

**Endometriosis and Bowel Symptoms**  
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Bowel symptoms are very common, occurring in as many as 80-90% of patients with [endometriosis](#) (Maroun P, 2009). Many patients have seen gastroenterologists (GI doctors) for assessment of possible GI causes of their pain, often more than one doctor, having extensive testing including CT scans, endoscopies, colonoscopies, GI motility studies, MRI enterography, etc., often costing thousands of dollars. If the initial doctor would focus on the underlying pelvic pain, they would understand that endometriosis is often the most common diagnosis. These referrals in endometriosis often results in the multi-year delay in diagnosis, something that can have a very detrimental physical, emotional, social and fiscal impact on patients. It is not only these factors that are greatly impacted, but with this delay, patients suffer unnecessarily, and their disease progresses. Severe disease can often be prevented by early diagnosis; misdiagnosis can often lead to further delays.

There are many different diagnoses (and misdiagnoses) that can occur in patients with endometriosis. These include irritable bowel syndrome (IBS); inflammatory bowel conditions (Crohn's disease and Ulcerative Colitis (UC)); food intolerances including gluten intolerance (or its extreme form of Celiac Disease) or lactose intolerance being the most common, lectin-containing foods (see the book "The Plant Paradox"); Small Intestinal Bacterial Overgrowth (SIBO); and gastroparesis among others. We will review these conditions and how they are diagnosed, and how, often, they are not the underlying cause of the painful abdominal and pelvic symptoms that we see in endometriosis patients.

What are some GI symptoms that endometriosis patients often suffer from? Bloating, abdominal cramping and pain, constipation, diarrhea, painful bowel movements, nausea and vomiting are commonly seen in patients with endometriosis. However, when accompanied by pelvic pain, painful periods, back ache, painful intercourse, ovulation pain, leg pain or ache, it is much more likely that these symptoms are the result of endometriosis and not a GI issue at all. That is not to say that sometimes GI consultation and assessment is needed, but often, endometriosis should be the first thing considered and evaluated for (i.e., a laparoscopy, which is the "gold standard" for the diagnosis of endometriosis). Some young endometriosis patients may present with GI symptoms even before the onset of menses, further complicating the diagnosis when their symptoms get worse when they start having periods.

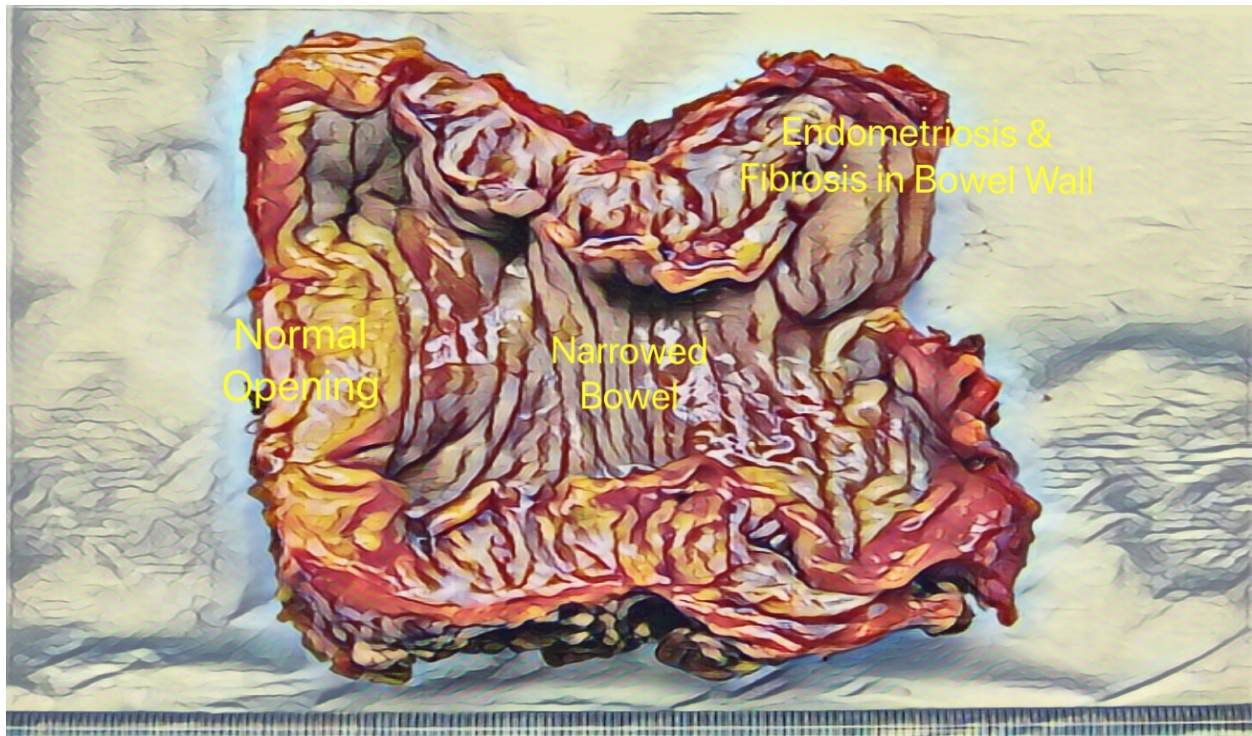
**Bloating** is often the most common symptom seen in over 80% of patients. Bloating (often described by patients as '[ENDO BELLY](#)') has many possible causes. While dietary and gut factors such as gluten intolerance, lactose intolerance, small intestinal bacterial overgrowth (SIBO) may explain much of the bloating that is seen, I believe another simple force may be the cause as well. Often patients with endometriosis wake up with a flat abdomen. Over the course of the day, the bowel, which goes to the lowest part of the abdomen (the pelvic area), floats in a small amount of peritoneal fluid that is always present. In patients with endometriosis (and possibly adenomyosis), there is a massive increase in the release of inflammatory mediators, which can be seen in the fluid surrounding the bowel. After several hours, the bowel becomes irritated and those inflammatory mediators including cytokines, interleukins and natural killer cells (*doesn't that name sound terrible?! But NK cells are a normal and important part of the immune system*), slow or alter the motility (or natural peristalsis or rhythmic contraction). As the motility is slowed over the course of several hours, the bloating gets worse and by the afternoon, patients often have extreme bloating, nausea, pressure and crampy abdominal pain. Patients often have a decreased appetite as a result of this, and in extreme cases, even acid reflux symptoms.

