Washington University in St. Louis
SCHOOL OF MEDICINE

Section of Colon and Rectal Surgery

Ileostomy Take-Down Recovery

Ileoanal pouch surgery is a curative surgical procedure for patients with Ulcerative Colitis and Familial Polyposis who wish to maintain bowel continence and avoid a permanent stoma. Ileoanal pouch surgery is performed in 2 or 3 stages; ileostomy take-down is the final stage. Patients who report the highest satisfaction following Ileoanal Pouch (J-Pouch) surgery are patients who are well informed and motivated to follow the dietary and medication routines necessary for optimal pouch performance.

The first year:

Following surgery it is normal to have 12-15 loose bowel movements daily. As your diet is advanced, fiber supplements can be added to bulk stools. Antidiarrheal medications can also be added to decrease the frequency of bowel movements. At the end of the first year many patients report an average 6 bowel movements daily. Normal can range from 4-12 daily bowel movements. It is suggested you keep track of your daily bowel movements and know the signs of symptoms of dehydration. (see signs of dehydration section below)

It can take a full 6 to 12 months to achieve ideal bowel function following IPAA surgery.

You will have frequent urges to have a bowel movement as the sphincter becomes accustom to holding stool. Try to delay emptying your pouch, often the urge will pass. As the pouch capacity increases and stool becomes more formed you will have fewer urges.

When having a bowel movement, do not try to push the stool out or sit on the toilet for longer than 5 minutes. Following surgery you may empty your pouch and a short time later have to return to the bathroom. The pouch fills as stool descends from the small intestine, you cannot speed this up by pushing. Over time the pouch will expand and repeat trips will not be necessary.

Complications:

- Bowel Obstruction
    - Bowel obstructions or blockages can occur as a result of scar tissue, kinking or twisting of the bowel.
    - Symptoms include; abdominal pain, nausea, vomiting, and a decrease or absence of bowel movements.
    - If you are experiencing symptoms of a bowel obstruction it is important to contact your surgeon or go to the emergency room for care.
- Pouchitis

- Pouchitis is inflammation of the lining of the pelvic pouch.
- Symptoms include but are not limited to; an increase in frequency of stools, loose stools that do not respond to changes in diet or antidiarrheal medications, abdominal cramping, leakage or loss of control of bowel movements, "not feeling well", blood in stool or tissue after bowel movements.
- Symptoms of pouchitis should be evaluated by your surgeon or gastroenterologist.
- Treatments may include antibiotics, probiotics, medications used for ulcerative colitis, or removal of the pouch if symptoms persist.

Diet:

- **Foods that help reduce diarrhea**: cheese, cheesecake, smooth nut butters, pretzels, white rice, tapioca, matzo, water crackers, marshmallows and jell-o, bananas, applesauce, oatmeal.
- When making changes to your diet to reduce output try one strategy at a time and for a few days to determine the benefit, or lack of benefit, to each strategy.
- Keep a food journal to track foods that you may not be tolerating well. It can be helpful to add new foods, one at a time every 3 days to get an accurate assessment of your response.
- Never try to decrease fluid intake to decrease the number of bowel movements you are having. Instead try anti-diarrheal medications (ex. Imodium) and foods known to slow output. (see list above)
- Sugar free foods that contain mannitol, sorbitol, isomalt, or xylitol can cause gas, bloating, diarrhea and abdominal cramping.
- Timing of meals is important. Traditionally the largest meal of the day is dinner, this may cause nighttime waking. Try having your largest meal of the day at lunchtime.
- Foods containing simple sugar can worsen diarrhea, this includes many sports drinks and juices.
- Common simple sugars: candy, sugar, pastries, honey, jam and jellies, sweetened drinks.
- Eat protein, fat, complex carbohydrates and soluble fiber (see below) at each meal.
- High fructose corn syrup commonly found in fruit drinks, baked goods and soda can cause diarrhea.

Fiber:

- To thicken stool slowly increase the amount of soluble fiber in your diet.
- Soluble fiber: Oat products (oatmeal, oat bran), barley, tapioca, pectin, banana flakes, legumes (cooked/canned chickpeas, kidney beans, and lentils).
- Eating soluble fiber with meals can increase its ability to thicken stool.
- Taking Psyllium powder (Metamucil, Konsyl) supplement prior to a meal may help slow output.

Fluids:

- Drink a glass of water every time you have a bowel movement.
- Drink 10-12 glasses of fluid a day. Some patients choose to use a "shot glass" and drink small amounts throughout the day rather than full glasses of water.

- If drinking alcohol or caffeine replace each glass with an additional glass of water.
- Drinking coffee and tea increase urine and salt output.
- Wait 30-45 minutes after a meal to consume liquids. (sipping with the meal is ok)
- If drinking sports drinks for electrolyte replacement try diluting the drink with water 1 : 1 to reduce the amount of sugar per serving. (ex. 1/2 cup water + 1/2 cup Gatorade).

Signs of Dehydration and Electrolyte Imbalances:

- Fatigue, nausea, vomiting, light headedness, dry mouth, stomach cramps, muscle cramps, decreased or dark urine, rapid weight loss, diarrhea or increased stoma output, increased thirst.
- Sodium and Potassium (electrolytes) can become depleted when output if high.
    - **Sodium:**
        - Sodium (Na+) low: loss of appetite, abdominal cramping, drowsiness, faintness, cold feeling in arms and legs.
        - Foods to help replace sodium**:** canned soups and vegetables, broth and bouillon cubes, tomato sauce, snack chips (pretzels, salted crackers, potato chips), processed foods (cheeses, meats), canned fish (tuna, salmon), ready to eat cereal (instant oatmeal), table salt, ketchup, soy and BBQ sauces), V8 juice, sports drinks.

