

Ulcerative Colitis:

Symptom Control and Quality of Life

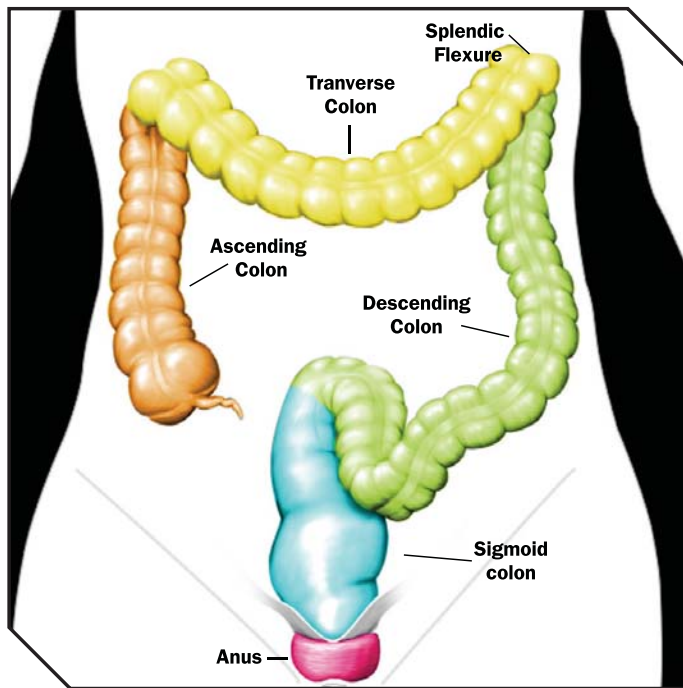


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Ulcerative Colitis Patient Education Resources are available at www.gastro.org/patient.

Created by the AGA Institute, this new multimedia educational series is designed to help you learn as much as possible about ulcerative colitis (UC).

This program gives you easy access to reliable information

about UC that you can review at your own pace. The goal of the program is to help you understand the disease and learn strategies for living your life to the fullest.

The program includes:

- Interactive, multimedia patient webcasts to help you become familiar with UC and its many effective treatment options.
- “Health U,” an online series of three courses offering expert information about UC.
- “Ask Your Doctor” discussion guides featuring helpful tips to prepare you for talking with your doctor about UC.
- A physician-run blog allowing you to read and respond to the most up-to-date thoughts about UC from doctors who treat it every day.

By providing you with this brochure, your doctor is joining our efforts to help you understand UC. Our mutual goal is to help you improve the quality of your life and to take an active role in your own treatment and care.



Ulcerative Colitis: An Overview

Ulcerative colitis (UC) is a disease that causes inflammation of the lining of the large bowel, including the colon and rectum. Inflammation, in turn, results in sores or breaks in the bowel lining, called ulcers. This injury may produce bleeding, pus and often urgency and pressure in the rectum. Some patients have diarrhea and others feel more constipated despite the feeling of urgency. Inflammation of the rectum may result in the inability to distinguish between gas and stool, which leads to “false alarms” and tremendous life disruption. Symptoms usually occur during discreet time periods known as flare-ups. Flare-ups tend to alternate with periods of no symptoms at all, known as remission.

More than half of people with this disease have mild UC, which can mean months or even years of remission. Other people have a more severe form of the disease with frequent attacks and more serious symptoms. Regardless of severity, patients need to keep track of their symptoms* for

signs of dehydration (i.e., thirst, dry mouth, or little or no urine), significant bleeding, worsening abdominal pain or fever. If these symptoms occur, it is important to seek urgent help, such as going to the emergency department of a hospital to get treated.

The cause of UC is not known. People with UC have abnormal immune systems, but no one knows if this is a cause or a result of the disease. Either way, the immune system’s reaction to normal bacteria in the digestive tract is thought to contribute to the disease. While stress is not a cause of the disease, it may trigger disease flare-ups in patients who were in remission.

