

*Patient information regarding care and surgery associated with* **ULCERATIVE COLITIS**

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## Ulcerative Colitis

Ulcerative colitis is an inflammation of the lining of the colon of unknown etiology. It always involves the rectum and often involves the colon to a variable degree. It almost never involves the small bowel and stomach which makes ulcerative colitis different than Crohn's disease. Some patients have minimal symptoms and are well controlled with medications. At least 1/3 of patients with ulcerative colitis develop severe symptoms that may ultimately require surgery. Ulcerative colitis can cause colon cancer in those who have had the disease for longer than 7-10 years. Therefore, surveillance with colonoscopy is indicated for patients with this disease.

## About the Colon and Rectum

The colon and rectum is about 5 feet long. Food passes through the stomach, then the small bowel, then the colon, and finally the rectum and anus. The small bowel is 12-20 feet and is largely responsible for absorption of nutrients and vitamins in food. The colon absorbs water but the small bowel can assume this function in the absence of the colon. In fact, there are several diseases that require removal of the entire colon and rectum. These patients generally lead normal lives and do not develop malnutrition because their small bowel is intact. Removing a portion or all of the colon and rectum may result in diarrhea, urgency, or gas/stool leakage but usually not.

## Symptoms

Symptoms of ulcerative colitis include rectal bleeding, bloody diarrhea, and abdominal cramps. Patients may also have weight loss, fever, and other symptoms. Many patients have mild or moderate forms of the disease, which may be readily controlled with medications. Others have more severe symptoms that warrant admission to the hospital. Surgery may be necessary if the disease is not able to be controlled with medication. About 40% of patients have disease limited to the rectum and left colon. Another 40% have disease of the entire colon and rectum.

Other diseases result in symptoms that may mimic ulcerative colitis and include irritable bowel syndrome (IBS), ischemic colitis, infectious colitis, Crohn's disease, antibiotic-associated (*C difficile*) colitis, and others.

# Medical Treatment

Ulcerative colitis is usually treated with medicines initially. These medications include azulfidine, cipro, metronidazole, mesalamine, prednisone, 6-MP, cyclosporine, infliximab, and others. Patients on these medications are usually managed by an internist or gastroenterologist. These medications may be required for a long period of time. Steroids, including prednisone, have significant side effects, would may preclude long term use.

Surgery may be indicated for patients who have life threatening complications of ulcerative colitis like excessive bleeding, perforation (rare), or fulminant colitis causing fever, decrease in blood pressure, high heart rate, dehydration, or other more urgent symptoms. Surgery may also be indicated in patients with ulcerative colitis not responsive to medical management, intractable symptoms, or biopsies at colonoscopy suggesting a premalignant or malignant condition.

## At the Time of Your Visit

When you are seen by the colorectal specialist, you will be asked several questions with respect to your history. If you have had blood tests, x-rays, colonoscopy, ultrasound, and CT scans, make sure these are made available to your colorectal specialist prior to your visit. Some of these tests may be ordered by the colorectal specialist if they have not already been done. A general examination to include heart, lungs, and abdomen will likely be performed. Following this examination, if enough information is available, a detailed discussion with your colorectal specialist regarding treatment options will follow.

If your operation involves the possibility of a colostomy or ileostomy, you should have an appointment with the enterostomal nurse prior to surgery. She will provide important information regarding life with a stoma, educate you regarding any nuances, and may mark an optimum site on your abdominal skin.

At the time your surgery is scheduled, you will be asked to undergo preprocedure testing which may include blood tests, a chest xray, and an EKG. You will also be instructed in a mechanical bowel prep which will clean out your colon in preparation for surgery and is described below.

## Surgical Treatment Options

### 1) Proctocolectomy and Ileostomy

This operation involves removing the entire colon, rectum, and anus. It requires a midline abdominal incision to remove the colon and a separate incision at the anus to remove the rectum and anus. This operation also requires a permanent ileostomy (bag constructed from small bowel). This operation was, at one time, the most common operation performed for ulcerative colitis. It cures the intestinal phase of the disease because ulcerative colitis

does not occur in the small bowel and stomach. Because all nutrients are absorbed in the small bowel, patients can lead normal lives after the removal of the entire colon and rectum with intact nutrition. Because of the advent of the pelvic pouch procedure (see below), this operation is not commonly performed for this disease today.