Check with your doctor before adding foods listed above if you are on a sodium restricted diet.

    - **Potassium**
        - Potassium (K+) low: fatigue, muscle weakness, gassy bloated feeling, shortness of breath, decreased sensation in arms and/or legs.
        - Foods to replace potassium: Potatoes, bananas, avocado, tomato (sauce, paste, soup), melon (cantaloupe, honeydew, watermelon), pumpkin, sweet potato, smooth nut butters (peanut, almond), brown sugar, molasses, maple syrup, chocolate, coffee, tea, coconut water, juices (orange, carrot, tomato, vegetable) sports drinks.

Medications:

- Your surgeon may recommend using over the counter Imodium AD to control output. You may take up to 8 tablets a day (16mg total). As with any strategy begin slowly when introducing Imodium AD. You may want to begin with 1 tab 2-4 times a day and advance to 2 tabs 4 times daily if necessary.
  Some patients find taking 1 Imodium prior to each meal and 2 at bedtime is most helpful.
- Psyllium powder (ex. Metamucil, Konsyl) taken with a full glass of water before meals may help decrease bowel movements.
- Over the counter probiotics can be helpful. (Align and Culturelle are available at your local pharmacy, VSL#3 can be ordered online)

Perianal Skin care:

It is important to begin a skin care routine when pouch function begins. Frequent liquid bowel movements and certain foods can irritate the anus and surrounding skin.

- Gently cleanse your skin with warm water after each bowel movement. A peri squirt bottle, sitz bath or shower work well. You may also use a soft damp washcloth, baby wipes, or Tucks pads to gently wipe the area. Pat the area dry after cleansing.
- If you are using soap and water to cleanse the area be sure to completely remove soap residue.
- After cleansing the perianal skin it is recommended that a barrier cream be applied to protect the skin from drainage. Products that contain zinc oxide and dimethicone provide protection and treat perianal skin irritation. Examples include Calmoseptine, A&D ointment, Desitin, Triple Paste, and Boudreaux Butt Paste.
- You do not need to completely remove the barrier cream after a bowel movement. Cleanse the area so that it is free of stool, dry gently and reapply a thin layer of barrier cream.
- A gauze pad tucked against the anal opening or a panty liner can help absorb moisture between bowel movements.
- Cotton underwear is preferred to synthetic materials. Cotton naturally absorbs moisture and allows air to circulate.
- **Certain foods are common anal irritants**:
    - Coffee and Tea
    - Spicy foods
    - Certain raw fruits and vegetables: oranges, apples, coleslaw, celery and corn.
    - Popcorn, nuts
    - Foods with seeds
    - Dried fruits
    - coconut

Leakage:

It is not unusual to have anal leakage following ileostomy takedown surgery. As your stool becomes thicker and the pouch stretches this should decrease. Some patients wear a panty liner or a cotton square or ball (cosmetic pads work well) against the anal for security during the day.

- Kegel Exercises can be done to strengthen the anal sphincter muscle following surgery.
    - Tighten the anal muscle (sphincter) as if you are trying to prevent a bowel movement. Hold for a count of 10 while squeezing, relax for a count of 10. Repeat each step 10 times. You can do 4 sets a day.

It may be difficult to distinguish between a bowel movement and the need to pass gas following surgery. This will improve with time.

Nighttime leakage can continue even after the first year due to relaxation of the anal sphincter. Wearing a pad at night can prevent soiling.

Adjusting to Life with a Pouch:

It is not uncommon following your final surgery to have emotional ups and downs. You may be relieved to have your surgeries behind you but find yourself frustrated and exhausted. Although your surgical wounds may be healed in a few weeks adapting to your pouch can take several months, up to a full year for some.

Pouch patients may go through a grieving process related to the loss of what was "normal" bowel function. The new normal of a pouch is one of trial and error, requiring patient. You may have good days where you are eager to get out and see family and friends followed by days where you feel isolated and misunderstood. High output, skin irritation, dietary changes, leakage, pouchitis and disrupted sleep all contribute to your sense of well-being. To feel frustrated or sad is normal.

If you feel that you are not adjusting to your new ileoanal pouch there is help. Contact you surgeon, primary care physician, or you ostomy nurse. Support groups are available and mental health counseling is available.

United Ostomy Association
www.uoaa.org

The J Pouch Group
www.j-pouch.org

WOCN (Wound Ostomy Continence Nurses Society)
To help locate a local Ostomy nurse in your area
www.wocn.org

The FAP Support Group
www.fapsupportgroup.org

Crohn's and Colitis Foundation of America, Inc.
www.ccfa.org

Sex:

Concern about sexual activity is common. Patients are anxious to resume sexual activity due to a renewed sense of well being after removal of diseased bowel and recovery from surgery. Anal sex is prohibited in patients who have an ileoanal pouch due to possible damage to the pouch. Speak to your surgeon prior to resuming sexual activity.

Women:

- It is important to let your OBGYN know you have an ileoanal pouch.
- Menstrual cycles can be disrupted following surgery. If your menstrual cycle does not resume in 1-2 months you should speak to your OBGYN.
- Birth control pills may not be fully absorbed during periods of high output. You may want to speak with your OBGYN regarding other forms of birth control.
- You may get pregnant with an ileoanal pouch. Caesarean section is often the recommended method of birthing for ileoanal pouch patients. A vaginal birth may injure your anal muscles and nerves, though women with ileoanal pouches have had successful vaginal births. It is important to discuss this with your OBGYN to make the best decision for you and your baby.

Men:

- Men who have had ileoanal pouch surgery are at risk for impotence and infertility related to retrograde ejaculation, 1-3%. If you have symptoms of impotence contact your surgeon for a referral to a urologist who can discuss possible treatments.