

New Patient Guide

Continent Diversion

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A publication of

The **Phoenix**

Welcome to the United Ostomy Associations of America

Dear New Ostomy Patient,

Welcome to the United Ostomy Associations of America and your free New Patient Guide. It is brought to you by UOAA, its over 300 local affiliated support groups throughout the United States, and by its official publication, *The Phoenix* magazine.

We believe that it is very important for you to have as much information about your ostomy as possible. Undoubtedly, you have heard many stories about people with an ostomy or related procedure, many of which are based on ignorance and "old-wives' tales." We are here to dispel those and help you move beyond the stigma!

In this magazine, you will find answers by medical professionals to many of your basic questions, hints about living with your ostomy and motivational stories describing quality of life accomplishments from some of the 700,000 people in the United States that have an ostomy. In fact, articles first appeared in *The Phoenix* magazine, with subscriptions being a major source of revenue for the UOAA.

UOAA is a volunteer-managed non-profit organization whose vision is the creation of a society where people with bowel and urinary diversions are universally accepted socially, in the work place, medically and psychologically. UOAA has a comprehensive website, www.uoaa.org that includes ostomy information, support group locations and discussion boards so that people with ostomies can connect, ask questions and share advice.

UOAA staffs a national Help Line at **800-826-0826**. Call to find the affiliated support group in your area or to talk to an ostomy nurse. Another free service offered by UOAA is provided by our advocacy legal specialist. If you experience some form of discrimination as a result of your surgery, call our Help Line and they will put you in touch with our specialist.

Membership in UOAA is through its affiliated support groups, or ASGs. If you are a member of a local support group, or one of UOAA's virtual networks, you are a member of UOAA. Our local ASGs have periodic

support and educational meetings where you can get answers to those questions that so many new patients have and where fellow members can share with you their experiences. You will find, upon attending, that you are greeted warmly and treated like a member of an extended family.

Be well,
UOAA's Management Board of Directors

P.S. This free New Patient Guide is made possible by subscriptions to *The Phoenix* magazine and donations to the UOAA. Your support is appreciated.

P.S.S. Visit www.phoenixuoaa.org to learn more about America's leading ostomy magazine.

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Continent Diversion New Patient Guide



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Ask Dr. Beck



Dr. Beck is board certified in General and Colon and Rectal Surgery and is a Fellow of the American College of Surgeons and the American Society of Colon and Rectal Surgeons. Dr. Beck conducts research into colorectal diseases, has authored and edited seven medical textbooks, written numerous scientific publications. Dr. Beck is a nationally recognized expert in inflammatory bowel disease, anal cancer, adhesions, sphincter saving surgery for cancer, and laparoscopic surgery.

Send questions to publisher@uoaa.org or P.O. Box 3605 Mission Viejo, CA 92690

Enlarging Stomas, Drainage, Lethargy and Watery Output

Bathroom Trips

I just had J-Pouch surgery six months ago and I am going to the bathroom 10-14 times a day. Is there a way to reduce the number of trips to the bathroom?

Dear New Patient,

There are a number of measures that can be tried to reduce the number of bowel movements after creation of an ileoanal anastomosis. The first option is dietary measures. Avoid foods that increase the number of bowel movements. Patients are helped by eating large breakfasts and lunches, then a small, early dinner.

Taking additional fiber helps many patients to form or bulk their stools. However, in some patients fiber produces more bowel movements. Trial and error is the only way to find how it will affect you.

The next option is medication. These are usually added in a step-wise fashion. We usually start with Imodium (available over the counter) at 2-4 mg orally 30 minutes before meals and at bedtime. The amount taken is gradually increased up to 16 mg (eight pills) per day. Sometimes the liquid form is more effective initially than the pills.

Next we add Lomotil (prescription) in a similar fashion: 1-2 pills orally 30 minutes before meals and at bedtime. The third drug used is codeine (30-60 mg) 1-4 times a day. The fourth medication is a morphine elixir (Roxinal) 5-20 drops 4 times a day.

Other options that may help some patients is Bismuth (Pepto-bismol) or a binding agent such as Questran (cholestyramine).

With some or all of these measures a patient's bowel frequency can be reduced while their intestine and kidneys adapt to

their new anatomy. This usually occurs over about 6 months. At that time we usually start reducing the medications the patient is taking.

Excersing

I had a Kock Pouch done about three months ago. I'd like to start running, cycling and swimming again, but I'm afraid I might hurt the pouch. Is there anything I should do to avoid problems? Are these activities safe with an internal pouch?

Dear New Patient,

Most physical activities are safe with a continent ileostomy. The major potential risk is either a blow to the abdominal wall or activity that transmits severe force to the body. An example would be a severe fall or a major automobile accident where the body is restrained (ie with a seat belt) but the force of the accident causes the pouch to be compressed or stretched.

With significant force, there is a risk the pouch could rupture or be torn away from its attachments to the abdominal wall. The chance of this happening is rare and can be minimized by emptying your pouch prior to engaging in physical activity.

With an empty pouch, activities like running, cycling and swimming should be fine.

Get Answers

Do you have a question for Dr. Beck or Nurse Junkin? You can e-mail your question to publisher@uoaa.org or you can mail it to:

The Phoenix Magazine,
P.O. Box 3605, Mission Viejo, CA 92690

Cramps

I had my final j-pouch surgery one month ago and I am doing OK except for really strong cramps. Is this normal? Should I take something for the cramps? Will they decrease over time?

Dear New Patient,

The cramps will usually decrease over time. They may result from a number of causes. Three of the more common reasons are irritable bowel syndrome (IBS), adhesions, or medications. Medications such as pain meds, psychiatric drugs, sedatives, or bowel agents such as Imodium may produce cramps at higher doses.

The first step is to review your medications and see if some can be eliminated or changed. Adhesions are common after any abdominal surgery. The presence of adhesions may cause some cramping as they may partially kink the bowel. These usually soften with time and the symptoms will improve. Irritable bowel syndrome is a motility disorder of the small bowel. It is often helped with changes in diet (usually adding fiber helps) or medications. Your primary care physician or gastroenterologist can often offer some suggestions.

Drainage

I am a little over two months out from having a k-pouch. I am still having a good deal of drainage from the barbie/ken butt area. Is this normal?

Dear New Patient,

A proctocolectomy removes the colon, rectum and anus. The surgery on the anus can be performed in a number of ways that range from removal of the anal lining to removing the anal lining and the anal muscles.