Diagnosing UC

Patients often find out they have UC when they see a doctor about symptoms such as diarrhea, stomach pain or blood in their stool. The doctor will do a physical exam and take a medical history, and may order blood tests to check for anemia or a high white blood cell count that can indicate bleeding and inflammation. A

Symptoms of UC

Symptoms of ulcerative colitis can interrupt daily activity and include the following:

- Diarrhea or frequent watery bowel movements
- Rectal bleeding
- Blood or pus in the stool
- Straining with bowel movements
- Abdominal cramping and gas
- Feeling tired
- Loss of appetite
- Weight loss
- Anemia

***See Appendix for Symptom Tracker**

Visit www.gastro.org/patient for more resources.

stool sample is also taken to rule out infections with bacteria or parasites.

Other tests, including colonoscopy or sigmoidoscopy, are often required. These tests involve a flexible, lighted tube connected to a computer and monitor. The tube is inserted into the body through the anus, and allows the doctor to examine the lining of the colon and rectum. During the exam, a sample of tissue from the lining of the colon may be taken for closer viewing with a microscope. This tissue sampling is called a biopsy.

X-rays with barium enemas or CT scans are also sometimes used to diagnose UC. All of these methods can be used to rule out other possible conditions, such as Crohn's disease, diverticulitis and cancer.

Once UC is diagnosed, it can usually be controlled with medicines and diet.

Treating UC

The goal of treatment for UC is to control symptoms and keep patients in remission for as long as possible. The type of treatment prescribed depends on the extent of colonic involvement and

severity of the disease. Although one important strategy is to avoid foods that can trigger symptoms, it's important to know that specific foods do not appear to cause UC or to prevent it. Some may find it necessary to avoid milk products, raw fruits and vegetables, or other foods during active flares. Alcohol and caffeine may exacerbate symptoms of diarrhea but do not appear to worsen the disease. Strictly eliminating entire types of food from the diet is generally not a good idea and should be discussed thoroughly with your health-care provider. A high- or low-fiber diet plus multivitamins may be prescribed, depending on symptoms. Many UC patients keep a journal of foods that do and do not trigger symptoms so that they can discuss this with their health-care provider.*

Although there is no medical cure, the condition can be treated effectively with prescription medications. Several types of drugs are effective in treating flare-ups and prolonging remissions. These include:

■ **Anti-inflammatory drugs:** These are the first-line treatment for UC. Examples are sulfasalazine, olsalazine,

Methods for diagnosing UC

Once UC is diagnosed, it can usually be controlled with medicines and diet.

- Physical exam and medical history
- Blood tests (red- and white-blood-cell counts)
- Stool sample (check for bacteria, viruses, parasites)
- Colonoscopy or sigmoidoscopy (scope inserted into the anus)
- Biopsy (sample of tissue taken)
- X-rays and CT scans

*See Appendix for UC Notes & Patterns

Questions for your health-care provider

1. What treatments should I consider?
2. What does each of the drugs do?
3. What side effects might these drugs have?
4. What can I do to manage these side effects?
5. What else do I need to know about my treatment plan?

Visit www.gastro.org/patient for additional questions to ask your health-care provider.

mesalamine and balsalazide.

■ **Corticosteroids:** Prednisone is an example of this type of drug. It is used during flare-ups, but not for bringing about long-term remission.

■ **Immunomodulators:** These drugs may be used to induce remission of more severe disease and some may be required subsequently to maintain remission. Examples are azathioprine, 6-mercaptopurine, infliximab or cyclosporine.

As with all drugs, the medications for UC may cause side effects.* It is important to speak to your doctor about side effects before taking a drug. People with UC should stay on steroid-free maintenance medications even when feeling well. Learning to manage side effects is an important strategy.

In some cases, surgery may be necessary to control bleeding, severe illness or related complications. Your health-care provider can discuss surgical options in greater detail.

Regular Screenings & Risk of Colon Cancer

There appears to be a small but significant risk of colorectal cancer in patients with UC, which is greater than the risk in the general population. This risk is related to how much of the colon has been involved with the disease, how

long the disease has been present, and additional risk factors such as family history of colon cancer and possibly the degree of inflammation over time.

Sometimes pre-cancer cell changes in the lining of the colon can be detected and treated early. This is what doctors look for during a colonoscopy or sigmoidoscopy as a marker of a patient at higher risk for colorectal cancer now or in the future.

It is recommended that UC patients have a screening colonoscopy after eight years of the disease, and subsequent exams every one to two years thereafter. Your health-care provider can discuss how often and when to have a colonoscopy with biopsy. UC is usually a lifelong illness, so becoming an active participant in cancer screening helps patients feel more in charge of their lives.

