

# The Patient with Newly Diagnosed Ulcerative Colitis:

## Anticipating the Questions and Individualizing the Answers



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### Abstract

*Informed patients are one of the most important assets available in the management of patients with ulcerative colitis. Clinical experience reinforces that most patients have similar questions upon diagnosis. Anticipating these questions and tailoring them to a particular patient's disease severity and extent should not only streamline follow-up but also mitigate confusion and augment the benefit of the plethora of information available in the 21st century. Using our local experience, we have defined the 10 most common questions asked by patients and modified the answers, where necessary, to improve their specificity to patients with ulcerative proctitis, left-sided ulcerative colitis, and pancolitis.*

*Key words: ulcerative colitis, patient, questions, classification, management*



### Key Point

*Patients can be relatively ill informed regarding the nature of UC, its management, and its ultimate prognosis.*

Ulcerative colitis (UC) is a common gastrointestinal affliction newly diagnosed in an estimated 5,000 Canadians annually.<sup>1</sup> To an experienced gastroenterologist, the clinical picture, laboratory features, and endoscopic appearance, combined with histopathological confirmation, allow the diagnosis to be made quickly and accurately in most cases. Although there has been a gradual increase in available therapies in recent years, the initial treatment algorithms for most patients have not changed

significantly over the past three decades.

Despite these factors, patients can remain relatively ill informed regarding the nature of the disease, its management, and its ultimate prognosis. Although some of the confusion may be attributable to mixed messages received from acquaintances and non-expert media sources, much of the failure can also be traced back to inadequate physician discussion and a lack of proper diagnostic categorization.

As with most diseases, the

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severity of active UC is seen across a broad spectrum, from symptoms perceived as a minor nuisance to those that are ultimately life threatening. Although most clinical scoring symptoms generally use symptoms such as stool frequency and bleeding, endoscopic severity, and effect on overall functional capacity to classify patients, disease extent is of equal and perhaps even greater value to the physician when initial treatment plans are made.

desirable and efficient means of transmitting information; certainly, medical issues are no exception. As a group of gastroenterologists experienced in the diagnosis and management of patients with UC, we sought to delineate, answer, and individualize the FAQs that we most frequently encounter in our initial discussions with a patient with newly diagnosed UC (Table 1). In this article, we present these FAQs and their answers.

**Table 1. Frequently Asked Questions**

<b>General Questions</b>	<b>Extent-Specific Questions</b>
What is ulcerative colitis (UC)?	What are my treatment options?
Which foods should I eat or avoid?	Will having UC lead to cancer?
Are the medications for UC safe?	Will I need surgery?
Can UC affect other parts of my body?	What do I do if my UC flares up?
How will having UC affect my plans for having a family?	How long should I take medication?

Generally, disease extent is divided into three categories: ulcerative proctitis (E1), left-sided disease (E2), and pancolitis (E3) for patients in whom the disease extends proximal to the splenic flexure (Figure 1).<sup>2</sup> Although up to half of patients see a change in disease extent (either increasing or decreasing) over the decade following diagnosis, basing not only treatment but discussion on disease extent is an effective and practical approach employed by many gastroenterologists.

A perusal of any information pamphlet or website makes it obvious that a simple approach with frequently asked questions (FAQs) is a highly

## General Questions

### What Is UC?

*Ulcerative* means a loss of the surface lining, and *colitis* means inflammation of that lining or mucosa. The inflammation is caused by an abnormal invasion of white blood cells into the mucosa. The exact cause of this attack is not known, but it is thought that a combination of genetic and environmental factors cause the immune system to react aggressively against the normal bacteria that inhabit the colon. This inflammation leads to excess production of fluid and mucus as well as bleeding

and increased intestinal contractions, causing diarrhea and abdominal pain. UC only affects the large bowel and generally involves an area starting in

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the rectum just above the anus, and continuing for a variable distance proximally depending on the disease extent. Physicians usually classify this extent into three categories: rectum only (ulcerative proctitis), up to the level adjacent to the spleen (left-sided colitis), or beyond the level of the spleen (pancolitis). Therapy is best tailored to the extent of disease.