When endometriosis is completely [excised](#) (with LAPEX), the bloating will often improve significantly. If it does not, then other factors such as diet, SIBO, or pelvic floor dysfunction must be ruled out and treated. I often recommend seeing a nutritionist in these situations, or simply starting by eliminating gluten and dairy initially, and if no improvement, seeing a gastroenterologist at that point. If problems such as persistent constipation are seen, especially in the setting of persistent pelvic pain, then [pelvic floor dysfunction](#) may need to be addressed with intra-vaginal therapy working of the muscles that should relax when having bowel movements (or emptying the bladder or having intercourse).

**Intestinal cramping** is also commonly associated with endometriosis. In our review of our own patients (Sinervo, 2002), over 40% had intestinal cramping. This is often due to bowel distension or the inflammatory mediators that bathe the bowel in the pelvis.

**Constipation** is also seen in many patients with endometriosis. In evaluation of our patients (Sinervo, 2002), over 20% had constipation. This may be a function of direct bowel involvement (seen in approximately 15-20% of patients), in which the bowel may have anatomic distortion (kinking or narrowing of the bowel), or adhesions (scarring between the bowel and other organs such as the uterus or ovaries). As well, inflammatory mediators can alter the motility of the bowel.

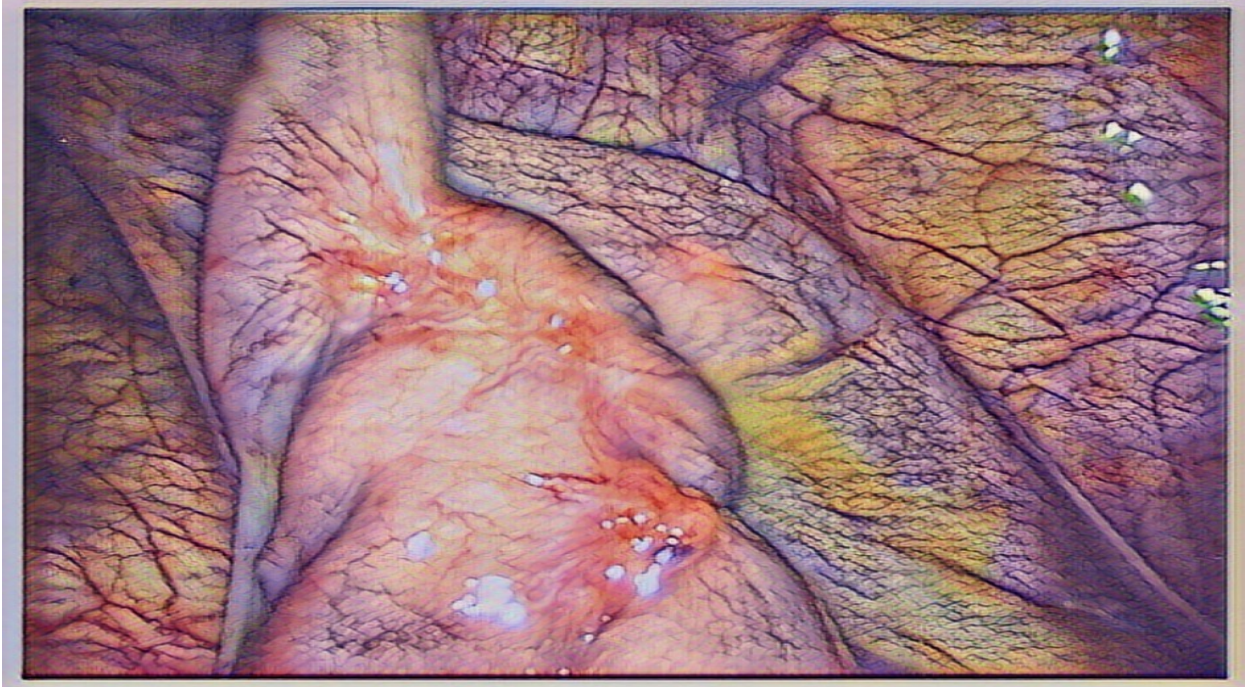
**Diarrhea** is seen in almost 2/3 of patients with endometriosis. This is often worse during or just before menses. This too could be a factor of inflammatory mediators, but in patients with invasive and obstructive endometriosis, they often have a combination of constipation followed by diarrhea. The large intestine is responsible for absorbing water. When there is an obstruction of the bowel, by adhesions or narrowing due to invasive endo and fibrosis, there is a relative obstruction of the bowel. When a patient is able to pass the hard stool above the lesion, they will often have a reflex diarrhea afterwards. This is why we often hear patients paradoxically having constipation and diarrhea, almost at the same time.



This stylized photo shows the narrowing that can occur with invasive endometriosis. © Center for Endometriosis Care.

