Crohn’s Disease and the Pelvic Pouch
By Yehuda Kariv, M.D., and Feza H. Remzi, M.D.

The pelvic pouch has become the procedure of choice for most patients with ulcerative colitis (UC) who require surgery. The pouch avoids the need for a permanent stoma by preserving the normal route of defecation.

In contrast to UC, Crohn’s disease (CD) can involve the small bowel and other parts of the gastrointestinal tract. It has a significant tendency for disease recurrence after surgery. Therefore, in patients with CD, the creation of a pelvic pouch has traditionally been considered a contraindication, or inadvisable.

In pelvic pouch patients, CD is associated with higher rates of perioperative and long-term complications. CD may manifest as an inflammatory process within the pouch, chronic fistulae, strictures and symptomatic small bowel disease proximal to the pouch. Severe recurrence of CD in the ileal pouch might require its removal.

Differentiation
Despite several classification systems and good clinical, endoscopic, radiological and histological tools, identifying the difference between CD and UC still is sometimes difficult.

In at least 10 percent of colitis patients, no differentiation can be made between UC and CD. Those patients are defined as having indeterminate colitis. In most CD patients who have undergone pelvic pouch procedures, the presumed diagnosis prior to surgery was ulcerative or indeterminate colitis, but those patients subsequently have been found to have CD.

Although controversial, there is limited data that suggests a pelvic pouch operation may be performed in very carefully selected patients with an established diagnosis of Crohn’s colitis before surgery. This is supported by several reports that have described an acceptable outcome of a pelvic pouch operation in CD patients free of small bowel and perineal disease before surgery.

A study done by the Cleveland Clinic Department of Colorectal Surgery on a small group of patients who had their diagnosis revised to CD after pouch surgery has demonstrated a CD recurrence rate of 35 percent, and overall pouch loss (the need for permanent stoma or pouch resection) in 12 percent of patients at four years postoperatively.

Most other studies on patients with an initial or final diagnosis of CD, however, have shown higher rates of CD recurrence and loss of the pouch (range: 10 percent to 56 percent). CD recurrence in the pouch is sometimes difficult to differentially diagnose. Features to support a diagnosis of CD of the pouch are granulomatous inflammation on histology, pre-pouch ileitis or chronic fistulae.

Therapeutic Options
In patients who develop CD of the pouch, medical therapeutic options are available to attempt pouch salvage. The combined strategies of anti-CD medications, anti-inflammatory drugs, immunosuppressives, antibiotics and probiotics are used with variable success rates.

In addition, there is increasing experience with Infliximab (Remicade) to treat CD of the pouch. Infliximab, an antibody...
Maintaining Hydration in Ileostomy and Pouch Patients

During the time you have an ileostomy, you may be at greater risk for dehydration. You may also be at risk for dehydration with the pelvic pouch during the post-op period and later, during times of extreme exercise or heat, during times of illness such as the flu, and when you are having diarrhea or frequent stools. Maintaining hydration is vital.

The body is more than 50–60 percent water. We need fluid to maintain daily body functions; without it, we could not survive. Therefore, it is important to consume adequate amounts and types of fluid each day to stay well hydrated. The foods you eat and the liquids you drink can affect bowel elimination. In most cases, you will be able to maintain adequate hydration status by drinking plenty of water. However, if you have significant and persistent diarrhea, you may need special oral rehydration solutions (ORS) to maximize absorption.

Why are ORS so special? The composition of these solutions is designed so that the cells lining the gastrointestinal tract will absorb it better. The solutions have an ideal number of particles and the appropriate concentration of salt and sugar. The optimal level of sodium in an ORS for people who have had parts of the bowel removed is between 90 and 120 mEq/liter.

The osmolality, or number of chemically active particles in the solution, also affects absorption. The distribution of water between the inside and the outside of the cell is determined by the number of particles (osmoles) in each compartment. Water moves from an area where there are few particles to an area in each compartment. Water moves from an area where there are few particles to an area where there are many particles. However, their relative lack of glucose and sodium make them inappropriate rehydration fluids. Examples are water, ice, sugar-free soft drinks and sugar-free Kool-Aid, Crystal Lite, coffee and tea. Isoosmolar or isotonic beverages contain particles in nearly the same concentration as they appear in the body. Because glucose and sodium enhance water absorption, selection of an isotonic beverage that contains both sugar (glucose) and sodium is the most effective means of oral rehydration. Examples are included in the table on the next page.