### Which Foods Should I Eat or Avoid?

It is important to consider diet in the management of UC; however, no diet has been shown to induce a flare or heal an inflamed colon. A well-balanced healthy diet that is high in protein, fruits and vegetables, whole grain breads, cereals, and good fats is recommended. During a flare, avoiding foods that increase bowel motions, such as caffeine, excessive alcohol, artificial sweeteners, and high fibre, may help to improve symptoms. Appropriate hydration, particularly during periods of increased diarrhea or exercise, is also very important.<sup>3</sup>

### Are the Medications for UC Safe?

Mesalamine is very safe. It occasionally causes headache or nausea, but generally side effects are uncom-

mon. Prednisone commonly causes side effects, including fluid retention, weight gain, anxiousness, sleep problems, abnormal hair growth, acne, infection, elevated blood sugar, high blood pressure, and thinning of the bones. These symptoms can be reduced by using prednisone only for short-term control of the disease. Azathioprine can cause nausea, hepatic or pancreatic problems, increase the risk of infection and may slightly increase the risk of getting cancer. Infliximab may cause infection, heart problems, and nervous system disease, and it also slightly increases the risk of cancer. It can cause an allergic reaction, but this is usually mild and easy to treat.<sup>4</sup>

### Can UC Affect Other Parts of My Body?

Although the colon is the primary site of inflammation, other parts of the body can be affected. Blood loss from the colon can lead to anemia, which often manifests initially as fatigue. Secondary inflammation in other parts of the body including the joints, eyes, skin, and even the liver can occur. This inflammation can also make the blood more likely to clot, making the patient more susceptible to serious clots affecting the legs and lungs. In most cases, control of the inflammation in the colon limits these manifestations, although some of these complications, particularly in the liver and spine, may run a course independent of the severity of the colitis.

### How Will Having UC Affect My Plans for a Family?

In most cases, male fertility is unaffected by UC, although medications such as sulfasalazine can have some



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impact on sperm counts. Female fertility is generally not affected by UC. Medications such as certain coated formulations of mesalamine containing phthalates, prednisone, azathioprine, and infliximab have theoretical effects on fetal development and may be adjusted after consultation with a specialist. In the event colectomy is required, it is generally accepted that ileoanal reconstructive surgery should be deferred until after attempts at conception because of a well-documented decrease in fertility related to surgery deep in the pelvis.<sup>5</sup>

## Extent-Specific Questions

### What Are My Treatment Options?

#### PROCTITIS

There is no cure for UC, but medications can heal the bowel lining (mucosa) and control symptoms. Mesalamine taken by rectal suppository or enema, usually prior to bedtime, is the first medication recommended by most specialists. Corticosteroids administered in a similar fashion or as a foam can also be used. In rare cases, oral therapy with mesalamine, corticosteroids (such as prednisone), or other systemic therapies such as azathioprine or infliximab, which affect the way the immune system interacts with the bowel bacteria and its mucosa, may be employed either instead of, or in addition to, these rectal therapies.<sup>6</sup>

#### LEFT-SIDED COLITIS

There is no cure for UC, but medications can heal the bowel lining (mucosa) and control symptoms. Oral mesalamine is usually the first medica-

tion employed by most specialists, and many recommend concurrent therapy with mesalamine enemas to increase the amount of medication applied to

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the mucosa and improve symptoms and healing rates. Corticosteroid enemas are an alternative. If unsuccessful, the next step is usually the administration of oral corticosteroids (prednisone), the dosage of which is tapered over months. If corticosteroids fail to control the disease, the addition of systemic therapies such as azathioprine or infliximab, which affect the way the immune system interacts with the bowel bacteria and its mucosa, may be employed.<sup>6</sup>

#### PANCOLITIS

There is no cure for UC, but medications can heal the bowel lining (mucosa) and control symptoms. Oral mesalamine is usually the first medication employed by most specialists when symptoms are not severe enough to consider hospital admission. If unsuccessful, the next step is usually the administration of oral corticosteroids (prednisone), the dosage of which is tapered over months. If corticosteroids fail to control the disease, the addition of systemic therapies such as azathioprine



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## COLORECTAL CANCER AFFECTS UP TO 6% OF THE GENERAL POPULATION OVER THEIR LIFETIME, WITH A SIGNIFICANTLY HIGHER RISK IN PATIENTS WITH A FAMILY HISTORY OF CRC.

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### Will Having UC Lead to Colon Cancer?