**Painful Bowel Movements** are seen in about 20% of patients with endometriosis. This often progresses from pain with bowel movements during menses, to pain with bowel movements all the time. This is often a function of the narrowing of the bowel, dysfunction or dysregulation of the nerves involving the bowel (endo can often increase the nerves in the area too), scarring of the bowel to the vagina and other structures. This improves significantly with mobilization of the bowel and bowel resection when needed. ***It was interesting that patients that were currently or previously treated with GnRH agonists had more severe abdominal pain than other patients*** (Ek, 2015).

**Nausea and Vomiting** is occasionally seen in patients with endo. Nausea is commonly seen. Vomiting is less commonly seen, either due to bowel distension and bloating or rarely in patients with obstructive symptoms (Vigano, 2018) with the narrowing of the bowel. With invasive bowel endometriosis, the vomiting is often only seen during menstruation, as the endo becomes more inflamed and swollen, narrowing the bowel more. This is more likely with small bowel endo and I have also seen in with endometriosis involving the transverse colon. Patients with more severe invasion of the sigmoid and rectum may also have vomiting, more likely due to pain, and secondarily due to obstruction.



Small bowel endometriosis causing intermittent obstruction.

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### ***IRRITABLE BOWEL SYNDROME***

[Irritable bowel syndrome](#) or IBS, is also known as spastic colon, irritable colon, spastic colitis or nervous stomach. Those with endometriosis are two- to three-fold more likely to be diagnosed with IBS than those without the disease (Saidi, 2020). Furthermore, in the meta-analysis of four qualifying studies, among those initially diagnosed with IBS, some studies reported a threefold risk of having endometriosis. Other studies have shown that the prevalence of IBS was much higher in endometriosis patients (odds ratio = 5.32, CI 2.88; 9.81) compared with patients who did not have endometriosis. In those without bowel involvement, the risk of IBS was even higher (OR=6.54, CI 3.22;13.29) (Schomacker, 2018). One study even demonstrated that among those with endometriosis, 52% had a diagnosis of IBS, confirming the potential misdiagnosis in this group (Lee, 2018). Endometriosis and

IBS may even share common pathophysiological mechanisms, such as mast cell activation, neuronal inflammation, dysbiosis and impaired intestinal permeability.

### **Symptoms of IBS:**

Abdominal pain

Change(s) in bowel habit(s)

Constipation

Diarrhea

Alternating constipation or diarrhea (which is often seen with more advanced invasive bowel endometriosis)

Pain is usually relieved with bowel movements

Bloating

Nausea

As many as 1 in 6 people in the U.S. have IBS. Women are twice as likely to have it than men. Sometimes, it can occur after an infection (SIBO must be ruled out as well in this case). It can occur at any age, but is most commonly diagnosed before age 35 (or possibly misdiagnosed as well in endometriosis patients!). Patients usually have to have these symptoms for 6 months to meet the criteria of IBS. Lifestyle changes may be implemented.

Patients are usually started on a low FODMAP diet. FODMAP's (Fermentable Oligosaccharides, Disaccharides, Monosaccharides, and Polyols which are short chain carbohydrates sugars and alcohols that are poorly absorbed), result in the fermentation and production of different gases within the large intestine causing bloating, pain and flatulence. These include foods with Fructose (fruits and vegetables), Fructans (some vegetables and wheats), Lactose (dairy products), galactans (legumes or beans, peas, nuts), and polyols (artificial sweeteners such as those used in diet beverages).

Food group	LOW FODMAP	HIGH FODMAP
Fruits	Bananas, blueberries, cantaloupe, cranberry, clementine, grapes, honeydew, Kiwi, oranges, papaya, pineapple, raspberry, rhubarb, strawberry	Apples, avocado, ripe bananas, blackberries, dates, figs, goji berries, mango, nectarines, peaches, pears, dried fruit, plums, prunes, raisins, watermelon
Vegetables and Legumes	Alfalfa, bean sprouts, broccoli, cabbage, carrots, collards, cucumber, eggplant, green beans, ginger, kale, lettuce, olives, potatoes, pumpkin, red peppers, squashes, tomato, turnip, yam, zucchini	Artichoke, asparagus, baked beans, black eyed peas, cauliflower, celery, sauerkraut, kidney beans, lima beans, leeks, mushrooms, peas, pickled vegetables, soy beans, peas, shallots
Cereals, Grains, Nuts, Cookies	Wheat and gluten free bread, corn bread, rice bread, spelt sourdough bread, almonds, brazil nuts, brown or whole grain rice, corn flakes, corn, corn tortillas, plain crackers, mixed nuts, macadamia nuts, peanuts, oats, popcorn, rice, seeds (chia, poppy, pumpkin, sesame, sunflower), corn tortilla chips, walnuts	Wheat products such as biscuits, bread, cakes, wheat based cereal bar, bran cereals, bread, cashews, muffins, pastries, cous cous, granola, muesli, pistachios, rye, semolina
Meats	Beef, chicken, lamb, pork, prosciutto, turkey, cold cuts, fish, seafood	Chorizo with garlic, sausages
Drinks and protein beverages	Alcohol such as vodka, gin, whiskey, wine (one drink), beer (one drink), coffee and espresso, coconut milk, coconut water, fruit juices up to half cup, protein powders, teas, water	Beer (if more than one bottle), cordials, large amounts of fruit juices or if added apple, pear or mango, Kombucha, run, high fructose drinks, teas – black with soy milk, chai, dandelion, fennel, chamomile, strong herbal, oolong, whey protein

**For a full list visit: <https://www.ibsdiets.org/fodmap-diet/fodmap-food-list/>**

Other lifestyle factors that may be helpful include decreasing stress (often with meditation or mindfulness), exercise, drinking large amounts of water and if necessary, OTC laxatives. The NIH also recommends use of probiotics (and possibly pre-biotics); mental therapies such as cognitive therapy, gut-directed hypotherapy; and relaxation therapies. Your doctor may recommend medications for diarrhea, constipation or bowel spasm (<https://www.niddk.nih.gov/health-information/digestive-diseases/irritable-bowel-syndrome/treatment>). When followed closely, these changes can help significantly.