The more tissue removed, the larger the residual cavity that is left to heal and the larger the perineal incision. If the cavity doesn't heal completely, fluid may form which will often drain out the perineum. This tissue fluid drainage is not "normal" but not uncommon. The drainage usually decreases with time and eventually stops altogether.

If the drainage continues, your surgeon should inspect the area to be sure that a residual cavity is not present or that all the intestinal lining tissue was not completely removed. Small cavities can often be treated

with a chemical sclerosing agent such as silver nitrate sticks. Larger cavities may need to be treated surgically.

One or Two Steps?

I had my colon removed several years ago, but now I'm going to try the j-pouch. My surgeon said the surgery will probably be a one-step procedure. I've been told that the two-step is better. Is this true?

Dear New Patient,

An elective (planned) restorative proctocolectomy or ileoanal pouch procedure can be performed in one or two stages. With a two-stage process, the first operation involves removing the colon and upper rectum, using small bowel to create a pelvic pouch which is connected to the anus, and creating a diverting loop ileostomy. The second stage or procedure involves closing the ileostomy.

With a one-stage procedure, the diverting ileostomy is not used. Restorative proctocolectomies are challenging and complicated procedures. Patients who need these operations are often ill, malnourished, and on immunosuppressive medications. The complications associated with the procedures are significant. The ileostomy diverts the intestinal contents from the pouch and provides time for the pouch to heal.

This diversion does not prevent complications such as a leak from the suture lines or infections. However, diversion does affect the significance of complications. In other words, a leak from an undiverted pouch can produce serious and potentially life threatening problems. A leak from a diverted pouch is often asymptomatic.

A two-stage procedure does have some disadvantages. Two operations and hospitalizations are required and each has a certain risk of complications. During the 6-12 weeks between procedures, the patient has an ileostomy which can produce skin irritation and electrolyte abnormalities.

The decision to choose one or two stages must involve the surgeon and the patient. Factors to take into account include, the experience of the surgeon, the patient's risk factors and tolerance of risk. The decision is not always easy and must be individualized. However, the majority of procedures performed are usually two-stage procedures.☺

Ask Nurse Junkin



Joan Junkin, MSN, APRN-CNS, CWOCN had her ostomy education through MD Anderson Cancer Center in 1997. She has worked as a wound and ostomy nurse since then at the University of Nebraska Medical Center in Omaha NE and BryanLGH Medical Center in Lincoln NE, where she currently sees patients with ostomies and continent diversions. She published an article in JWOCN about the importance of teaching about sexuality for persons with a urinary or fecal diversion. This won the 2006 CLInical Manuscript award from WOCN.

Send questions to publisher@uoaa.org or P.O. Box 3605 Mission Viejo, CA 92690

Pouch Flushing, Bottom Burn, Intimacy

Indiana Pouch Flush

How do you flush out an Indiana pouch? Is there a way to make the solution at home? How often should I flush?

These are questions that should definitely be answered by your surgeon because each has their own preferences and some are determined by the technique they use in operating room.

Kock Pouch

I just got a Kock pouch and wondering what I'm going to use to cover the stoma. I've read that I only need a plaster and my stoma nurse says I should use one of those coaster-type stoma caps. What works best?

What works best is something only you can determine. Each person has their own preferences. I would recommend that you get samples from several companies of the stoma caps (Coloplast, Convatec and Hollister for instance) and there is a company that makes one called the AMD patch specifically for continent diversions.

J-Pouch "Take Down"

I recently had my j-pouch "take down" surgery and I'm experiencing a lot of bowel movements - up to 20 times a day. My bottom is really sore and burns. What can I use to stop the pain and start healing that area?

To start with I would recommend that you eat frequent small amounts, especially starchy foods, which help thicken and neutralize your stools. If this does not help them slow down, speak to your surgeon or gastroenterologist about medication to

slow the bowel at first.

To care for the burned skin: best to start with a soft, disposable pre-moistened cloth rather than rough fabric cloths. If you can't get any, you could use a paper towel, slightly moistened, and pat the area dry after each bowel movement rather than rubbing. It also helps to apply a thin coat of petrolatum (ie Vaseline) to the cloth before wiping gently, Secondly: after GENTLY patting the area clean, apply a zinc oxide ointment (ie Desitin or Calmoseptine which adds a bit of calamine lotion to sooth) to a non-stick dressing such as a Telfa or an ARD (made by Birchwood Labs- only about \$5 for a box of 24) and tuck that in right over the burned area. If you use the ARDs they are flushable, if you use the Telfa type, they are NOT!

If you use these 2 steps each time you leak, you will soon be healed. Do NOT try to scrub or wash all the old ointment off each time- just soak the stool off the top layer- and leave the rest on. Then apply the new dressing with the zinc oxide on it to the same area.

Incision Site

I'm getting a lot of fluid leaking out of the incision site for the j-pouch surgery, but I don't have a temperature. Is this something I should be worried about?

This is definitely something to see your surgeon about. Most likely it is a minor issue, but the surgeon needs to be aware of it and assess the problem. Some of the possible causes include something called a seroma (a leak of serous fluid- not serious, but sometimes requires cautery in the office); adipose tissue (if your abdomen includes quite a bit of adipose tissue, then

extra clear fluid would be expected because that type of tissue has a high water content); as you suspected, infection is also a possibility- even if you don't have a temperature.

If the body has walled off the infection (called an abscess) then sometimes you don't have a temperature at first. It will be helpful for the surgeon to have a written record of your daily temperatures, how much and what color of drainage is on each dressing when you change it and how often you had to change the dressing. Be sure to also mention any odor you may have noticed. If you change the dressing right before seeing the surgeon, bring it with you in a self-sealing plastic bag so they can see what the amount and type is.

Bottom Burn

My wife has butt burn right now and is wondering if it is due to any foods or drinks she has had. Are there foods or drinks that cause this?

If she has a j-pouch type diversion it is likely related to her intake, especially if her take-down was recent. It is helpful to have frequent small amounts of starchy foods to help neutralize the stool. Foods like banana, unsweetened applesauce, potatoes, crackers (many like animal crackers the best for slowing the stool down), or bread products are helpful to slow the stool.

To start with, it helps to have a small amount every hour- this prevents your stomach from over-producing acid. Don't forget to include small amounts of fluid each time. Many find it useful to avoid fluids containing caffeine or highly acidic fluids such as fruit juices to start with. I would recommend going to the UOAA website and checking out the dietary guideline resources they offer. Another popular way to slow stool is marshmallows, although you would want to limit that option due to the high calorie/ high sugar content.