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Getting Enough Fluid

The amount of fluid required will vary by the individual. If you have an ileostomy, your oral intake should exceed your ostomy output. You should always consume enough fluid to maintain adequate urine output. In general, most people will have to drink between one and three liters of fluid each day.

Drinking Fluids the Right Way

Beverages should be sipped continuously with the largest amounts taken between meals and smaller amounts with meals. Do not dilute your ORS with ice cubes. However, you can make ORS ice cubes by putting the ORS solution in the ice cube tray and freezing it. Many patients drink the ORS unflavored. You can flavor it with sugar-free Kool-Aid, Crystal Lite or Wyler’s Diet beverage crystals. You also may mix a powdered ORS with your favorite diet soda.

Avoid highly concentrated (hypersmolar) drinks like fruit juice, regular soda pop and sugar-sweetened beverages. Throughout the day, you may drink beverages that are low in sugar (low concentrated, hypoosmolar), but avoid diet beverages sweetened with xylitol or sorbitol because these sweeteners are not absorbed by the gastrointestinal tract and may increase stool output. Fruit juices are not recommended because they are high in natural sugar, which may increase stool output. If you must include fruit juice in your diet, decrease the amount of concentrated sugar in the juice by mixing one-part fruit juice and one-part water, Diet Sprite or Diet 7-Up.

Remember Fiber

Fiber is an important part of our diet, adding bulk to the stool and holding water. There are two types of fiber: soluble (gums, pectins) and insoluble (cellulose, hemi-cellulose, lignin). Soluble fiber forms a gel-like material in water and helps restore regularity. Soluble fiber also can slow gastrointestinal transit time. Soluble fibers are fermented in the lower part of the GI tract, forming short chain fatty acids that are used as fuel sources to the colon or the newly connected pelvic pouch. Food sources of soluble fiber include ripe bananas, rice, applesauce, toast, tapioca, oatmeal and oat products, dried beans, barley, winter squash, apples, carrots, potatoes and pectin.

Insoluble fiber does not dissolve in water and moves through your digestive system largely intact. It helps keep you regular by bulking up the stool. Food sources of insoluble fiber include whole wheat, cereals, apple skins, whole grains and carrots. Foods containing large amounts of insoluble fiber may or may not be tolerated depending upon your risk of intestinal obstruction.

If you slowly increase your intake of soluble fiber foods at each meal, you will probably find that your stool will thicken. If gas and bloating become a problem and stool output increases, you may need to consider alternatives.
Fiber supplements may be used to increase fiber intake. The powder forms can be added to liquids, especially oral rehydration solutions and sipped throughout the day. When it is not convenient to consume a liquid, a chewable tablet or wafer may be more suitable.

**Anti-diarrheal Medications**

Your doctor may prescribe some anti-diarrheal medications to slow down your ostomy output or stool frequency. In general, these should be taken 30 minutes before meals in order to maximize their effectiveness. *POG*

*If you experience irritation or frequency, try to eat more applesauce, bananas, white rice, mild cheeses, pasta without tomato sauce (try a little olive oil or sprinkle a little cheese on your pasta), creamy peanut butter, broiled or baked chicken, tapioca pudding, skinless potatoes, pretzels, toast, oatmeal, marshmallows, cooked carrots / squash / yams. Baked foods are better than fried foods. These foods tend to make stools more formed and less irritating.*

*If these measures don’t help, you may need to check with your physician to see if you would be an appropriate candidate for a bowel stopper such as Imodium or Lomotil. Some people require both to slow down their stools for a time. Check with your physician to see if a soluble fiber supplement (powder, tablet or wafer) might help.*

Popular skin care products used for anal burning or irritation include Calmoseptine, Desitin, A&D cream with aloe, Aloe Vesta, ILEX paste, Pinxav or Butt Paste, which can be ordered online or from your pharmacy. Other options include Lidocaine ointment or Analpram, available by prescription only. Again, check with your physician. Try one or two products to see which works best for you or alternate between them. If things don’t improve over time, consider coming back to The Cleveland Clinic Digestive Disease Center for further evaluation.