## Medical Therapies for IBS:

### Diarrhea

- Loperamide (Imodium)
- Antibiotics such as Xifaxin (often used with SIBO)
- Vibersi
- Lotronex

### Constipation

- Fiber
- Laxatives such as Miralax, Dulcolax, Magnesium
- Linzess
- Amitiza
- Trulance
- Movantik (for opioid-induced constipation)

### Other medications which help with GI pain:

Antispasmodics such as hycosamine (Levsin or Levbid), dicyclomine (Bentyl), propantheline (Pro-Banthine), peppermint oil, tea or tablets.

Some anti-depressants in low doses such as tricyclic antidepressants (amitriptyline) or SSRI's such as Celexa, Zoloft, Lexapro, Paxil or Prozac may help with how the brain perceives abdominal pain.

Avoidance of triggers such as certain foods (use a food diary to help diagnose triggers), which often include caffeine, alcohol, and beverages with sugar (or artificial sweeteners as well).

Recent studies have looked at the interaction of nickel sensitivity resulting in allergic contact mucositis (prevalence >30%), and may present with IBS-like symptoms and extra-intestinal symptoms. A recent study by Borghini et al. showed that as many as 90% with endometriosis were positive for oral nickel sensitivity, and there was a significant reduction in GI, extra-intestinal and gynecologic symptoms. This suggests a low nickel diet may help if IBS or IBS-like symptoms are present.

## ***Inflammatory Bowel Disease (IBD)***

Inflammatory bowel syndrome includes Crohn's Disease and Ulcerative Colitis (UC). Both of these conditions have symptoms including crampy abdominal pain, rectal urgency (urge to have a bowel movement), decreased appetite, diarrhea, blood in stools, fever, dehydration, fatigue and weight loss. Crohn's may also have painful rectal sores with drainage, mouth sores while UC may have joint pain or soreness, canker sores, light sensitivity for the eyes, anemia, skin sores, and feeling or incomplete emptying of the rectum. UC only affects the large intestine (colon), while Crohn's may affect the large and small bowel, and cause inflammation in other parts of the body.

These conditions have to be differentiated from other conditions, especially IBS, since they may cause long-term damage to the bowel, including an elevated risk of colorectal cancer (2% after 10 years, 10% after 20 years and 18% after 30 years) (Lakatos, 2008). Crohn's can result in abscesses, bowel scarring and fistulas (connections between other organs or even the skin. Crohn's disease can also result in an increased incidence of fractures by 30-40%, blood clots (DVT) by threefold, a variety of extra-intestinal manifestations such as ankylosing spondylitis, iritis and uveitis, erythema nodosum and diseases such as asthma, bronchitis, pericarditis, rheumatoid arthritis, and multiple sclerosis. The risk of colorectal cancers and small bowel cancers are also increased (Peyrin-Biroulet, 2011).

Crohn's disease and UC can be diagnosed with several different tests whereas, IBS does not have the changes seen during colonoscopy that are present with IBD. Both UC and Crohn's have antibody testing which can be positive (ASCA for Crohn's and pANCA for UC); CBC may demonstrate anemia and infection; C-reactive protein and Erythrocyte Sedimentation Rate (ESR) may show increased inflammation; electrolyte panel may show reduced potassium from diarrhea; iron and B12 may be reduced due to malabsorption. GI testing including barium and plain x-rays; CT scanning for abscesses and other abnormalities; colonoscopy is the gold standard since it can biopsy the tissues for pathological changes characteristic of each disease.



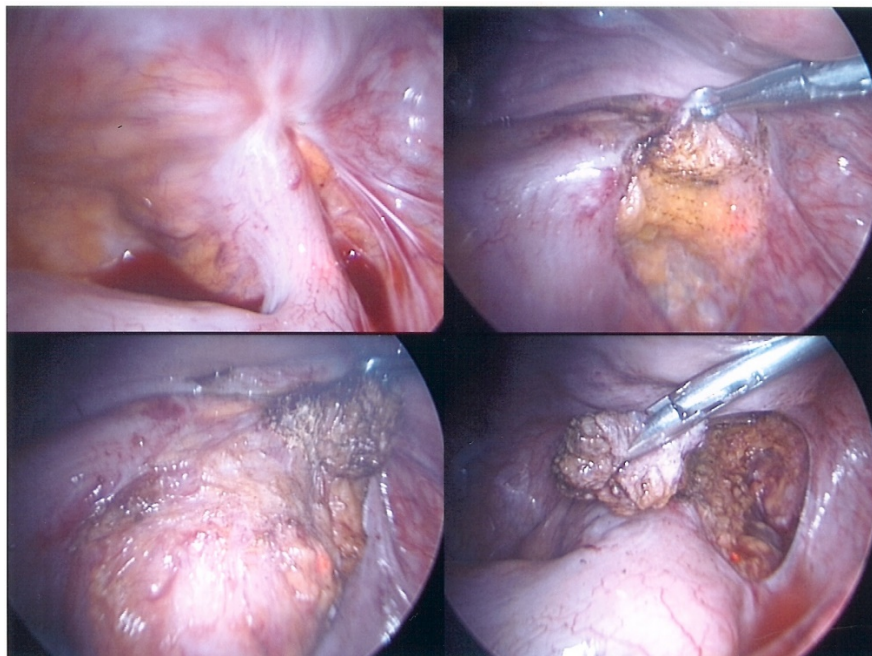
## ***Small Intestinal Bacterial Overgrowth (SIBO)***