Insistent Itch

My ileostomy reversal and "take down" surgery was two weeks ago. The burning on my back side is being controlled, but I have an itch that seems to come from a deeper area. It's very uncomfortable and I can't seem to not scratch it. Is it OK to scratch? If not, how can I stop it from itching?

Please check with your surgeon about this. You should have a post-op visit coming up soon. One reason for this is that the nerves have been disturbed during surgery and may still be irritated. In this case it will likely decrease over time. Another reason is pouchitis, an inflammation

of the internal pouch. This is something that would need medicine to treat.

Nightly Accident

I have had a j-pouch for two years. Each night when I'm asleep, I have more than just a leak, it's a full bowel movement. I have tried wafers , diet etc. How can I fix this problem?

You have the right idea about trying to alter your diet to help this problem. It may also require medication to alter your bowel habits. You could work with a dietician that deals specifically with diversions. If this is not successful, or you have already tried that route, then you would want to find a gastroenterologist that is familiar with continent diversions or short gut syndrome issues. They have medications that can assist with changing the bowel movement patterns.

Intimacy

I have a kock pouch for stool and I worry that when I have sex that will cause a leak. What can I do?

There are several things to consider here. Has your surgical incision healed well enough so that pain will not be an issue? If not, you may consider a position that avoids pressure on the incision.

Secondly, prior to having intercourse, empty the pouch. Then, you may consider wearing a cap or patch just to feel more confident. Some people like to wear a cloth tube around their mid-section to protect their diversion opening and keep any patch or cap from dislodging during sex. There are very nice, soft, attractive ones available.

THE UOAA has a nice resource on sexuality and also that is naturally a popular topic on the various web sites available to persons with diversions. Do keep in mind that although it is common for couples to use various orifices for sexual pleasure, it is important not to use the opening for your pouch. First of all, it does not have nerve endings that will add to your pleasure, but also it would most likely damage the delicate internal valve to insert anything other than your soft flexible catheter into the opening. Damaging the valve would cause leaks and possibly even more serious complications.

One last thought for you. By now you have likely found certain foods that help slow and thicken your stool. If you use them prior to a sexual encounter this will add yet another layer of security for you, since the thicker your stool is the less likely it would be to leak at any time.☺

Continent Internal Pouches

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Prior to 1980, the only surgical operation to cure ulcerative colitis and familial polyposis was total proctocolectomy (complete removal of the colon and the rectum) with permanent end (Brooke) ileostomy.

Despite the challenges of living with a conventional ileostomy, most people with a well-constructed ostomy are able to live normal, healthy and active lives.

Over the past 25 years, new surgical alternatives have been developed and refined that give patients alternatives to a lifelong conventional ostomy. These alternative procedures include continent ileostomies, pelvic pouches and "pull-throughs." Each category has several variations.

Continent ileostomies include the Kock pouch, T-pouch and Barnett Continent Intestinal Reservoir, (BCIR). Pelvic pouches are also called ileoanal pouch anastomosis (IAPA) and further described by the shape of the pouch: j-pouch (the most common), s-pouch, w-pouch. Pull-through procedures involve removing a section of intestine and reconnecting the bowel without creating a pouch. Both IAPA and pull-throughs allow for a normal route of evacuation.

Internal Pouches

A continent ileostomy is a reservoir constructed from the small intestine that is able to store a significant amount of fecal waste. The Kock pouch and BCIR are constructed from small intestine with an exit stoma for feces flush with skin and below the belt line. The main candidates are patients who have had their anal sphincter muscles removed and currently have an ostomy or have poorly functioning anal sphincter muscles and are not candidates for a pelvic pouch or have a pelvic pouch that doesn't work adequately.

The IAPA or pelvic pouch, is also a reservoir constructed from the small bowel, but it is connected to the anus and sphincter muscles directly and exit of feces occurs through one's natural orifice.

History

The continent ileostomy was first pioneered by Dr. Nils Kock, a Swedish surgeon, in 1969 and has since undergone many changes and improvements that have made it very reliable and a life-changing option.

Since its introduction by Dr. Kock, the continent ileostomy is currently offered by only a limited number of centers in the USA and around the world, as it has largely been replaced by the IAPA, specifically the j-pouch procedure. Results from these centers are quite good and patient satisfaction very high. Modifications over the years have included improving the length of the valve and surgical technique that keep the valve from slipping. The creation by the late Dr. William Barnett of the "living collar" has decreased slippage to less than 10%. A slipped valve remains one of the most common complications of the continent ileostomy.

Reduction of complications is also shown when the surgery is performed by a board certified colon-rectal surgeon who specializes in pouch and continent reservoir surgery.

Candidates

The first step is to discuss it with your surgeon (see sidebar). The primary criteria are an ileostomy and both the rectum and anus have been removed. A minimum of 14 feet of small bowel is recommended to minimize the potential for short bowel syndrome if the continent reservoir fails and needs to be removed. Morbid obesity is a contra-indication due to the high incidence of valve dysfunction due to thick abdominal wall fat.

A very select group of patients with Crohn's disease may be considered. If you are not a candidate for a pelvic pouch or have one that has failed, a continent ileostomy is currently the only alternative to have an appliance-free life.

Patients with a colostomy frequently ask if they are candidates. The pouch is made from small bowel, so any remaining large intestine would have to be removed. If only a couple of feet remain, this is not an issue. If the majority of your colon is intact, this is a radical surgical option to consider. Only after extensive discussion and the concurrence of your primary doctors should this option be considered.

Continent Ileostomies

Approximately two feet of small bowel is used to create the continent reservoir (see figure A). The stoma is flush on the right side, usually parallel with the hip bone.

