

*Patient information regarding care and surgery associated with CROHN'S DISEASE*

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## Crohn's Disease

Crohn's disease is an inflammation of the gastrointestinal tract that usually involves the small bowel and colon, but may also involve the stomach, rectum, and anal canal. Some patients have minimal symptoms and are well controlled with medications. About 80% of patients with Crohn's disease have more severe symptoms that may ultimately require surgery. Some patients with Crohn's disease are at increased risk for colon cancer and may be suitable candidates for surveillance with colonoscopy.

## About the Intestinal Tract

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 Crohn's disease may include abdominal pain, diarrhea, nausea, vomiting, fever, and others. Many patients with early disease have abdominal pain and diarrhea. Others with disease of longer duration may have abdominal cramps and distention with decreased bowel movements consistent with an obstructive pattern. Some patients with Crohn's disease have ulcers and fistulas that may involve the anus and rectum. Crohn's disease may involve any part of the gastrointestinal tract from the mouth to the anus. Most often, however, it involves the small bowel and colorectum. About 30% of patients have disease limited to the small bowel, 30% have disease limited to the colorectum, and 40% have concomitant small bowel and colonic disease.

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

## Medical Treatment

Crohn's disease is usually treated with medicines initially. These medications include azulfidine, metronidazole, mesalamine, prednisone, 6-MP, cyclosporine, infliximab, and others. An internist or gastroenterologist usually manages patients on these medications. These medications may be required for a long period of time. Steroids, including prednisone, have significant side effects, which may preclude long-term use.

Surgery may be indicated for patients who have more unusual life threatening complications of Crohn's disease like excessive bleeding, perforation, or fulminant colitis causing fever, decrease in blood pressure, high heart rate, dehydration, or other more urgent symptoms. Surgery is more often indicated in patients with Crohn's disease not responsive to medical management, intractable symptoms, or biopsies at colonoscopy suggesting a pre-malignant or malignant condition.

## At the Time of Your Visit

When the colorectal specialist sees you, 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. The colorectal specialist may order some of these tests 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 pre-procedure testing which may include blood tests, a chest x-ray, 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.

## Treatment Options

Because Crohn's disease may involve any part of the GI tract from the mouth to the anus, it is possible removing the involved segment may not cure the disease. In general, about 30-50% of patients who have an operation for Crohn's disease will need another operation for recurrent Crohn's disease. A smaller number of patients may require a 3<sup>rd</sup>, 4<sup>th</sup>, or 5<sup>th</sup> operation for Crohn's disease. However, many patients do not develop a recurrence requiring re-operation and most patients feel much better after successful removal of a diseased segment of bowel.

The goal of operative intervention in patients with Crohn's disease is to remove the segment of bowel causing symptoms. This may include a portion of small bowel alone, a

portion of large bowel (colon) alone, a portion of small bowel and colon, all of the colon, all of the colon and rectum, some or all of the colon, rectum, and anus. Surgeons tend to be conservative especially with small bowel when possible because it is the small bowel that is largely responsible for maintaining nutrition and weight.

## 1) Segmental Removal of Small or Large Bowel

This operation generally involves removing a segment of small or large bowel (or both) responsible for symptoms. This segment may be variable lengths and is typically inflamed and/or narrowed. If the conditions are favorable (no severe sepsis or nutritional deficiencies), then the operation usually entails connecting the 2 ends with sutures or staples without the need for a stoma (ileostomy or colostomy). This is perhaps the most common operative option for Crohn's disease. Sometimes a large abscess, severe sepsis, or other unfavorable conditions may warrant a temporary or permanent stoma. The operation usually requires an up and down (midline) incision.

## 2) Proctocolectomy and Ileostomy

This operation is usually an option for the patient with significant disease of the rectum and anus. It involves the 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). 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. Patients who also require excision of small bowel are at risk for nutritional deficiencies and weight loss.

## 3) Subtotal Colectomy

This operation is performed by removing the colon and connecting the small bowel to the rectum. It is generally performed in patients with disease of the colon with relative sparing of the rectum and anus. 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 or recurrent disease 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 or recurrent Crohn's disease, or the development of cancer in the rectum.

## 4) Subtotal Colectomy and Ileostomy

Some patients with Crohn's disease of the colon 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 connection between the small bowel and rectum under healthier circumstances if the rectum is not too diseased. If the rectum and/or anus are too diseased to warrant connection of the small bowel to the rectum, then removal of the rectum and anus may be required at a later date either because of persistent or recurrent disease or the risk of cancer.

## 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 that 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 narcotic 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, our enterostomal nurse will visit you, 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 placed in your bladder 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 an uncomplicated surgery and a successful outcome. This is not always predictable, however, and something that cannot be guaranteed.

The risks of surgery for Crohn's Disease 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
- 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. a structure that carries urine from kidneys to bladder
- 9) injury to bowel, spleen, and blood vessels
- 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 to not 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 or rectal dissection
  - c. pain with intercourse in women
- 14) possible temporary or permanent colostomy (bag) or ileostomy
- 15) stoma complications
  - a. for those patients with ileostomy or colostomy
  - b. retraction, ischemia (poor blood supply), hernia, prolapse
- 16) 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)
- 17) incisional hernia
  - a. may require operation to repair
- 18) anastomotic stricture
  - a. may result in constipation (unusual)
  - b. may require dilatation through scope to repair
  - c. may require operation to repair
- 19) persistent abdominal pain
- 20) short bowel syndrome
  - a. rarely, a patient who loses enough bowel (several feet) may develop nutritional depletion to the point of requiring intravenous nutrition
- 21) dehydration
  - a. any patient with an ileostomy may develop dehydration or need medications that slow the gastrointestinal tract
- 22) death

## 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 (34-712-8150) if you develop a fever  $>100.5$  degrees and you 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 a colonoscopy starting at age 40 or 10 years prior to the age of the youngest relative with colorectal cancer. The test should be repeated every 3-5 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 the Crohn's and Colitis Foundation of America at [www.ccfa.org](http://www.ccfa.org)