SIBO is a bowel condition that occurs when there is an abnormal overgrowth of bacteria within the small bowel, especially bacteria that are not commonly found in that portion of the bowel. It is commonly seen after surgery (or when the bowel has a condition that slows the passage of food within the gut, allowing for even more rapid growth of these inflammatory bacteria). Normally, the small bowel does not allow the production of large amounts of bacteria due to its rapid transit time (usually 90-120 minutes to go from the stomach to the large intestine) and the presence of bile. It is more common with certain medical conditions such as Crohn's, radiation enteritis (inflammation of the bowel after radiation), scleroderma, celiac disease, diabetes and other conditions that slow the motility of the bowel. Endometriosis may be the cause of SIBO in some situations, especially when bowel surgery has been performed or when the endometriosis has caused severe distortion and scarring of the bowel. SIBO can result in malabsorption and weakened bones due to reduced calcium absorption.

Some studies suggest that as many as 50% or more of patients with IBS may have SIBO, and since so many patients with endometriosis have IBS, they may also have SIBO by connection (Moraru et al., 2014; Ghoshal et al., 2017). SIBO can usually be diagnosed with a lactulose-hydrogen test. The gold standard is with small bowel aspirate and fluid culture testing. A sample of the fluid in the small intestine is sampled and tested for increased bacteria. The initial treatment of SIBO is with antibiotics (Xifaxin – an antibiotic that is not absorbed and remains within the bowel, reducing bacterial byproducts and altering microbiota). Xifaxin is usually well tolerated and highly effective. Patients usually have to have some dietary changes including decrease in complex carbohydrates, procedures and simple sugars. It is expensive (costing around \$1,400 if not covered). Sometimes, repeating testing may be required or suggested a month or so after treatment to ensure complete resolution.

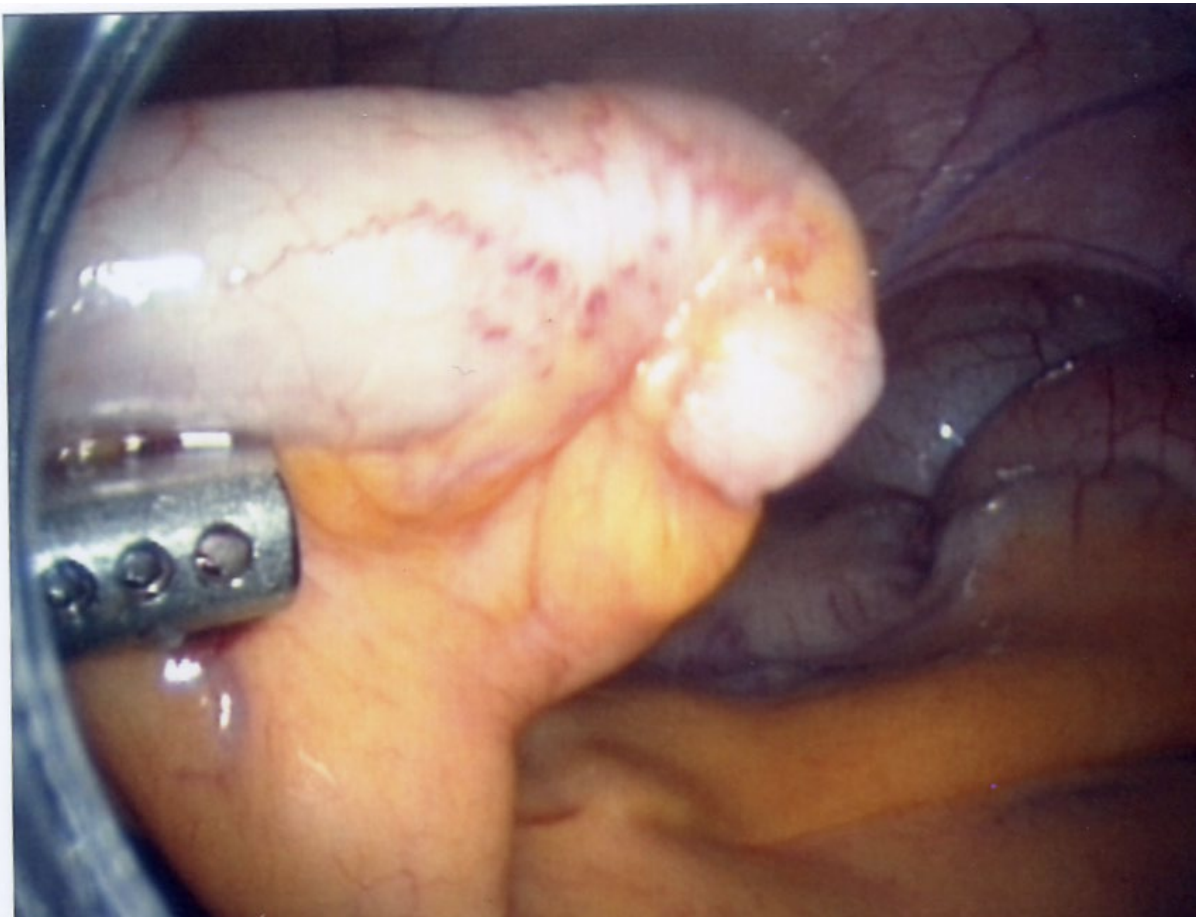
## ***Endometriosis & Bowel Involvement***