In addition, there is some evidence that the anti-inflammatory medications may prevent colorectal cancer, so there are several important reasons to stay on maintenance medications when the disease is in remission.

Working Toward Symptom Control

People living with UC may feel some stress while they are first learning to manage symptoms. This can be true even when symptoms are mild and

**See Appendix for Medicine Tracker
Visit www.gastro.org/patient for more resources.*

generally controlled with treatment. Some patients complain that their life has become centered on UC and always being near a bathroom. Planning ahead may help to reduce worry. Knowing where public restrooms are located can also relieve stress.

Exercise is another important way to reduce symptoms and stress. Asking your health-care provider how much activity and when to start an exercise program can help you get started.

Another strategy is to learn about stress management. Taking steps to reduce stress and anxiety may help. Some activities that promote relaxation include:

- Mindful activities, such as yoga or meditation.
- Taking deep, relaxing breaths or practicing breathing techniques.
- Progressive relaxation or visualization exercises.
- Personal stress busters—such as listening to music, soaking in the tub, enjoying nature.

Emotional Issues & Quality of Life

UC can interrupt daily living and turn things upside down. Some people get relief when they learn what is causing their symptoms, but a diagnosis of UC

can also cause people to feel upset, confused and anxious. Some people feel shame or embarrassment, anger or sadness. Of course, everyone's emotional response to illness is different, but no matter what the response is, learning to cope with a new disease is an important step in managing it.

Common concerns among newly diagnosed UC patients include:

- How can I deal with physical symptoms such as diarrhea and gas when I am out in public?
- Will the symptoms make it hard for me to work or resume daily activity?
- Can I continue my usual activities such as sports and exercise?
- How will my family, friends and co-workers respond to me now?
- Will this change my ability to have intimate relationships?

Learning new coping skills takes time and requires help and support. Begin by turning to your health-care team for answers to your questions, information about treatment and ideas for increasing your support system.

Resuming Every Day Life

For people with UC, it is important to continue with the work of living.

Other questions for your health-care provider

- Are there precautions I can take to minimize my risk of colon cancer?
- How often should I get a screening or surveillance colonoscopy to detect early signs of cancer?
- What happens if pre-cancer cells are detected?

Visit www.gastro.org/patient for additional questions to ask your health-care provider.

Personal stress busters

1. Read a book
2. Shop for new clothes
3. Play a song, CD or tape
4. E-mail a friend
5. Try yoga
6. Take a nap
7. Cook a meal
8. Take a drive
9. See a movie
10. Sleep in
11. Take a bath
12. Surf the Internet
13. Go for a walk
14. Meditate

With a doctor's approval, work and exercise can usually resume once symptoms are under control. By law, employers are required to make adjustments to allow persons with disabilities and illness to continue to work. Travel and other activities can be accomplished with planning and reasonable precautions.

Having UC can affect the personal aspects of life too. Self-image, sexuality and sexual functioning may suffer. Some medications may affect sexual drive or function. The support of one's family is key to maintaining a healthy self-image. Family members and partners can provide reassurance, understanding and loving support. Parents of adolescents with UC need to help their teenagers develop a positive body image and normal expectations for intimacy. Above all, individuals with any chronic disease need encouragement to focus on their abilities rather than their disabilities.

Joining a support group to meet and talk to other individuals with UC can help. Many patients also benefit from speaking to a counselor or therapist to assist them in developing coping skills and dealing with stress.

Use reliable sources of information, such as trusted Internet sites and expe-

rienced professionals. Ask lots of questions and be assertive about gaining control of this condition. If you are knowledgeable about the disease and available therapies, you will be more successful and empowered to control the disease and maintain your health. ■

Tips for staying in control

1. Follow your treatment plan exactly as prescribed—stay on your medications!
2. Discuss with your health-care provider any problems with the medical regimen that may limit your ability to adhere to the recommendations.
3. Make your doctor your partner in controlling your symptoms (i.e., ask how you can take care of yourself, what to do when your symptoms flare-up, how often you need to have a regular check-up).
4. During bouts of diarrhea, try to avoid dehydration. Drink clear fluids such as water, juice, tea or bouillon. Suck on ice chips.
5. Learn ways to relieve stress.
6. Recognize the signs and symptoms of a flare-up.

