

After Ileostomy Take-Down

HOME CARE INSTRUCTIONS FOR IPAA PATIENTS

The final stage of the ileal pouch anal anastomosis (IPAA) is completed when you have takedown surgery. This means that the temporary detour for stool through the ileostomy is closed. Stool will now be passed through the ileal pouch made by your surgeon, then out of your body through the anal opening. You may hear your IPAA called a pouch, ileoanal reservoir, an ileoanal pouch or a J-pouch.

Over the next year

It is common to pass 4-15 or more liquid stools each day for the first few months after your takedown surgery. At first you may feel an urgent need to pass stool and may even have leakage through your anus. This will improve over the next six months to a year as your pouch adapts and stretches, and your sphincter muscles become stronger. Stools will become thicker as your bowels start to absorb more water, which helps to decrease leakage. A year after takedown surgery, six stools a day is average, but 4-12 times per day is still normal.

You may leak stool during the day, but it is more common at night because your anal sphincter muscles relax while you sleep. It may take up to a year before you have nighttime control. After the first year, 10% to 20% of patients will continue to have some leakage when they sleep. About 25% of patients choose to wear pads during the day for security.

Helpful Hints About Diarrhea

Diarrhea is described as very high volumes of watery stool. If you have diarrhea, take 1-2 Imodium tablets four times a day (up to 8 tablets in 24 hours or 16 mg total) until your diarrhea is controlled. Start slowly with the Imodium. Too much too soon may make your stools too thick. A good start would be one tablet four times a day. Then add another additional tablet each time if stools do not thicken.

- If diarrhea lasts more than 2 days even after you have taken Imodium, or if you have symptoms of dehydration (see *Fluids* and *Call your surgeon...* on this sheet), call your surgeon or the clinic.

- Thickening loose stool may help decrease the leaking. You may take bulk-forming agents such as Metamucil or Citrucel (1-2 rounded

teaspoons with 3-4 ounces of water at mealtimes) to help thicken loose stool. Metamucil also comes in capsules, but your body may not have time to absorb capsules if stool is passing through quickly.

- Sometimes separating food from liquids when you eat can help to slow the bowels and passage of stool. If you drink large amounts of liquid with your meals, food may move through the ileoanal pouch more quickly. While you are eating, try to take only a few sips to help you swallow, and then drink the majority of liquid 30 minutes later.

Other Helpful Hints

When you have the urge to have a bowel movement, use deep breathing and sphincter tightening (Kegel exercises) to try to delay having a bowel

movement. This helps to stretch the ileoanal pouch so it holds more. As the pouch capacity increases, you will not need to have bowel movements so often.

- It may be hard to tell the difference between a need to pass stool and a need to pass gas. Some patients can only pass gas without stool if they are lying down. It is best to sit on a toilet even if you think it is only gas, until you feel that you are able to tell the difference.

Kegel Exercises

Tighten your anal muscle or sphincter as if you are trying to prevent a bowel movement. Hold for a count of 10 while squeezing tightly. Then relax for a count of 10. Repeat each step 10 times to make one set of exercises. You can do up to 4 sets a day or more.

Fluids

You should drink at least 2 quarts of fluids a day. That is approximately a cup every 2 hours during the day, or eight 8-ounce cups. You need to drink more if you have diarrhea or if you are sweating from hot weather, exercise, or fever. Avoiding fluids to decrease stool output will make you dehydrated.

Helpful Hints About Fluids

Anything that turns to a liquid in your mouth is a fluid. Examples are frozen yogurt, ice cream, Jello and popsicles.

- Drink plenty of non-caffeinated, non-alcoholic fluids. Water, sports drinks, and juice are good choices. Be careful of the sugar content if you have diabetes.

- You need to drink a variety of liquids, not just water. Water does not contain potassium or sodium that your body loses when you have diarrhea and when you sweat.

Be aware of the signs of dehydration

- Weakness and fatigue
- Urinating less often
- Urine that has a dark yellow color, like tea or cola
- Increased thirst
- Skin that “tents.” Gently pinch yourself on your forearm. If it remains raised in a “tent” after you remove your fingers, you may be dehydrated.
- Dizziness and/or confusion
- Dry mouth



Diet

Foods that gave you diarrhea before your takedown surgery may continue to give you loose, watery stools. At first, continue to follow a low residue diet. Eventually you can eat or drink whatever you like, within reason. Certain foods will continue to affect your output. See the food list in your ileostomy packet.