As mentioned previously, bowel symptoms are commonly seen in patients with endometriosis. Although as many as 90% may have bowel symptoms, only around 15-20% may have actual direct bowel involvement (range 3-37%) (Ferrero, 2011). The great majority of endometriosis on the bowel (about 80%) can be removed with excision and avoiding deep excision, discoid resection or segmental resection of the bowel. Many patients may respond to hormonal manipulation including birth control, progestins, GnRH agonists, and aromatase inhibitors; however, many patients may not respond to these treatments or tolerate them and ultimately will need surgical intervention. It is very important to go to a high volume endometriosis specialist with extensive experience with bowel endometriosis, or there is a very good chance that there will be incomplete treatment or in some cases, no treatment of the endometriosis due to fear of complications in inexperienced hands. At the Center for Endometriosis Care (CEC), we have been using a multi-disciplinary approach for the management of deeply invasive endometriosis for all forms of endometriosis (for example, urologists for bladder and ureteral endo; thoracic surgeons for [diaphragmatic and thoracic endo](#); and general surgeons and colorectal surgeons for deeply invasive endometriosis requiring bowel resection. We have managed over a few thousand cases of bowel endometriosis and performed between 600-650 bowel resections and discoid resections (as of February 2021) with this approach.



As can be seen in these images, there is a deep nodule of endometriosis drawing the bowel to the right in image 1, mobilization of the uterosacral nodule in Image 2, separation of the nodule from the bowel in Image 3, and the nodule and normal bowel after excision in Image 4. © Center for Endometriosis Care.

When surgery for endometriosis is undertaken, it is important to evaluate the bowel completely, which means not just looking at the bowel seen in the pelvis. While the majority of invasive endometriosis involving the bowel requiring resection is seen in the pelvis, ***as much as 10% lies outside the pelvis or concurrently with rectosigmoid endometriosis.*** Over 90% of invasive bowel endometriosis involves the rectosigmoid colon with 20-30% involving the rectum and 60% involving the sigmoid colon. 10% involves the ileum (last part of the small bowel) and cecum. About 5-10% of cases may involve the appendix; however, there are often other changes in the appendix that suggest that it may have had other problems such as stiffness, thickening, or scarring which may reflect previous inflammation, subacute appendicitis, or even carcinoid tumors. Some studies have found that over 80% of appendixes may have some pathology associated with them, with fibrous obliteration of the lumen being the most common finding (scarring closing off the opening within the appendix) (Lyons, 2001).



The clubbing seen at the tip of the appendix is indicative of invasive endometriosis. © Center for Endometriosis Care.

## ***Diagnosis of Invasive Bowel Endometriosis***

**Pelvic examination** is the initial assessment for all endometriosis and this is particularly important with bowel endometriosis. The uterus is often retroverted and fixed (tilted backwards and does not move), and there is often thickening of the uterosacral ligaments. Endometriosis may be seen involving the posterior vagina. ***It is extremely important to perform a rectovaginal exam since this may demonstrate invasive nodules that are palpable in the majority of patients requiring bowel resection.***

**Transvaginal ultrasound (TVUS)** is the most sensitive means of diagnosing invasive bowel endometriosis. Many studies have shown that over 90% of invasive bowel lesions can be detected with TVUS when performed by trained sonographers. There are many signs that can be looked for including a negative slide sign (the bowel does not slide past the cervix and uterus since it is scarred to the bowel); thickening of the bowel and narrowing of the bowel lumen; nodularity of the uterosacral ligaments and bowel wall among other findings. When the circumference of the involved bowel involves more than 40% and involves more than 3 cm of the bowel length is involved, this is usually a marker that a bowel resection may be needed. When less than this involvement, a discoid resection or removal of the lesion itself is often adequate to treat the endo, avoiding a resection.

**MRI** can also be used to diagnosis deeply invasive endometriosis involving the bowel. It too can diagnose invasive bowel endometriosis over 90% of cases, but as with all imaging, this is largely dependent on the experience of the radiologist reviewing the images. It may have the benefit of seeing lesions higher up on the sigmoid colon, and cecal lesions.