*If you have any other suggestions or products that have helped you “get to the bottom” of perianal care, please drop us a line. We want to hear your thoughts!*

Sincerely,

FROM THE DESK OF
Miriam M. Preen, B.S.N., R.N.

Note: This article was reviewed by a Cleveland Clinic colorectal surgeon and does not substitute for medical advice and evaluation by your personal physician.

This issue, my topic is “getting to the bottom” of perianal care! Some patients encounter perianal irritation, particularly during the first year or so after pouch surgery because of stool frequency. Over time, this may improve as frequency decreases and the pouch starts to expand and increase absorption. To reduce irritation, gently clean the area, keep it dry and use alcohol-free cleansing cloths (avoiding harsh soaps or scented toilet papers). You may place a wisp of cotton in the area to wick away moisture if needed.

For some people, diet affects stool consistency, frequency and the level of anal irritation. Some dietary changes that may help reduce irritation include limiting high sugar foods such as donuts, candy, pop, fruit juices (especially apple) and acidic fruits such as berries or oranges. Avoiding chocolate and caffeinated items (e.g., coffee and iced tea) and alcohol, and limiting spicy foods and tomato sauces may help. Over time, you may be able to slowly add some of these items back into your diet one at a time in small amounts.

Commercially Available Oral Rehydration Solutions

<table>
<thead>
<tr>
<th>Manufacturer</th>
<th>Product Name</th>
<th>Carbohydrate g/Liter</th>
<th>Sodium mEq/Liter</th>
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</thead>
<tbody>
<tr>
<td>WHO powder*</td>
<td>Oral Rehydration Packet</td>
<td>20 g glucose</td>
<td></td>
</tr>
<tr>
<td>Cera Products**</td>
<td>Ceralyte 70/90</td>
<td>20 g rice syrup solids</td>
<td>70 and 90</td>
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<tr>
<td>Ross ***</td>
<td>Rehydrate</td>
<td>25 g dextrose</td>
<td>75</td>
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<tr>
<td>Ross***</td>
<td>Pedialyte</td>
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<td>Mead Johnson+</td>
<td>Enfalyte</td>
<td>32 g rice syrup solids</td>
<td>78</td>
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<td>Pediatric oral electrolyte</td>
<td>25 g dextrose &amp; 5 g fructose</td>
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<td>Wal-Mart</td>
<td>Parent’s Choice</td>
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</tr>
<tr>
<td>Kroger</td>
<td>Comforts</td>
<td>20 g dextrose &amp; 5 g fructose</td>
<td>45</td>
</tr>
<tr>
<td>Giant</td>
<td>Super G Oral Electrolyte Solution</td>
<td>20 g dextrose &amp; 5 g fructose</td>
<td>45</td>
</tr>
</tbody>
</table>

* Jianas Brothers 816/421-2880
** Cera Products, Inc. 888/237-2598
*** Ross 800/544-7495
+ Mead Johnson 800/831-3959
The Cleveland Clinic is a miraculous hospital that I would recommend to anyone. From the minute I was admitted, I was treated with superior care. Doctors and nurses were closely monitoring me. The staff started me on the right treatment plan, too. I had been taking four injections of IV steroids, Asacol pills and enemas. The doctors had me on ice chips because they wanted my colon to rest. The doctors were hoping I would go back into remission, so they waited five days. My potassium and protein levels were getting very low, and I progressively lost weight. I became anemic and malnourished, so I needed a blood transfusion. The doctors knew that my colon was getting more injurious, so they decided I needed an operation.

Dr. Victor Fazio, the Chairman of the Colorectal Department, performed my surgery. He removed my entire colon, leaving me with an ileostomy. If it weren’t for Dr. Fazio, I would not be here today. Dr. Fazio told me my colon was “megatoxic.”