#### PROCTITIS

Colorectal cancer (CRC) affects up to 6% of the general population over their lifetime, with a significantly higher risk in patients with a family history of CRC. Most studies do not suggest that patients with isolated ulcerative proctitis have an increased risk of CRC, but patients with proctitis should follow population-based CRC surveillance protocols (including colonoscopy) and be aware that new symptoms such as rectal bleeding should not always be attributed to a simple disease flare.<sup>7</sup>

#### LEFT-SIDED COLITIS

CRC affects up to 6% of the general population over their lifetime, with a significantly higher risk in patients with a family history of CRC. Patients with isolated left-sided UC have a modestly increased risk of CRC that does not usually become significant until the second decade after the onset of symptoms. It is recommended that patients have surveillance colonoscopy at 3-year intervals starting 15 years after diagnosis.<sup>7</sup>

#### PANCOLITIS

CRC affects up to 6% of the general population over their lifetime, with a significantly higher risk in patients with a family history of CRC. Patients with UC affecting the majority of their colon have an increased lifetime risk of CRC that may be as high as 10–20%. The increase in risk appears to occur late in the first decade after the onset of symptoms. It is recommended that patients with pancolitis undergo initial surveillance colonoscopy 8 years after diagnosis, with a 3-year surveillance interval that may decrease over subsequent decades.<sup>7</sup>

### Will I Need Surgery?

#### PROCTITIS

In the vast majority of patients, ulcerative proctitis can be managed medically, using rectal or oral therapies. Although in a minority of patients the disease can progress higher up into the colon, surgery is virtually never required if this does not occur.