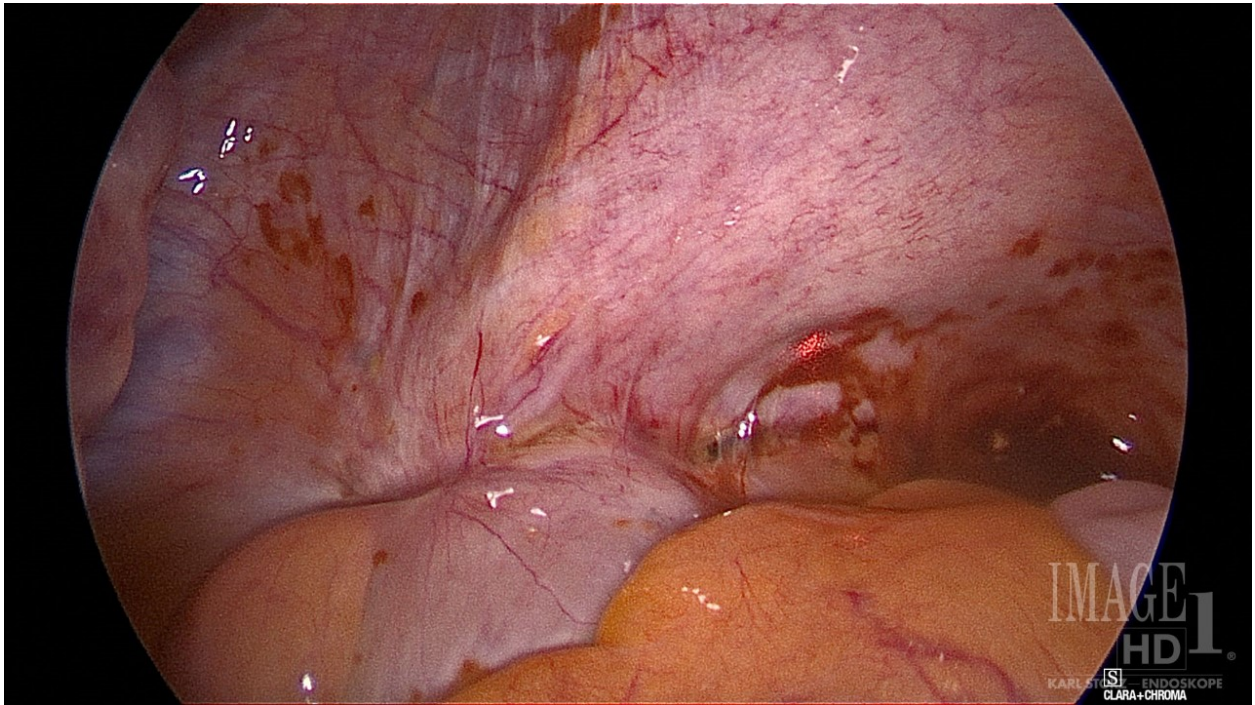
**Colonoscopy** is often ordered by gynecologists and gastroenterologists if they are concerned about invasive bowel endometriosis. However, only 4% of invasive bowel lesions are detected through colonoscopy (Milone, 2015). More commonly, the GI doctor will see that there is a narrowing or stricture of the bowel, or that the colon is tortuous (more kinked than usual). It may be helpful in ruling out other GI issues such as Crohn's, UC and cancer, but if there is known or suspected advanced endometriosis, it is rarely helpful.

Before any endometriosis surgery is performed, a patient should undergo a [bowel prep](#) to clean out the bowel. This is controversial, as some studies suggest that it is not needed; however, it is often a preference of the colorectal surgeon performing the surgery and we feel that it allows for better visualization, manipulation during surgery, a smaller incision to remove the bowel if a resection is performed and potentially more room to work with a decompressed bowel.

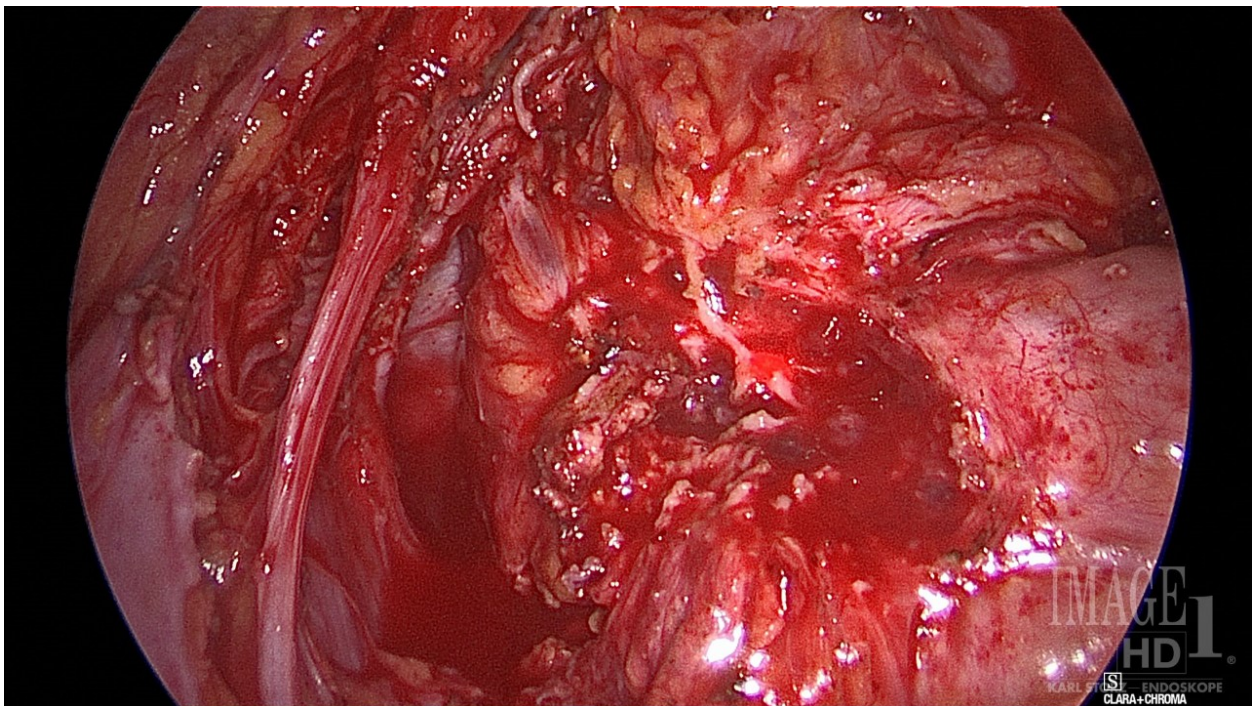
When bowel endometriosis is discovered, often we are able to restore all the distorted anatomy and remove all the endometriosis involving the bowel without the need of the colorectal surgeon. However, when there is deeply invasive endometriosis requiring either a discoid resection or segmental resection, the colorectal surgeon is consulted. Having had a long-time relationship with our colorectal and general surgeons, we have created a dedicated, multidisciplinary team that is able to manage all invasive bowel lesions laparoscopically. When treated laparoscopically (through 3-4 small incisions usually less than a cm each), it allows for the patient to have a much shorter and less painful recovery than would be the case if a laparotomy (large abdominal incision usually at least 6 or more inches in length).