The most common indications for this operation today are:

- 1) poor sphincter muscles or nerves with inability to control bowel movements
- 2) concomitant rectal cancer
- 3) patient preference

This operation can sometimes be done while sparing the anal sphincter muscles and lowermost rectum in patients who want to be considered for a pelvic pouch in the future. However, if the pelvic pouch is not ultimately performed in this circumstance, a second operation to remove the remaining rectum and anus will likely be necessary.

## 2) Subtotal Colectomy

This operation is performed by removing the colon and connecting the small bowel to the rectum. Since ulcerative colitis almost always involves the rectum, this operation is rarely used for this disease. The advantage is that the rectum remains and there is no colostomy but the disadvantage is that the remaining rectum is at risk for persistent ulcerative colitis and cancer. A significant percentage of patients with this operation subsequently need another operation to remove the rectum due to poor functional results (stool urgency and leakage), persistent ulcerative colitis, or the development of cancer in the rectum.

## 3) Restorative Proctocolectomy with Ileoanal J Pouch (Pelvic Pouch)

This ileoanal J pouch is the most commonly utilized operation for ulcerative colitis today. It involves the removal of the entire colon and most of the rectum. The anal canal and, sometimes, the lowermost rectum is preserved. A new rectum is constructed from the end of the small bowel and stapled or sutured to the lowermost rectum or top of the anal canal. Therefore intestinal continuity is preserved without the need for a permanent ileostomy. However, the vast majority of the time, a temporary loop ileostomy is constructed to divert the fecal stream for 3 months allowing the new rectum (ileoanal pouch) to heal without the fecal stream going by it. Should the pouch develop a leak, the temporary ileostomy prevents the fecal stream from contaminating the leak and, therefore, decreases the risk for sepsis. The temporary ileostomy also allows the patient to recover from a major abdominal operation without having to deal with frequent bowel movements immediately after surgery.

This temporary ileostomy is then returned to the abdomen 3 months after surgery. This is another operation that requires another anesthetic but can almost always be done through a smaller incision around the ileostomy (rather than through the midline incision), and is associated with a quicker recovery time. Time may be needed to adjust to bowel movement frequency after ileostomy takedown. Most patients have 5-7 BMs per 24 hours. About 25-50% require slowing medications (Imodium or lomotil) to have acceptable bowel

movement frequencies. About 10-20% have some leakage at night during sleep requiring the use of a perineal pad.

A small number of patients develop inflammation of the lowermost rectum after this operation requiring topical medications. Up to 10% of patients ultimately require pouch excision due to septic complications or poor functional results in which case a permanent ileostomy will be necessary. Therefore, at least 90% of patients go back to school or work and have normal or near normal lifestyles without a permanent ileostomy.

#### 4) Subtotal Colectomy and Ileostomy

Some patients with ulcerative colitis present quite ill, are hospitalized, and do not respond to medical treatment. Those patients who are operated on under more urgent conditions may not be candidates for a definitive operation at that time. Often, under these circumstances, the patient will be taken to the operating room at which time the entire colon will be removed, an ileostomy constructed, and the remaining rectum is closed and left in the pelvis. This allows the patient to recover from the systemic and sometimes life threatening effects of fulminant colitis. Once the patient has recovered, he or she may then be a candidate for a pelvic pouch procedure several months later under healthier circumstances.

#### 5) Continent Ileostomy

A continent ileostomy is essentially a pouch placed on the abdominal wall instead of the pelvis. Because the abdominal wall does not have sphincter muscles to control bowel movements, the operation also involves creating a nipple valve and collar to provide this control. This operation is an option for patients who have had a proctocolectomy and permanent ileostomy or have poor anal sphincter muscle function but want to control their bowel movements. The operation is much more complicated than the pelvic pouch and requires more staple and suture lines, which along with the nuances of the nipple valve and collar, make it an operation at increased risk for complications and need for reoperation. Perhaps for these reasons, the operation is not performed as often as in the past, especially with the advent of the pelvic pouch.