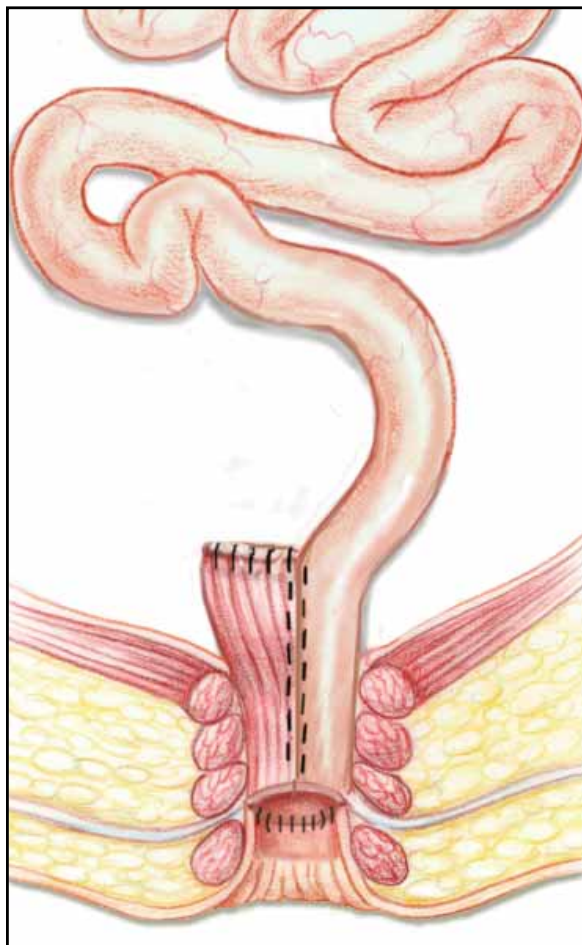
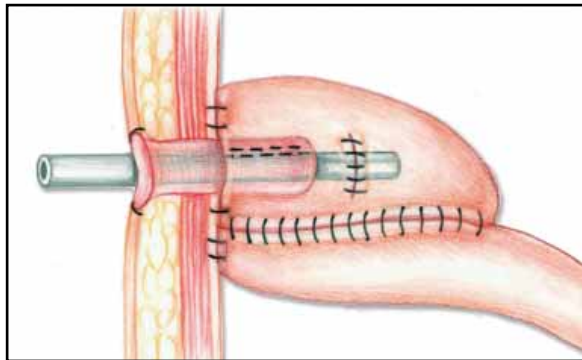
Postoperatively, the continent reservoir is allowed to rest by an indwelling catheter for two-to-three weeks. This is to allow the new reservoir suture line to heal properly to prevent leakage problems. Some patients will need to be on suction in the hospital for several weeks, but others may be discharged within a week with a catheter sutured to the skin or held in place with a fixation device and connected to a leg bag.

After two to six weeks, “self intubation” begins at two-hour intervals, eventually working up to three to four times a day. A small pad is needed to cover the stoma in order to absorb mucous drainage that occurs periodically. Change in diet is minimal provided you chew your food well and increase your fluid intake to keep your stool a thin consistency.

There are very few restrictions in the life style with a continent ostomy, although vigorous physical activity should only be performed with an empty pouch. Direct trauma to the pouch may cause problems, especially if the pouch is full.

Patient Commitment

Continent ileostomy surgery is demanding, both on the surgeons who need to contribute a high level of skill and commitment to long-term care and on the patient. Therefore, it is best to consult board certified colon-rectal surgeons who are comfortable with all surgical options and have significant experience with the creation and



Left: Figure A, continent ileostomy (notice the catheter for emptying). Figure B, the “j-pouch” variation of an ileoanal pouch anastomosis.

care of continent procedures.

Patients must be highly motivated and realize there is a significant amount of risk that may require further surgery to correct potential problems.

Like all surgeries, continent ileostomies have pros and cons. The obvious advantage is an appliance-free life. The cost of supplies is significantly reduced compared to a conventional ileostomy. The average cost of the tubes used to intubate and drain the reservoirs is only \$25-50 and need to be replaced only two to three times a year. For those who have problems with their ileostomy, it can be a new-found freedom.

The disadvantages are complications that will require additional surgery to repair; these include slipped valve, intestinal fistula and pouchitis. Complications not unique to this type of surgery would include bleeding, intestinal obstruction and peristomal hernias.

Complications

1: Pouchitis: This refers to an inflammation of the pouch. It is generally a condition wherein the patient will develop

abnormal cramps, feeling poorly, frequent bowel movements and possible fever.

- A) Mild – diet change, antispasmodics and antidiarrheal medication.
- B) Moderate – antibiotics or probiotics.
- C) Severe – hospitalization, bowel rest and IV antibiotics; possible steroid therapy. In the rare instance where pouchitis does not respond to therapy, pouch removal may be required.

2. Stoma Stenosis: This is the narrowing of the stoma that may occur during healing. A simple outpatient surgery can repair this.

3. Slipped valve: The valve has become desuscepted. The valve is coming apart and returning to its original state. When this occurs, it will become shorter, the access segment will appear longer and not straight. Therefore, intubations will become difficult and the pouch will leak intestinal waste through the stoma. This will require surgery to repair.

4. Fistula: An abnormal sinus with the gastrointestinal tract. Place of occurrence will depend on treatment: TPN (no eating by mouth), bowel rest and surgery.

Pelvic Pouches

In the 1940s and 1950s, procedures that connected the small intestine directly to the anal sphincter often resulted in severe fecal urgency (the sudden, unstoppable urge to defecate), frequency and perianal skin breakdown. In the 1980s, pelvic pouches evolved from the continent ileostomy. By allowing passage of stool through the anal orifice, the procedures are the closest to the natural way of eliminating fecal waste.

Construction

The pelvic pouch also requires the usage of 8 to 18 inches of the small bowel to construct a substitute rectum. Once the colon and rectum are removed, preserving only the anus, the small intestines have minimal capacity to store stool. To make a functional reservoir, the small bowel is folded on itself and the adjacent bowel loops sewn or stapled together.

Finding a Surgeon

Creating an internal pouch requires a high level of training and skill. An internal reservoir that is not constructed properly could necessitate additional surgeries to repair. If repair is not possible, the pouch will need to be removed or bypassed. Therefore, it is important to consult surgeons with experience constructing internal reservoirs and managing the possible complications after surgery.

Begin your search by talking to your primary care physician, ostomy nurse, gastrointestinal doctor or current surgeon if you have one. If you are a candidate, explain your interest to get their opinion.

Referrals from someone who has had the surgery are helpful to get a patient's perspective. Affiliated support groups of the UOAA, including the Continent Diversion Network, Pull Thru Network (for minors) and Quality of Life Association have members who have had surgery.

Professional societies are an excellent resource to find qualified surgeons. The American Society of Colon and Rectal Surgeons has over 2,600 members and also certifies surgeons who meet educational, credentialing and examination requirements. ASCRS can be reached at 847-290-9184, ascrs@fascrs.org and www.fascrs.org.

The Society of American Gastrointestinal and Endoscopic Surgeons has over 5,000 members who use endoscopy and laparoscopy as an integral part of their practice. SAGE can be reached at 310-437-0544, by e-mail at sagesweb@sages.org and on the internet at www.sages.org.