My body was rested for 10 months. In May 2001, Dr. Fazio constructed the J-pouch. With any surgery, there are risks. Two weeks later, I came down with peritonitis (abdominal infection). Again, I was safely treated with emergency surgery. My J-pouch reconnection was in September 2001.

Dealing with an ileostomy and then adjusting to a J-pouch was difficult. At first, I would have to use the bathroom numerous times a day, but as months passed, the internal J-pouch stretched. Now I have been medicine-free for more than three years!

Since surgery, I have been focusing on loving life day to day. I know deep down that I still have an illness, and I really have to focus on eating right, exercising and keeping my spirits high. During all my surgeries, I still attended college. I have lower energy than other people, but I am determined to fight and earn a degree. Right after the reconnection, I was accepted into a dental hygiene program. I graduated in May 2004 and am now a registered dental hygienist.

I recently married a beautiful man from Slovakia named Josef. I told him right away about my illness but that made him love me even more. We married on September 24, 2004!

I would like to say thank you to Dr. Fazio. He travels all over the world and the U.S. to improve others with digestive disorders. I felt very honored and grateful to receive him as my surgeon. I label him as my hero because he took me under his care and rescued me. He spends many hours at The Cleveland Clinic helping others in need. I wish one day I could make such an impact on somebody’s life the way Dr. Fazio assisted me. He is my hero, not only to me, but to my grandmother, Theresa. He performed an ileostomy surgery in 1971 for her. I sense that it was a coincidence that 30 years later he was operating on me also.

Dr. Fazio made me realize that staying healthy is the number one priority. When I was ill with chronic ulcerative colitis or when I was weak from major surgeries, I understood how my life could change so quickly. People never know when they are going to develop an illness. Today, I live one day at a time and I appreciate the little things that surround me. What Dr. Fazio did for me was his job as a surgeon, but for me it was additional: it was the best gift anyone could award me, a second chance in life.

Rebecca A. Janis
Amherst, Ohio

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I am a 41-year-old woman, with three children, ages 18, 15 and 3. My J-pouch surgery was in 2002, and I still can’t believe how wonderful it is to feel just about normal again. Ten years ago, I was diagnosed with ulcerative colitis and was told that it was something I would be able to control with diet and learning how to relieve stress. So, for five years, my colitis was only active three times and was controlled with medication.

Then one winter, I was catching everything that was going around and my family doctor kept putting me on antibiotics over and over again. After two months of antibiotics, I got a severe bowel infection, which my local doctor kept trying to treat for me. I would heal for a while and then become sick again.

While I was trying to get better, I remarried and was pregnant with my third child at 38. My colitis wasn’t getting any better and, after my daughter’s birth, things really turned for the worse. I was diagnosed with cervical cancer on top of the ulcerative colitis. Now, I was facing a hysterectomy and still my colitis was very active. My surgery went well, but my colitis still continued to worsen to the point of not being able to pull myself out of bed. I was wearing Depends. I couldn’t even hold my baby without having to sit on the toilet all day. I knew I had to have someone help me, because none of the medications or treatments my local doctors were giving me was working.

I came to The Cleveland Clinic and after talking with a wonderful surgeon, I was on my way for the J-pouch surgery. I felt so extremely comfortable with him and all the staff at The Cleveland Clinic. One day after my first bowel surgery, I wanted to go home. I was up walking around and feeling so incredibly well. My healing was fast and, with little to no pain, I was on my way again to have the second part of the J-pouch surgery. I couldn’t believe how great I felt after both surgeries and how I’ve gotten my life back. I do have some arthritis that I deal with, but I am so happy to be able to live normally again!

I thank God every day for sending me to The Cleveland Clinic and for the wonderful surgeons and staff. When people ask me if these surgeries were worth it, I say YES! It was the best decision I have ever made for my life!

Lisa Harmon
Sigel, Pennsylvania

“Well, think of it this way,” my gastroenterologist told me, “We’ve got you running on retreads. You will probably need surgery in 10 years or less.” I was recovering from a nasty flare-up of ulcerative colitis that landed me in the hospital for 10 days. I was 17 and, up to that point, had never had any major illness. Now my doctor was telling me I would end up having surgery to remove my colon!