Visit www.gastro.org/patient for more resources.

Appendix

UC Symptom Tracker

Keep track of your symptoms. Fill out the chart below (make extra copies for future use) and bring the completed charts to your next doctor's visit. It is also good to have this information handy in case you need to go to the hospital. See below for examples of how to use this chart.

Symptom	Describe	Severity	Date	Report to Doc?
Diarrhea	Watery, loose, every half hour	Moderate to severe	4/12-4/13	LM with nurse
Urgency	Mucous, blood only	Cramping moderately		

Medicine Tracker

Do you know your medicines? Do you know the possible side effects? Fill out the information below, and keep this list with you in your wallet or purse:

Allergies: _____

1. Medicine: _____
Dose: _____
Possible Side Effects: _____

3. Medicine: _____
Dose: _____
Possible Side Effects: _____

2. Medicine: _____
Dose: _____
Possible Side Effects: _____

4. Medicine: _____
Dose: _____
Possible Side Effects: _____

Doctor Tracker

What are your doctors' names and telephone numbers?

Name: _____ **Phone:** _____

Name: _____ **Phone:** _____

Name: _____ **Phone:** _____

Name: _____ **Phone:** _____

Name: _____ **Phone:** _____

UC Notes & Patterns

It's good to keep track of how you are feeling, what you are eating, and if you are controlling stress and getting the right amount of exercise. Some patients find it helpful to keep a daily log of UC-related information. Noticing patterns in foods and stress that trigger flare-ups may help you take steps to get in better control. You can get started here, today, by answering the following questions:

What have I been eating and how has it made me feel?

Have I had diarrhea or urgency frequently?

Have I had cramps? If so, generally how soon after eating?

Have I been feeling a lot of stress this week? _____

Have I taken my medications as prescribed and on time? If "yes," how did they make me feel?

It is very important to remember that there is no reason to feel alone with this disease. If you, a loved one, or a friend is diagnosed with ulcerative colitis, information and assistance is available from your doctor, and from people and organizations whose mission is to provide the support you need.

General Information, Support & Clinical Trials:

- American Gastroenterological Association (AGA) Institute
(301) 654-2055
www.gastro.org

- Crohn's & Colitis Foundation of America (CCFA)
(800) 932-2423
www.ccfa.org

- National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK)
www.niddk.nih.gov
www.clinicaltrials.gov

- Centers for Disease Control and Prevention
www.cdc.gov

Information about Ostomy Care:

- United Ostomy Associations of America, Inc.
(800) 826-0826
www.uoa.org

- Wound Ostomy & Continence Nurses Society
(888) 224-9626
www.wocn.org

Information for Children and Youth:

- Reach Out For Youth with Ileitis and Colitis, Inc.
(631) 293-3102
www.reachoutforyouth.org

- North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN)
(215) 233-0808
www.naspghan.org

Educational resources are available through the Digestive Health Initiative® (DHI®) and found online at www.gastro.org/patient and www.fdhn.org including patient webcasts, a “Health U” online program, “Ask Your Doctor” discussion guides and a physician-run blog for patients.

The **patient-centered webcasts** offer an interactive, multimedia format with editorially independent, objective and balanced information about ulcerative colitis. Users can opt-in to receive updates on the information.

The online “**Health U**” provides information through an engaging multimedia format in easy-to-understand language. Its health videos are easily accessed from any computer at any time. It has been designed for

people with busy schedules who want to learn about their health at their own pace. Each course is led by an instructor and divided into interactive health lectures. Simply log-in to begin the learning experience and take the course in one sitting or come back to finish later. The online system will keep track of your progress and remind you of where you left off upon your return.

The “**Ask Your Doctor**” discussion guides are available in a printer-friendly version, encouraging and preparing patients for discussions with their health-care professional.

A **patient blog** features the opportunity for frequent, ongoing communication about ulcerative colitis. The content is provided by physicians. Consumers can register to receive blog updates.

The Digestive Health Initiative® (DHI®) is an education and outreach program to increase awareness among consumers and the larger health-care community about the prevention, early detection and treatment of various digestive health disorders.

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