### Preparation for Operation

Those patients who are not operated on emergently may be asked to drink a solution that clears the colon and rectum of stool. This preparation is usually done at home the day prior to surgery. You may be asked to take antibiotics by mouth every hour for 3 doses after completing the mechanical bowel preparation. You will be asked not to eat or drink anything after midnight prior to surgery but you may take your medications with a sip of water. You will be asked to arrive at the hospital several hours prior to the scheduled surgery time. Upon arrival you will meet the nursing staff who will ask you historical questions and prepare you.

You will meet the anesthesiologist who will explain anesthetic options. The vast majority of our patients have an epidural anesthetic in addition to a general anesthetic. The epidural catheter is left in your back (well secured) for about 4 days after surgery as it is the best method to obtain pain control without many of the mental cloudy side effects. You will be expected to walk with or without assistance the day after surgery. We expect you to feel comfortable especially if you have an epidural catheter in place. You will likely start on liquids within 2-3 days after surgery and will be eating regular food prior to discharge from the hospital. If you have an ileostomy or colostomy, an enterostomal nurse will visit you and educate and instruct you with regard to care of the stoma.

The most suitable operations will be discussed with you in detail at the time of your office visit. The operation is typically done through a midline (up and down) incision. You will likely have a catheter in your bladder placed at the time of surgery. You may or may not have a tube placed in your nose to your stomach at the time of surgery.

Options and risks will be discussed at length at the time of your office visit. If anything is not clear or if you have questions, you should feel free to ask your colorectal specialist during this office visit.

## Risks of Surgery

Our hope and expectation is that you have uncomplicated surgery and a successful outcome. This is not always predictable, however, and something that cannot be guaranteed.

The risks of surgery for ulcerative colitis include

- 1) bleeding
- 2) infection
  - a. abdominal wound or intra-abdominal infection or abscess
- 3) \*anastomotic leak (suture or staple line leak)
  - a. may require antibiotics, longer hospitalization, drainage with CT scan guidance, or another surgery to resolve
  - b. may require temporary or permanent colostomy or ileostomy
  - c. may result in death from sepsis (rare)
- 4) abscess
  - a. may require antibiotics, longer hospitalization, drainage with CT scan guidance, or another surgery to resolve
- 5) bowel movement frequency
- 6) \*bowel movement leakage
- 7) \*bowel movement urgency
- 8) injury to ureter
  - a. structure than carries urine from kidneys to bladder

- 9) injury to other bowel, spleen, or blood vessels
  - injury to spleen may require removal and lead to increased risk for infection
- 10) injury to or dysfunction of urinary bladder
- 11) bowel obstruction
  - a. usually from adhesions from surgery
  - b. can occur in 10-20% of patients
  - c. may require another operation
- 12) ileus
  - a. the bowels normally stop working for a few days after surgery. If they continue not to function after this, it is referred to as an ileus
- 13) sexual dysfunction
  - a. impotence or retrograde ejaculation in men (rare)
  - b. depends on age and level of rectal dissection
  - c. pain with intercourse in women
- 14) possible temporary or permanent colostomy (bag) or ileostomy
  - a. implies use of appliance on abdominal wall to collect stool from the bowel
- 15) stoma complications
  - a. those patients with ileostomy or colostomy
  - b. retraction, ischemia (poor blood supply), hernia, prolapse
- 16) possible need to abandon pouch
  - intraoperative findings may require that pouch be abandoned
    - a) pouch may not reach lower rectum (4-6%)
    - b) possible discovery of Crohn's disease
    - c) other findings
- 17) general operative complications
  - a. heart attack : especially those with heart history
  - b. pneumonia
  - c. sepsis
  - d. blood clot in leg
  - e. blood clot from leg to lung (can be life threatening)
  - f. urinary tract infection
  - g. leg nerve injuries (result of retractors or leg stirrups: rare)
- 18) incisional hernia
  - a. may require operation to repair

- 19) \*anastomotic stricture
  - a. may result in constipation (unusual)
  - b. may require dilation through scope to repair
  - c. may require operation to repair
- 20) nonhealing perineal wounds and persistent sinuses
  - a. some patients who require removal of the anus may have a wound that takes a long time to heal or never heals (rare)