Internal pouches can provide an improved quality of life. Finding the right surgeon is paramount due to the high level of skill and experience required as well as the important follow-up care to address any complications that may arise.



The operation is performed in either one, two or three stages, depending on the health of the patient and the health of the intestines. Usually, a temporary loop ileostomy is used to allow proper healing of the pouch for approximately three months.

Candidates

The j-pouch is the current "gold standard" and first choice procedure

to offer those patients who have had medically refractory ulcerative colitis or familial adenomatous polyposis syndrome. This procedure can only be performed on patients who still have their anal canal and properly functioning sphincters.

Sometimes, during surgery, it is determined that the pelvic pouch cannot be connected to the anus

continued on page 19

Yes You Can!

The Phoenix ostomy magazine is filled with 72 pages of inspiration, education and information to help ostomy patients return to a full, active and productive life. Just ask ostomate Jessica Grossman (right) who headed an ostomy awareness campaign!



Each Issue includes:

- Ask Nurse Muchoney
- Ask Dr. Rafferty
- New Products
- Personal Stories
- Management Techniques
- Support Group Listing
- And much more!!

"The Phoenix magazine is the most important tool that ostomates can get a hold of."

- M. Bauer, Nebraska

"I didn't know anything about ostomies. The Phoenix magazine has helped me so much."

- R. Hodges, Arizona

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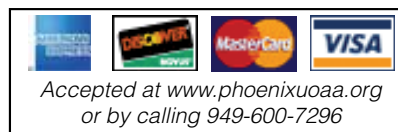
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ContDivNPG

Her Winning Ways

From J-Pouch Surgery to “Road Rules” Champion

By Joanne Olshan

If you met Jodi Weatherton, you might get the impression that she's the “girl next door.” She's young and pretty, intelligent, athletic and full of personality. But in the 25 years that Jodi has lived, she has been faced with challenges that most people won't experience in a lifetime. To her, it's all just a matter of fact and as she nonchalantly puts it, “no big deal.”

So how does one manage that kind of mindset after having endured excruciating pain at the tender age of 11, a two and a half month hospital stay, four blood transfusions, three major surgeries at 16 and countless moments of anguish? For all of the complexities of life dished out to Weatherton, her answer is surprisingly simple.

Weatherton was born in Herndon, Virginia. Her dad was a salesman so the family moved quite a bit before ending up back in Virginia in the city of Vienna. Because of the frequent moves, Weatherton never really got a chance to sustain friendships during her earlier years. Still, her family was close-knit with strong Christian

values and younger brother Andrew was her best friend. All in all, Weatherton considered her childhood to be normal...until her eleventh year.

When she woke in the night screaming with pain, Weatherton's mom Donna, who was a nurse, was fairly certain of the cause. Donna's mother-in-law had intestinal problems that led to the partial removal of her large intestine. A trip to the hospital for a seemingly endless run of tests, most of which Weatherton does not remember except for a lower GI, revealed a clump of cells that looked like Crohn's disease cells. Accordingly, she was given medicine for Crohn's disease and sent home. Remarkably the pain vanished and the disease went into remission.

It wasn't until five years later when Weatherton was 16 and living in Massachusetts that the pain flared up again. This time doctors prescribed oral steroids. Weatherton remembers gaining sixteen pounds in a week from the medication, but she remained on the steroids for a couple of months, and then was slowly weaned off. Again, the disease went into remission.

The relief was short-lived; Weatherton found herself running to the bathroom with severe diarrhea coupled with severe pain. “It was difficult to live a normal life,” recalls Weatherton. “Socializing and sports were especially challenging.” As a dedicated member of the track team, jumping the hurdles became a huge dilemma for Weatherton. Uncomfortable about talking to her coach, she instead chose to remedy the situation by wearing a large pad. Afterward a friend would help her run to the bathroom. Despite ongoing problems, the





medicine did help and she managed to finish the track season in her 16th year.

But in the spring of that same year, Weatherton's problems went from severe diarrhea with blood to stools that were entirely blood-filled. Not wanting to see more doctors or return to the hospital, she hid her condition from her mother. When the bleeding wouldn't stop, Weatherton became frightened and eventually told her mom. She was immediately admitted to Boston Children's Hospital for what would be a 2 1/2 month stay. Donna remembers the incredible team of doctors. But even more incredible to Weatherton's mom was that throughout the entire ordeal, her daughter never once said, "why me?"

Weatherton had no idea of what she was about to go through and in hindsight says she was better off. A new series of tests diagnosed her condition as ulcerative colitis. In addition to receiving four blood transfusions, Weatherton had to make some major adjustments. Fortunately she had tremendous support from her family and from her friends who would bring Weatherton schoolwork and keep her company. Her mother made arrangements with the hospital to stay with her daughter for the entire time she was there.

She remembers all the wheelchair rides her mom would give her just to pass the time, and Weatherton's dad, who was working in Boston then, stopped by the hospital every night on his way home. Her longtime boyfriend was also a constant presence during her recuperation and the two went from hospital room to Junior Prom even though she was not fully recovered.

Now Weatherton needed to make a decision about treatment. Doctors offered her two options: drugs with side effects or surgery. "I had never even broken a bone, so surgery was a huge step," she says. Weatherton opted for drug therapy which consisted of ten pills a day and resulted in tremors. Her hands would shake if she got excited and she says, "I never felt quite right and I never had a normal stool." When she came home from the hospital, the severe problems resurfaced and it seemed surgery was unavoidable.

This time when Weatherton reentered the hospital, it was for a restorative proctocolectomy, also called a J-Pouch. Normally achieved in a two-stage surgery, Weatherton would have to go under the knife three times because she was so ill. The operation involves removal of the entire colon and all, or nearly all, of the rectum but leaving the anal sphincter muscle intact. What is known as a J-Pouch (because it looks like the letter "J") is constructed from 10 to 12 inches of the small intestine as a reservoir for waste and replaces the function of the rectum. The pouch is then connected to the remaining anal sphincter muscle so that elimination remains relatively the same.

In Weatherton's case, the first surgery entailed removal of the whole large intestine. Afterward, wearing an ileostomy bag for three months was hard, because she says, "the kids at school did not understand and I felt embarrassed." The second surgery involved the construction of the J-Pouch from normal small intestine which is then sewn or stapled to the anal muscles and a temporary "loop" ileostomy is created to allow the bowel to heal and to protect the newly formed J-Pouch.