Helpful Hints About Diet

- Spicy foods and raw vegetables may burn or irritate the skin around your anal opening.
- Foods that improve stool thickness help prevent leakage and frequency.
- Continue to eat a low residue diet for the first 2-4 weeks after takedown surgery. After this, gradually increase fiber until you are eating a regular diet.
- If you are unsure how you will react to certain foods, introduce them slowly and in small amounts. If you cannot tolerate a certain food, try it again in a few weeks.
- In the first few weeks after surgery, you can usually tolerate 4-6 small meals a day better than three large ones.
- A regular eating schedule is important. Skipping meals to try to decrease bowel movements will cause you to have more gas.
- Eating a snack between meals helps some people reduce gas.
- It is common to fill up quickly and have a poor appetite for a few weeks after your surgery.

Medicines

Medicines are dissolved and absorbed into the body at different locations in the food tract or intestine. When you have high output, your bowel is passing fluid and food rapidly through the intestine, and pills may not have time to become fully absorbed. Because of this, it is very important that your pharmacist and physicians are aware that you have an ileoanal pouch.

Helpful Hints About Medicines

- During periods of high output, look in your stool for undissolved pills. Medicines may need to be changed to a liquid form.
- Check with your doctor if you take antibiotics or birth control pills. They may need to be changed to a different form.
- If you are going to have surgery or a test, your bowels and pouch can be cleaned by eating or drinking only clear liquids--no other food--for 12 hours beforehand. You should not need a full bowel preparation because it may make you dehydrated.
- You should never take laxatives or enemas unless your surgeon or gastrointestinal physician explains why you need them. They are rarely needed, and you should question and understand the purpose for the enema or laxative.
- At first, do not put any suppositories or other medicines through your anus unless your surgeon recommends it.
- Ask your pharmacist if any of your liquid medicines contain sorbitol. It can cause loose stools.

Skin care

The skin around your anus can be irritated after passing stool, so proper skin care is very important.

Helpful Hints About Skin Care

For the first few weeks after your surgery

- After each bowel movement, gently clean the skin with lukewarm water using a squirt bottle, a soft paper cloth, toilet paper, cotton balls, baby-wipes, or Tucks pads. Then pat dry. Some patients have found that toilet paper with added lotion is less irritating.
- After each bowel movement, apply a heavy moisture barrier cream to protect skin from drainage. Products with dimethicone are non-greasy and provide a clear, effective barrier. Products with zinc oxide are also good barriers. Your surgeon or ostomy nurse can recommend an appropriate skin barrier product to try after your surgery.

In general

- You do not need to completely remove the moisture barrier cream from your skin after each bowel movement. Gently clean stool from your skin and reapply the barrier cream.
- Avoid rubbing or scratching the skin, even with toilet paper. Think about how raw your nose gets when you have a cold and have to keep blowing your nose!
- If you use soap, rinse well. No-rinse cleansers are also available.
- Avoid soaps, cleansers, and toilet paper that contain perfumes because they may irritate your skin.
- A small pad may be used to collect extra leakage between bowel movements. Change pads when soiled to keep stool from sitting on your skin.
- Wear clean cotton underwear rather than nylon or polyester. Cotton absorbs perspiration and allows air to circulate.

Incision care

You will have a small opening in the area where your ileostomy stoma was located. Within this opening there will be a thin ribbon dressing or a plastic drain that will draw out fluid. This should be removed before you are released from the hospital. If the drain or tube is not removed before you leave the hospital, you will be asked to remove it at home. You can easily remove the drain or tube by gently pulling on it. Sometimes wetting the area in the shower can make it easier.

Flush the incision in the shower daily when you go home and place a dry dressing over it to protect the skin and keep your clothes clean. It usually takes 2-4 weeks for this incision to heal completely. You can expect drainage, but if the area becomes red like a spreading sunburn or has a foul-smelling drainage, please contact your surgeon. If you had a larger incision or opening with staples, they should be removed 7 to 10 days after your surgery. Contact the clinic if an appointment was not made for you to have the staples removed, or if a plan was not made for someone else such as your local doctor or the home care nurse to remove them.

Sex

- You may resume sexual activity as soon as you feel comfortable and after it is okayed by your surgeon. This is usually around 4 weeks after your original ileoanal pouch surgery and 1-2 weeks after ileostomy takedown.
- Anal sex is prohibited due to possible damage to your ileoanal pouch.