The time to consider surgical options came a lot sooner than I’d expected. About three years after that first big flare-up, I was making an appointment to see Dr. Scott Strong at The Cleveland Clinic. After talking to Clinical Research Nurse Jane Bast, she got me in contact with a college student like myself who also had pelvic pouch surgery. Having surgery was a big decision, but I felt more comfortable after talking to someone who’d already been through it and knowing that I had a great team of people supporting me.

My first surgery was in May 2000 and the second in December of that year. The temporary ileostomy took some getting used to, but I found it to be manageable. I had one or two near-disasters with that ostomy, but now the stories are funny. Gross but funny!

I have been very pleased with the pouch, and it’s made such a difference in my life. I no longer have that lovely moon face or have to carry around a pill box, and I feel healthy. Minor inconveniences are nothing compared to dealing with colitis. But, best of all, I don’t have to plan my life around an unpredictable illness.

At the time of this writing, I am preparing for my second trip to Africa to volunteer on board a hospital ship. Before the surgery, I could only have dreamed of doing something like this.

While I would not wish this illness on anyone, I know my experiences have shaped the person I am today. I am so thankful for good health, my family, friends and my church. I feel blessed to have had excellent care from Dr. Strong and the great team at the Digestive Disease Center. Today I am a nurse, and I hope that having been a patient myself helps me be more compassionate with anyone who is hurting, sick and anxious.

Maybe you are reading my writings because you, too, are a “graduate” of pouch surgery. If so, I hope you have been able to find the positive aspects in your own experience and enjoy hearing others’ stories, or maybe you are considering surgery yourself. If you are, don’t be afraid to ask questions, find people to talk to and make a decision that YOU are comfortable with. Remember Charles Swindoll’s observation: “Life is 10 percent what happens to you and 90 percent how you react to it.”

Monica Schmucker
Louisville, Ohio

The Department of Colorectal Surgery recently completed its 3,000th pelvic pouch procedure in November 2005.

Congratulations!
against the inflammatory mediator tumor necrosis factor (TNF), is known to be beneficial in treatment of CD-related complications. It has been recently suggested to be beneficial in the treatment of patients with a pelvic pouch who develop CD-related symptoms resistant to conventional medical therapies. Sometimes surgical interventions are required to treat complications like abscesses, fistulae, strictures and bowel obstruction. These might cure CD-related complications or provide symptomatic relief and do not necessarily signal a failing pouch. A redo operation, where the pouch is revised by either repair or removal and creation of a new pouch, is also a possibility that might be considered for selected patients. Sometimes, despite all efforts, the pouch fails. Then a permanent stoma with or without removal of the pouch is required. Carefully selected patients might be offered the creation of a continent ileostomy (K-Pouch) that may eliminate the need for an external appliance and potentially improve quality of life, but this may be associated with a considerably high rate of complications.

Keeping the Pouch with Crohn’s

Although the rates of pouch failure and complications in CD patients who undergo pouch surgery are higher compared to UC, the majority are expected to keep their pouch with good functional outcome.

Medical and surgical treatments are available to assist in reaching this goal. Such results may be improved by the continued development of medical strategies for the long-term suppression of CD. Until then, pouch surgery cannot routinely be offered to patients with a known diagnosis of Crohn’s proctocolitis. However, in very carefully selected cases, prospective evaluation of this procedure should continue.

Pouchitis Studies

Bo Shen, M.D., Staff Physician in the Cleveland Clinic Department of Gastroenterology, is currently conducting two studies on pouchitis:

1. Randomized, Double-blind, Placebo-controlled Clinical Trial of Amitriptyline in the Treatment of Patients with Irritable Pouch Syndrome and its Effect on Parameters of Electronic Barostat (12 weeks).

2. Randomized, Double-blind, Placebo-controlled Clinical Trial of Rifaximin in the Treatment of Patients with Antibiotic-dependent Pouchitis (36 weeks).

If you would like more information about the studies, please call Kerry at 216/445-5202 or 800/223-2273, ext. 55202.