During her senior year in high school Weatherton

had her final surgery which reversed the “loop” and closed the ileostomy. “I am one of the lucky cases,” she explains. “Many people cannot have this type of surgery. People who do have the surgery often have constant problems with the pouch because they have Crohn’s disease or they are not able to control it and have accidents.”

Her doctor gave her strict instructions to ensure the success of the J-Pouch and Weatherton complied. “I was very diligent. I had to have enemas every night for a month and train the muscles to work again. It wasn’t fun, but I did it. I’ve had the pouch for eight years now without ever having pouchitis and I’m pain-free.”

Even before the worst of her problems were behind her, Weatherton seemed determined to get back to the things that mattered the most to her. She participated in sports after every surgery including volleyball and basketball. After her third surgery she took on a role in the school play and as her senior year came to a close, she graduated with the rest of her class. “I never thought I wouldn’t live a normal life,” Weatherton says. She credits the positive influences in her life, particularly her mom, for being able to look on the bright side of things. Their closeness has given her strength during the most trying of times.

But normal could be a little tricky as Weatherton would discover after entering college. She first attended Geneva College in Beaver Falls, Pennsylvania, and then transferred two years later to Virginia Commonwealth University in Richmond where she graduated in August of 2004 with a degree in psychology.

Weatherton admits that she struggled with her condition while in college. She lived in the dorm and in the beginning nobody but her roommate knew about her surgery or the reason why she had to go the bathroom more often than the average person. She remembers one uncomfortable moment that also served as a turning point. “I was putting on my book bag and my shirt rose up a bit. A boy noticed my scar and asked about it. But I thought, this is me and it’s part of my life, so I can’t let it be awkward.”

Close friend Tiffany Perpilar has known Weatherton for seven years. They met while in college. Perpilar says that Weatherton shared her condition with her

right away but that she never felt sorry for herself or made a big deal about it. Other than carefully planning what she was going to eat and always turning on the water when she used the bathroom, Perpilar says that Weatherton was not only a very positive person but also a very caring, generous and outgoing individual. “She loved sports and was really into studying. Jodi is strong-willed but very sweet,” says Perpilar.

Weatherton describes dating as “interesting” and says that there is always that nervous feeling that she’ll have to talk about her surgery and her frequent trips to the bathroom. Generally, however, most of her dates don’t ask or don’t seem to care. Still, she is always concerned about having access to a bathroom wherever she goes and long vacations are

definitely out at the moment. But she’s not complaining. On the contrary, Weatherton doesn’t seem to have room in her life for negativity and perhaps this positive attitude is how she landed a spot on MTV’s Road Rules.

In September of 2004, after finishing college, Weatherton decided to audition for the popular MTV series. The show involves traveling around the country in an RV with other contestants and competing in a variety of challenges requiring not only guts, but incredible athletic ability. On each of the episodes, players who lose challenges are eliminated until there are only four final contestants, two guys and two girls.

Weatherton thought it sounded like fun so she called her parents and asked them to help her make an audition tape. According to Donna, she and Weatherton’s father weren’t thrilled with the idea but agreed to help anyway. “I was pretty sure that when the producers found out about Jodi’s surgery, they wouldn’t select her,” said Donna. Weatherton’s parents filmed her water-skiing, wakeboarding, riding her dirt bike and making chocolate chip cookies. Within a week after receiving Weatherton’s audition tape, the show’s producers called. During the 3 1/2 month interview process Weatherton told the producers about her surgery but did not get into the details. In the end she was selected as one of the twenty contestants from among 30,000 applicants.

As filming was about to begin, Weatherton was relieved to learn that the RV bathroom was not to be



*Above: Weatherton posing with a fellow cast member of the MTV show “The Gauntlet.”
Opposite: Relaxing with the winning rookie team on the “The Gauntlet II.”*

used. Instead, she says, "We made tons of bathroom stops." She describes the experience as amazing and says she made friends despite the fact that the producers deliberately choose players who might clash to create some drama during the show. Weatherton she had to bungee jump, repel down a waterfall and walk a tight rope 150 feet in the air between two buildings.

With time to spare before filming of the final Road Rules episode that she was to appear on, Weatherton enrolled in Ecola Bible School in Cannon Beach, Oregon. As amazing as the whole MTV experience was, Weatherton felt that she had drifted away from what was really important to her. She had grown up in a Christian home and her faith had always been an important part of who she was. Deciding it was time to rediscover her relationship with God, she attended Ecola for seven months, graduating with a short term Bible degree.

Following Bible school, Weatherton returned to MTV for the filming of her last episode of Road Rules. She had made it into the final four and had already been rewarded with a car from winning a challenge on a previous episode. But this latest competition offered the top male and female contestants a whopping \$150,000 cash prize for each. The episode, which recently aired on January 18th took place in sunny Rio de Janeiro. Weatherton looked tanned and in tip-top shape. But more importantly, she had an undeniable look of determination and spoke with confidence.

The challenge began with a lengthy uphill run through a winding trail. At the end of the trail contestants find four gigantic puzzle pieces that have to be carried to another location one by one and put together according to color. For a moment Weatherton becomes frustrated with the puzzle but seems unfazed by the physical demands of this challenge. When the puzzle is completed, contestants run back down the trail where they encounter a teeter-totter that they must balance on evenly for a given amount of time. Finally, contestants run to the finish line to collect their flag which signals when each has completed all the challenges. So which girl won? Weatherton, of course.

She could have continued to be on more Road Rules episodes but the general atmosphere on the show presented too many issues that contradicted her newly restored faith in Christianity. So she returned home

to get what she refers to as "a real job." Following in her father's footsteps, she became a commercial sales representative this past October. She enjoys the profession and is interested in getting into pharmaceutical sales.

Eventually, she'd also like to get married and have kids.

Outside of work, Weatherton continues to stay fit at the gym she attends at least three or four times a week and plays basketball there just for fun. Ever the sports enthusiast, she played on a softball league through her church where she also volunteers whenever she can.

In addition, Weatherton makes time for the occasional speaking engagement at church conferences and youth groups but always seems a bit surprised when she's invited to do so. As inspirational as her life is to others, she really doesn't understand what all the fuss is about. Most recently she spoke at the Y.O.D.A.A. Conference. The young ostomates in the audience listened intently as she shared her life after J-Pouch surgery.