When a bowel resection or discoid resection is required, the procedure is no longer out-patient, and the patient may require 2-5 days in the hospital for recovery. During that time, pain is managed, prophylactic antibiotics are given and we advance the diet to ensure that bowel function is tolerated. If a patient is from outside the Atlanta area, our policy is to remain in town for 3 more days after release from the hospital. Bloating is common for up to 4-6 weeks, as is fatigue. Long-term, we can expect significant improvement in bowel function with significant reduction in painful bowel movements, constipation and diarrhea, pelvic pain, bloating, and nausea. Recurrences are very low for segmental resection patients long-term, and less than 5-10% for discoid and shaving or superficial resection of the bowel endo. The risk of serious post-operative complications occur less than 5% of the time. The risk of long-term complications are rare, and the most serious being stenosis or narrowing of the bowel at the re-anastomosis site (where the bowel was reconnected after the bowel resection). The risk of colostomy is less than 1-4%, depending on where the bowel resection was performed, and we have never had a permanent colostomy. Sometimes, colostomy is needed if the bowel resection was very low (less than 7-8 cm from the anal verge).

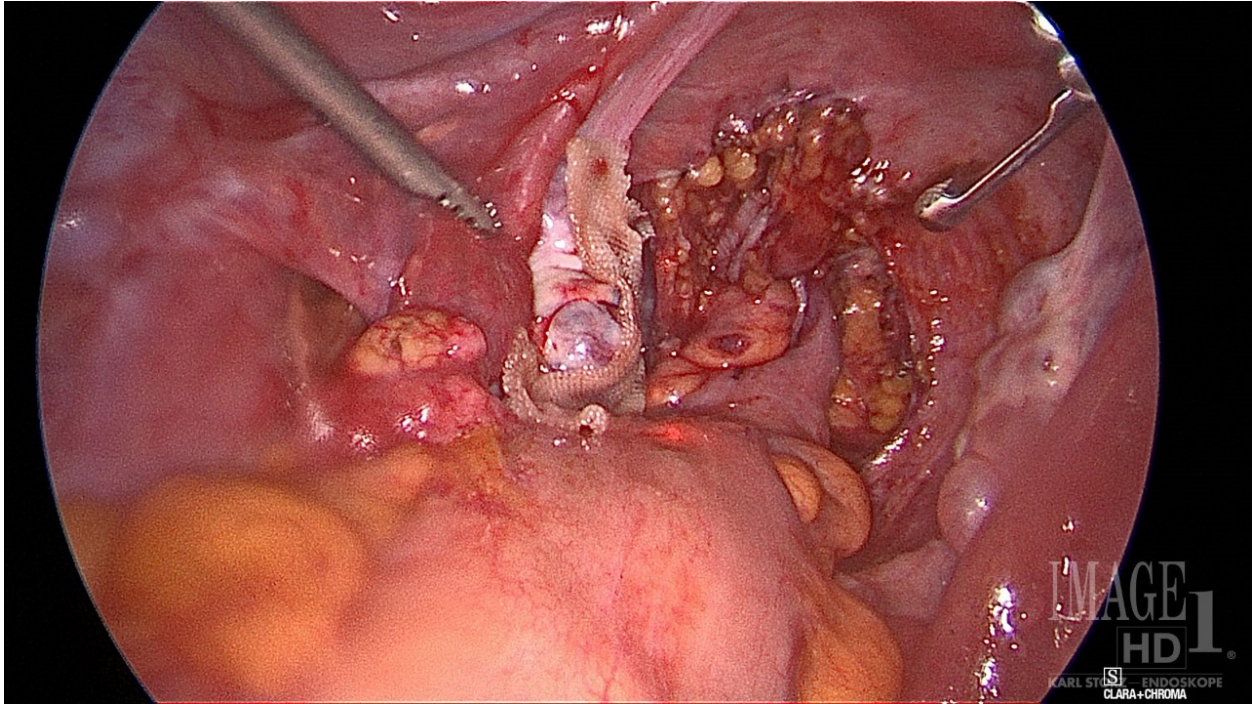
Different techniques for managing bowel endometriosis can be seen on the surgical video section on the website (<https://centerforendo.com/surgical-video-library>).



Bowel adhered to uterosacral ligament. © Center for Endometriosis Care.



Large nodule narrowing the bowel. © Center for Endometriosis Care.



Bowel & pelvis after resection and re-anastomosis. This patient, who had previously undergone egg retrieval, went on to successfully conceive and deliver a baby. © Center for Endometriosis Care.

### **Summary**

Bowel symptoms are very common in patients with endometriosis and can often be confused and even misdiagnosed with other bowel conditions. However, with appropriate evaluation, **bowel endometriosis can be recognized and completely excised** with thorough, meticulous deep excision and there is a high likelihood of improved function and decreased pain. It is important to consider invasive bowel endometriosis when bowel symptoms are combined with symptoms of pelvic pain consistent with endometriosis. It is important to seek out a specialist trained in the advanced minimally-invasive techniques for complete excision of endometriosis with a multi-disciplinary team. If your doctor does not use a multidisciplinary team, there is a very good chance that disease will be left behind, and severe symptoms may persist.

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