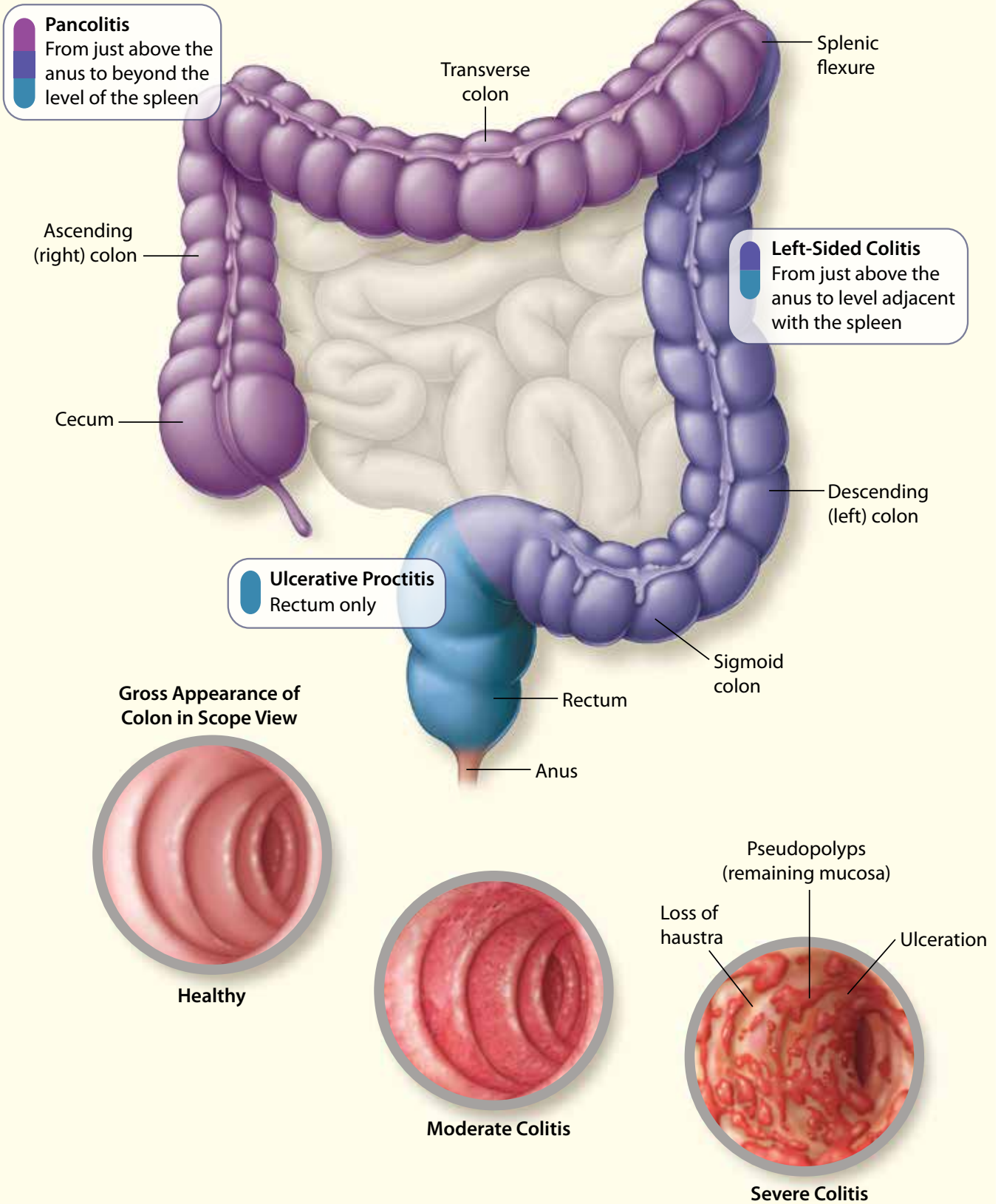
#### LEFT-SIDED COLITIS

In a large majority of patients, left-sided UC can be managed medically, often using a combination of rectal and oral therapies. In a minority of patients, disease can become refractory or more extensive, and surgery, although rarely emergent, can become the preferred therapeutic option.

#### PANCOLITIS

Advances in therapy, particularly the use of infliximab, have seen a decrease in the need for surgery (colectomy) for the treatment of UC. Unfortunate patients who fail to appropriately respond or who become refractory to oral therapy for UC often require admission to hospital.

Figure 1:  
**Ulcerative Colitis Classification**



If this is necessary, up to 20% may require colectomy during that hospital stay, with another 20% requiring the procedure over the subsequent 5 years.

### What Do I Do If My UC Flares Up?

#### PROCTITIS

Most patients with a flare experience rectal bleeding and increased stool frequency and may make frequent trips to the toilet with only a minimal output of bloody mucus. If this occurs, rectal therapy with mesalamine, as either suppositories or enemas, should be the first treatment to be increased or re-initiated. A minority of patients do better with rectal steroid therapy, while some patients prefer to increase oral mesalamine therapy prior to seeking further advice from their primary care physician or gastroenterologist.

#### LEFT-SIDED COLITIS

Most patients with a flare experience bloody diarrhea, often with cramps. It is still important to consider exposure to infections or antibiotic-related infections. The collection of a fresh stool specimen for laboratory analysis to rule out infection is never unreasonable. Re-initiation of, or an increase in, mesalamine dosage to as much as 4,000 mg daily is usually the initial recommendation, often with co-administration of mesalamine or corticosteroid enemas nightly. Further advice from the primary care physician or gastroenterologist is often required, particularly if systemic corticosteroids are contemplated.

#### PANCOLITIS

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is still important to consider exposure to infections or antibiotic-related infections. Collection of a fresh stool specimen for laboratory analysis to rule out infection is never unreasonable. Re-initiation of, or an increase in, mesalamine dosage to as much as 4,000 mg daily is usually the initial recommendation. Medical attention should be sought immediately if abdominal pain is severe, particularly if associated with abdominal distension or fever. Anti-diarrheals, such as loperamide, should generally be avoided. Further advice from the primary care physician or gastroenterologist is usually required, particularly if systemic corticosteroids are contemplated.

### How Long Should I Take Medication?

#### PROCTITIS

Rectal therapy, particularly with mesalamine suppositories, is felt by most physicians to be the preferred maintenance therapy. Using these suppositories two or three times weekly is likely to decrease the risk of recurrence. In patients who choose not to continue maintenance therapy, it is recommended that a prescription for such therapy be easily available for the initiation of nightly treatment should symptoms develop.

#### LEFT-SIDED COLITIS

Maintenance therapy with mesalamine enemas two or three times weekly may be used, although most patients choose oral mesalamine dosing of approximately 2,000 mg daily, which may reduce the risk of a disease flare by as much as half. If patients have required oral corticosteroid therapy, many use azathioprine or



## Key Points

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even infliximab for at least a year or more to maintain remission.

### PANCOLITIS

Maintenance therapy with mesalamine in dosages of 2,000–4,000 mg daily is standard to maintain remission of disease, reducing the risk of flares by up to half. Some population studies have suggested that patients who take such maintenance therapy have a lower risk of CRC, increasing the therapy's potential benefit over the long term. If patients have required oral corticosteroid therapy, many use azathioprine or even infliximab for at least a year or more to maintain remission.

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## Clinical Pearls

Clinical experience reinforces that most patients have similar questions upon diagnosis with UC.

Anticipating these questions and tailoring them to a particular patient's disease severity and extent should streamline follow-up and also mitigate confusion.