Having walked in their shoes, it's important for Weatherton to convey the message that having a positive attitude is paramount. She considers herself "really lucky" and explains that young people can bounce back quicker from J-Pouch surgery but emphasizes that success is also based on frame of mind. "I have always been driven; driven about sports, about drama and even about being sick. It takes a certain mindset to get through anything."

While the MTV experience may stand out as one of Weatherton's most notable accomplishments, it does not define her. To both young and old alike, she is a shining example of what can happen when, despite obstacles, you embrace the possibilities. Hers is a story about having faith, about staying positive and about surrounding yourself with people who believe in you.

Weatherton lists her parents as her heroes because, she writes, "They never gave up on me, have always been there for me and most of all, they always love me." But the most revealing post on her page by far, is her favorite saying which reads; one thing you can be sure of in life is change, don't let it hold you back, learn something from it and grow through it. It speaks volumes about Weatherton's rock-solid character and gives one the feeling that no matter what the future has in store for this courageous young woman, she'll be ready.☺



Continent Urinary Diversions

Understanding and Managing an Internal Pouch

By Roni Olsen, Metro Denver UOAA

During the second revision of my husband Ben's ileal conduit, it was removed and replaced with an internal continent Kock pouch with an abdominal stoma. With gritty determination, he fought his way back to health. Now 74, he continues to enjoy a busy and physically active lifestyle.

As a result, we learned a great deal about urostomies in general and the pros and cons of the three different types of urinary diversions: an ileal conduit that requires an external appliance, an internal continent Kock pouch that requires convenient catheterization through an abdominal stoma, and the internal continent pouch/neobladder that is reconnected to the urethra to provide near-normal urination.

We also learned a urinary diversion provides a second chance at life for those whose urinary bladders must be removed. Understanding the critical role of ostomy surgery is essential to both the physical and psychological adjustment to the altered body function and diminished self-esteem that routinely accompany most ostomy surgeries.

As body strength is regained, dealing with an ostomy actually becomes routine, but the psychological adjustment often takes a much longer period. Some people will have the support of a caring family and/or friends to help them through the process, while others less fortunate may have to fight the uphill battle alone. Whatever the circumstance, each urostomate's attitude is ultimately the key to life with a urinary diversion. An ostomy need not permanently limit a person's activities, abilities, interests or horizons. The urostomate in tune with life will understand that each day is to be treasured and not wasted.

Internal Continent Pouches

There are two types of internal continent urinary pouches (also called reservoirs): the internal pouch with an abdominal stoma and the internal pouch that is reconnected to the urethra (neobladder). These internal continent urinary pouches with abdominal stomas are

similar to a normal urinary bladder, except they are not connected to the urethra. Instead, they are connected to an abdominal stoma located on the abdomen. These pouches are emptied by patient self-catheterization through the stoma. The most common internal continent urinary pouches include the Kock pouch and the Indiana pouch and several variations, including the Mainz, Miami, Florida, Studer and Mitrofanoff pouches.

Kock Pouches

The Kock continent urinary pouch (pronounced "coke") is made from approximately two feet of ileum. A valve is created at each end of the pouch. The ureters are connected to the internal valve which prevents reflux to the kidneys and the end of the other valve is brought to the abdominal surface to form a small continent stoma. The Kock pouch is emptied by inserting a flexible silicone catheter with a coude' tip ('elbow' or angled tip) into the stoma four to eight times a day.

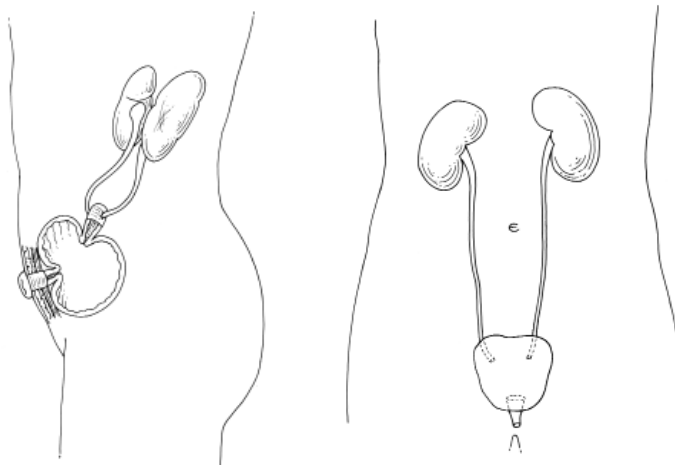
Indiana Pouch

The Indiana-type pouches are easier to construct than the Kock pouch, but they hold a smaller volume of urine. Typically, segments of both small and large intestine are used to form these pouches and usually the ileo-cecal valve (the valve between the large and small intestine) becomes the continence valve. Stomas for these pouches are frequently placed in the bellybutton, and catheterizing is usually required every four to six hours. In some cases, patients are also instructed to irrigate their pouches to help remove mucus, generally a few times a week.

Any feeling of fullness or discomfort in any of these pouches, or feeling of cramping or nausea, usually means the pouch needs to be emptied. Excessive fluid intake at any time may result in the need for more frequent catheterization. Regardless of the time between catheterizations, these feelings should never be ignored. Catheterization of the stoma is convenient, easy, painless and maintenance is minimal. Since they don't leak, they don't require an external appliance and their stomas can be made almost flush with the skin.

Catheterization of the Internal Continent Pouch

Techniques for catheterization will vary slightly



Left: Internal continent pouch. Right: neobladder.

because the shape and angle of the stoma or nipple valve and depth of the abdominal wall varies from patient to patient. Fortunately, a wide variety of catheters are available to accommodate these differences. Usually, the patient is taught to catheterize the pouch in both a sitting and standing position and is also encouraged to relax the abdomen. In either case, relaxation of the abdomen is far easier said than done during the first few weeks of self-catheterization. Although the process of poking a drain tube into the abdomen seems like an outrageously bizarre task at first, catheterization is actually simple, quick and painless. It rather quickly becomes routine.

Catheterization of the continent pouch is not a sterile procedure; at best it is only as clean as the local tap water. The procedure works best when two hands are used to hold and manipulate the catheter; therefore, hands should be washed with soap and water prior. By holding the flexible catheter firmly near the tip, it can usually be gently inserted into the stoma. Catheterization does not require force, but sometimes a slight push, twist or a combination of the two is needed. Even though the mucosal lining of the stoma continuously exudes a small amount of mucus, additional lubrication may be needed for catheterization.

