org

Crohn's and Colitis Foundation of Canada
http://www.crohnsandcolitis.ca/

Pelvic Floor Exercises:

Canadian Nurse Continence Advisors
http://www.cnca.ca/PME.html

Physiotherapy Association of British Columbia: Incontinence and Pelvic Floor Rehabilitation
https://bcphysio.org/content/incontinence-and-pelvic-floor-rehabilitation

Pelvic Health Solutions
http://pelvichealthsolutions.ca/

Red Lion Pouch Support
http://pouchsupport.org/

Online Support Groups:

There are many support groups on Facebook. Some are better than others so be cautious as you search for one that can support your needs.

United Ostomy Association of America
www.uoa.org

United Ostomy Association (UOA) Canada
www.ostomycanada.ca (You can find your local UOA chapter at this website.)

United Ostomy Association of Canada support groups
www.ostomycanada.ca/support/canadian-chapters/
You may be able to meet in groups or individually other people who have had a pelvic pouch surgery.

Resource Booklets accessible online:

Enhanced Recovery After Surgery
http://colorectal.providencehealthcare.org/patient-info/enhanced-recovery-after-surgery

- Bowel Surgery: Your Guide to Recovery
- Caring For Your Ostomy
- Ileostomy Diet

Medical Literature:

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Nurses Society. Philadelphia: Wolters Kluwer (2016).

UOAA: Ileoanal Reservoir Guide
Chapman, G.M., Sinclair, L., & Langevin, J.M. (2009).
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Journal of Crohn's and Colitis, 8(10), 1261-1266. doi:10.1016/j.crohns.2014.03.001 (2014).

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World Journal of Surgery, 42 (11), 3746 - 3754. doi:10.1007/s00268-018-4602-1 (2018).

Functional outcomes following ileal pouch-anal anastomosis (IPAA) in older patients: A systematic review.
Ramage, L., Qiu, S., Georgiou, P., Tekkis, P., & Tan, E.
International Journal of Colorectal Disease, 31(3), 481-492. doi:10.1007/s00384-015-2475-4 (2016)

A Handbook for New Ostomy Patients.
Vancouver United Ostomy Association Chapter Inc (2017).
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The Pelvic Pouch Procedure (Rev.ed).
Witkowski, K., McLeod, R., & Tjan, J.
Mount Sinai Hospital. Toronto (2010)

Notes

How you want to be treated.

www.providencehealthcare.org