21) possible death

\* does not apply to patients with proctocolectomy and ileostomy because there is no anastomosis (staple or suture line connection) and the stool is completely diverted

In addition to the above risks, those patients who have a pelvic pouch procedure are at risk for

- 1) pouch sinuses and fistulas
  - may sometimes result in loss of the pouch
- 2) pouch fistula to vagina
  - may sometimes result in loss of the pouch
- 3) pouchitis
  - inflammation of pouch that often resolves with antibiotics
- 4) dehydration
  - any patient with an ileostomy may develop dehydration or need medications to slow down the gastrointestinal tract
- 5) short bowel syndrome
  - very rarely, a patient who has a failed pouch resulting in its removal may develop nutritional depletion to the point of requiring intravenous nutrition
- 6) pouch ischemia
  - poor blood supply to pouch
- 7) Crohn's disease
  - Some patients who are thought to have ulcerative colitis subsequently are found to have Crohn's disease. These patients are at increased risk for pouch inflammation, pouch complications, and loss of the pouch

8) pouch prolapse

rare complication that may be difficult to treat without loss of pouch

9) pouch excision

may occur in up to 10% of patients who have pelvic pouch usually due to infectious complications like leaks and fistulas described above, but may also be due to poor functional results with frequent bowel movements and incontinence (stool leakage)

## After Surgery

After major abdominal surgery, expect to be in the hospital 5-8 days. Some patients are ready for discharge as early as 4 days after surgery. Some may remain longer than 8 days if the bowels are slow to recover or if a complication develops. The specimen removed at the time of surgery is sent to the pathologist who examines it. About 4 working days (not including Saturday and Sunday) after surgery, a pathology report will be generated. Your colorectal surgeon will review this report with you and discuss its implications.

## After Discharge

Prior to discharge from the hospital, you will receive oral and typewritten discharge instructions. If you have an abdominal incision you should not lift anything greater than 10 pounds for 6 weeks from your surgery date. Unless otherwise instructed, you may eat a regular diet, walk, climb stairs. You should not drive until at least your first office visit at which time you will be further instructed. You may ride in a car. You should call our office (734-712-8150) if you develop a fever  $> 100.5$  degrees and should take your temperature at least 4 times a day. You should also call for nausea, vomiting, problems with the incision including unusual pain, redness, warmth, swelling, separation of skin or underlying tissues, constipation or diarrhea, or other problems that you feel need to be addressed. If you develop chest pain or shortness of breath or leg swelling, you should call your primary physician or our office or come to the emergency room. If you feel it is an emergency, call 911.

Most patients take 6 weeks off from work after having abdominal surgery. You may feel more tired than usual. You may take naps more frequently than usual. Do not be alarmed if you feel fatigued and are not your old self for about 6 weeks after surgery.

## Colorectal Cancer Screening

Those individuals without risk factors for colorectal cancer (rectal bleeding, positive family history of colon cancer) should be screened for colon cancer starting at age 50 years. There are several options which include testing stool for blood, flexible sigmoidoscopy, and colonoscopy. You should discuss the most appropriate option with your primary care

physician or colorectal specialist. If you have rectal bleeding, colorectal cancer screening may be warranted at an earlier age depending on other factors involved. If you have a first degree relative with colorectal cancer, you should have colonoscopy starting at age 40 years or 10 years prior to the age of the youngest relative with colorectal cancer. The test should be repeated every 3 to 5 years if normal and possibly sooner if polyps are found. Others at risk for colorectal cancer that warrant further investigation are those with a history of inflammatory bowel disease (ulcerative colitis and Crohn's disease) and possibly those with other cancers (breast, uterus, ovary). At this time, many colorectal specialists advocate 2 colonoscopies 10 years apart starting at age 50 for those without other risk factors. Again, you should discuss these options with your colorectal specialist.

## Websites

For additional information try the American Society of Colon and Rectal Surgeons at [www.fascrs.org](http://www.fascrs.org) and [www.uoaa.org](http://www.uoaa.org)