If so, the catheter tip can be moistened with tap water or a small amount of a water-soluble jelly. Non-water soluble products should never be used. After the tip of the catheter slides into the stoma and on through the nipple valve into the pouch, the outside end of the catheter should be slowly turned downward and positioned to drain the urine into the toilet or a convenient container. A few squares of toilet paper in the toilet helps minimize

splashing. Once urination is completed, the catheter is simply pulled back out through the stoma.

Occasionally, mucus buildup may partially or completely block the catheter. Sometimes, a rotation of the catheter or slight abdominal grunt or two, or a cough, will push the mucus plug through the catheter and allow urine flow to continue. If not, the catheter should be rinsed under the tap until the mucus passes and then reinserted into the stoma. Always carry a clean, spare catheter.

Also keep all supplies in carry-on luggage when traveling and do not leave supplies in a hot car or any other place that is overly warm. In most cases, a small, moisture-proof pad needs to be worn over the stoma to absorb normal stomal secretions.

A third of a thin sanitary pad held in place with two pieces of half-inch wide micropore tape makes a satisfactory and economical cover. Catheters fit easily into sandwich bags as well as a pocket, purse, backpack, or glove compartment and at least one clean catheter should always be available.

Catheter cleaning is also not a sterile procedure. Recommendations for cleaning vary from rinsing with a soapy water solution to soaking in Betadine (very messy) or soaking in a solution of four parts Hibiclens to one part water. Whichever procedure is used, the catheters should be thoroughly rinsed inside and out with tap water, then air dried before re-use. If traveling abroad, bottled water is advised. Again, ETs can provide helpful information on catheterization and equipment maintenance procedures.

Continent Bladder Replacements

For men and women who meet special criteria, the T-pouch orthotopic bladder (similar to the Kock pouch), and the neobladder (Studer and variations) are internal pouches that can actually be reconnected to the urethra to provide near-normal urination. Patients may require lengthy rehabilitation and exercise to strengthen and retrain the muscles and nerves that control the urinary sphincter. The majority find continence is easily maintained during the daytime, but may need to wear a pad as a safety measure.

Nighttime incontinence, however, remains a problem for many, and some never achieve 100% continence. Some people wear Depends, and some get up a few times during the night to urinate. Some men use a penile sheath (also called condom catheter) with a tube connected to a collection jug. In some cases, hypercontinence (inability to urinate) is an issue

and those individuals have to catheterize through their urethras to empty their neobladders. The bladder cancer website, <http://blcwebcafe.org>, has several members with neobladders. Their experiences range from total continence to hypercontinence. They are a knowledgeable and excellent source for information and tips on dealing with neobladders.

General Information

Urostomates need to be aware that any symptoms of kidney infection (chills, fever, flank pain, dehydration, unusual fatigue, change in the volume, color or odor of urinary output, or a change in the amount or color of mucus) require immediate medical attention. An infected kidney is not only excruciatingly painful, but may result in permanently impaired kidney function.

Early oral antibiotic treatment may control a minor kidney infection. Urine cultures and blood tests help determine the specific bacteria involved, so the appropriate antibiotic can be given. If stronger, intravenous antibiotics are needed, this generally means a few days in the hospital as well as a few weeks for

recovery. Extensive antibiotic therapy is not the solution to recurrent kidney infections and may result in a resistant strain of bacteria.

Recurrent kidney infections warrant further examination, usually an IVP and/or loop-o-gram, or pouch-o-gram, to determine whether or not there is an obstruction or stricture that needs correction.

Resources

Check with the UOAA for names of ostomy nurses and for members with urostomies. Local UOAA support groups should have the names of nurses in their communities. National UOAA at 800-826-0826 can supply the name and number for all support groups.

Finding an ET or wound, ostomy and continence nurse with good urinary diversion experience may take some effort. See the website www.wocn.org, click on services and resources, click on referrals, then click on consultant registry for a list of names.

Another excellent place to find support is through the WebCafe's free email list/support group for bladder cancer warriors, see: <http://blcwebcafe.org>.

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continued from page 10

due to inadequate length of the small intestine. In these unusual situations, a continent ileostomy can be immediately created so the patient does not have to undergo a subsequent operation or have an unexpected permanent ileostomy.

Those with other medical conditions that make anesthesia and surgery excessively risky or have known small bowel Crohn's disease are not considered viable candidates.

After Surgery

Immediately post-operatively, it is common to experience urgency, frequency and slight bowel incontinence. Once the pouch has healed and had a chance to enlarge, approximately three to eight bowel movements a day can be expected. The average is four to six times a day. There are very few dietary or activity restrictions.

Pros and Cons

The main advantage of an ileoanal pouch is the ability to evacuate stool in the usual fashion through the anus. There is no need for supplies or catheters.

Some patients experience "butt burn" after surgery. This is due to high stool frequency and slight incontinence. This subsides after the initial adjustment period. Like the continent ileostomy, pouchitis is the most common complication. Bowel obstruction, pelvic infection, fistula and stenosis are also complications of this surgery.

Complications

1. Pouchitis – urgency, frequency, painful straining, bleeding and incontinence. See continent ileostomy for treatment options.

2. Bowel obstruction – nausea, vomiting, bloated and unable to pass stool. Early in recovery, this can be due to food not chewed properly. Later, it is caused by adhesions that kink the small intestines. The majority of obstruction can be resolved without surgery.

3. Pelvic infection – fever, chills, lack of energy. The cause is a result of a leak where the bowel is newly connected. This occurs in about 6% of patients and can be treated with antibiotics or by placing a drain in the site that is infected.

4. Stenosis – incomplete emptying of the bowel or frequent, urgent bowel movements. It is rarely a significant problem and can resolve by gentle dilation of the anastomosis digitally or with specialized dilators.

Summary

Patient satisfaction and quality of life scores with ileal internal reservoir surgery have been high. As the operations continue to evolve, patients are also having fewer complications and better function over the long term. Many of the problems experienced early in the development of these procedures have been greatly reduced or eliminated.

Psychosocial adjustment to the reservoirs depends on many things, such as whether complications occur, the ability to resume a normal lifestyle and the expertise of the health care team in providing routine care, education and emotional support in managing any complications that may develop.

The ability to return to a normal, healthy life without an external appliance or without urgency and rectal bleeding from ulcerative colitis, can help achieve a sense of emotional well-being. There is

usually a great sense of relief after these procedures and even elation at having been given a second chance at life because the patient's perceived health has greatly improved.

The need for surgery and the choice of operation are major decisions. Patients are encouraged to learn as much as possible about their disease and the treatment options.

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