Women

- Tell your OB/GYN doctor that you have an ileoanal pouch.
- Women's menstrual cycles can be disrupted after any operation, but pregnancy is still possible. Your cycle should resume in 1-2 months after surgery. If it does not, contact your primary care doctor or OB/GYN.
- Birth control pills may need to be changed to another form because the medicine may not be absorbed into your body during periods of high output. Contact the doctor who prescribed them.
- Having an ileoanal pouch does not prevent you from getting pregnant. Discuss with your surgeon how long you should wait after your surgery if you are planning to become pregnant.
- Caesarean section is often the recommended method of birthing due to the possibility of injury to the anal muscles during a vaginal delivery, but it is up to your OB/GYN to decide what is safest for you and your baby.

Men

- Men risk sexual dysfunction. Impotence or infertility occurs in 1-3% of men after this surgery. If you have a problem with impotence, contact your surgeon for referral to a urologist to talk about what is available to assist you.

Returning to work

Everyone's recovery time varies. It is recommended that you gradually increase your workload as you feel able. Returning to work after surgery can also depend on the type of work you do. If you have a desk job, you may return to work in about 2 weeks. If your job requires a lot of physical activity, you may need to wait 4 weeks to return to your job. You should talk with your surgeon to decide.

Helpful Hints for Living

- As a good rule of thumb: if it hurts, stop.
- It is important to know the location of bathrooms in places where you often go. Always keep creams, underwear, pads and other supplies with you in case of leakage away from home, especially the first few weeks after the ileostomy takedown.
- Always wear a Medic-Alert identification bracelet or necklace stating that you have a total colectomy-ileoanal pouch. You can also buy a label to be placed on a watchband. The Medic-Alert phone number is 1-888-633-4298 or the website is www.medicalert.org

Your emotions

At first, living with an ileoanal pouch may make you feel different or isolated. You may go through a grieving process

because of the loss of what you have always experienced as normal. You may not know anyone else who has an ileoanal pouch, and you may feel alone. You may feel just fine one day and down and depressed the next. If you have problems with incontinence, skin problems, pouchitis, or other difficulties because of your ileoanal pouch, you may become discouraged or sad. All of these feelings are normal and are part of the healing process, but coping can be difficult.

If you feel that coping is too difficult and that you are not adjusting to life with an ileoanal pouch, there is help for you. Your ostomy nurse can guide you in the rehabilitation process and can put you in contact with community resources and support groups. Mental health counseling is also an option.

Complications

You may have certain complications related to your ileoanal pouch, and you should report them to your surgeon.

Pouchitis is an inflammation of the ileoanal pouch possibly due to an overgrowth of bacteria. Symptoms include sudden onset of frequent stools, cramping or pain, urgency, and sometimes bleeding. Many patients who have ulcerative colitis say that pouchitis feels like their colitis has come back.

Obstruction is a blockage of the small intestines, usually due to food or a narrowing of the bowel due to scarring.

Symptoms of a partial blockage include moderate to severe cramping, bloating, nausea and frequent explosive stools.

Symptoms of a complete blockage are vomiting and having no stools.

Anal stricture is a narrowing in the opening between your anus and the ileoanal pouch. This can be stretched easily in the clinic with a finger exam but may require a trip to the operating room.

Bleeding can be a result of pouchitis or irritation from the suture line in the ileoanal pouch. You may see some bright red blood if you are having frequent bowel movements or pouch irritation. If you have severe or continuous bleeding, call your surgeon immediately.

Pelvic infection can cause fever over 101.5° F and severe pelvic pain and pressure. Call your surgeon immediately.

Skin breakdown. Follow the instructions in *Helpful Hints About Skin Care* very carefully, and if there is no improvement, call your surgeon.

Call your surgeon if you have...

- severe cramping abdominal pain that your pain medicine does not help
- fever over 101.5° F
- nausea or vomiting when you cannot keep anything down, even liquids
- no stool for 12-16 hours
- more than 10 stools a day even though you have followed your diet, have had plenty of fluids, and have taken anti-diarrheal medicine
- continuous bleeding or a large amount of blood in your stool
- skin irritations that have not improved even though you followed these skin care instructions
- any other problems, questions, or concerns related to your ileoanal pouch

For More Information or Support

The J-Pouch Group
www.j-pouch.org

Crohn's & Colitis Foundation of America, Inc
(CCFA)
www.ccfa.org
1-800-932-2423

The FAP Support Group
www.fapsupportgroup.org

The United Ostomy Association of America
www.uoaa.org

The Vanderbilt Colorectal Group
www.vanderbiltcolorectal.com

Vanderbilt Colon and Rectal Surgery Clinic

(615) 322-2063

Monday through Friday

8am - 5pm

(615) 343-4612

After business hours and on holidays

Call (615) 322-6633

If you have questions for the ostomy nurse

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