A GUIDE FOR PATIENTS

Ulcerative Colitis

DVD INSIDE

FEATURING
Casey Abrams
Musician, composer, and UC patient

WITH
Dr. Stephen B. Hanauer

AMERICAN COLLEGE OF GASTROENTEROLOGY

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DVD inside back cover:

The *Ulcerative Colitis: A Guide for Patients* DVD (14 min) features the stories of four ulcerative colitis patients—including musician and composer Casey Abrams—with expert commentary from Dr. Stephen Hanauer.
Introduction

If you’re reading this booklet, you—or someone you care about—has probably been diagnosed with a disease called ulcerative colitis (UC). The word “ulcerative” refers to sore spots that may bleed on the lining of the colon, which makes up most of the large intestine. “Colitis” means the colon is inflamed (irritated and swollen).

Having UC may cause unpleasant symptoms such as diarrhea with blood or mucus, and abdominal cramping and pain. These symptoms can be uncomfortable and disruptive. Other symptoms can include weight loss and tiredness.

If you have been recently diagnosed with UC, or even if you have been dealing with it for some time, you may have questions about the disease and how best to cope. You should talk to your doctor about any questions or concerns you may have. This booklet and DVD program may be able to help!

It’s important to know you’re not alone. UC affects about 500,000 people in the United States. Many doctors know about this condition and can help you find treatments that work. Although there is no medicine that can cure UC, it can be managed to reduce your symptoms.

In this booklet and DVD, you’ll learn about:

• UC and its causes
• Managing the disease
• How to build a support team of family and friends
What is Ulcerative Colitis?

UC is a type of *inflammatory bowel disease* (IBD). In people with UC, the lining of the colon and rectum become irritated and swollen. This is called “inflammation.” In addition, areas of the lining can develop sores that may bleed, called ulcers. Sometimes UC just affects the lower part of the large intestine—the rectum. In other people, part, or all, of the colon is affected.

The other type of inflammatory bowel disease is Crohn’s disease. Crohn’s disease can affect not just the large intestine, but the entire length of the digestive tract including the mouth, throat, stomach, and small intestine. In contrast, UC affects *only* the large intestine.

To understand UC, it helps to understand the basics of your digestive system. The food you eat gets digested mainly in your stomach. Nutrients are then absorbed as the food passes through the small intestine. The role of the large intestine is to absorb water from what remains, and eliminate the waste material from the body. When a portion of the large intestine is inflamed, it cannot do its job and there is more water in the stool, causing diarrhea.

**Did You Know?**

Inflammatory bowel diseases, such as ulcerative colitis, are *not* the same as irritable bowel syndrome (IBS). The names sound similar, and both IBD and IBS may cause cramping and/or diarrhea. But the colons of people with IBS do not become damaged, as they do in those with IBD. Also, treatments for IBS and IBD are different.
What Causes UC?

The exact cause of UC is still not clearly understood. Some people may be more likely to develop UC because of genes they inherit from their parents. It is also thought that UC may develop when a person’s immune system mistakenly attacks the lining of the colon. Finally, some studies suggest that certain factors may increase the chance of a person getting UC. These factors include: using antibiotics or non-steroidal anti-inflammatory medicine, taking birth control pills, or eating a high-fat diet.

Importantly, however, UC does not seem to be caused by emotional stress. It is also not caused by your diet, although certain foods, or food products, may trigger symptoms in some people.

Signs and Symptoms of UC

The most common signs and symptoms of UC are diarrhea with blood or mucus, and discomfort in the belly area (abdomen). Other signs and symptoms include:

- An urgent need to have a bowel movement
- Feeling tired
- Nausea or loss of appetite
- Weight loss
- Fever
- Anemia—a condition in which the body has fewer red blood cells than normal

Less common symptoms include:

- Joint pain or soreness
- Eye irritation
- Certain rashes
- Severe abdominal cramping
It’s important to get properly diagnosed by your doctor, because the symptoms of UC can also be caused by other conditions such as a bacterial infection or Crohn’s disease. For the diagnosis, you may be referred to a doctor who specializes in digestive diseases—a gastroenterologist.

Blood tests may be used to look for signs of inflammation or low red blood cell counts (anemia). Tests of your stool may show if your symptoms are caused by an infection of some kind.

The most accurate way to diagnose UC and rule out other possible conditions is for a doctor to directly look at the inside of your large intestine. This is done by using a flexible, narrow tube with a light and a tiny camera at one end. The device is inserted into the anus and gently guided through the large intestine. In order for your doctor to see the wall of the large intestine clearly, it needs to be empty. You will be told how to do this before the test. In some cases, a medicine will be used to help you relax for the test.

There are two common tests that can be done to look inside your large intestine. With a colonoscopy, the rectum and the entire length of the colon are inspected. With a sigmoidoscopy, just the rectum and lower parts of the colon are inspected. In both cases, the doctor will look at the lining of the large intestine. Sometimes a small tissue sample is taken for examination under a microscope. This is called a biopsy. The results of these tests will allow your doctor to determine the severity and extent of your disease.
Once you have been diagnosed with UC, you and your doctor will work together to create a treatment plan. There is no “one-size-fits-all” treatment for UC. Each person, and each person’s situation, is different. The goal for everyone with UC, however, is the same: to reduce and control current symptoms and, once controlled, prevent future flare-ups. Most people do this by learning to identify and avoid triggers and/or using some type of medicine.

Medicines for UC aim to reduce the inflammation and swelling in the colon and heal the ulcers. There are four types of medicines that might help:

- **Aminosalicylates** (reduce inflammation in the lining of the colon)
- **Corticosteroids** (used to treat flares)
- **Immunomodulators** (help reduce or control the activity of the immune system)
- **Biologics** (another class of medicines to control inflammation)
Some medicines for UC are taken as a pill by mouth, or given as an injection or infusion. Other times they are given directly into the large intestine with a suppository, foam, or enema to get the medicine to where it’s needed.

Although most people with UC can manage their condition by effective, long-term medical therapies, some people may require surgery. Removal of the large intestine may be recommended if a person does not respond to medicines, has unacceptable side effects, or has other serious conditions or complications.

Several kinds of surgeries are available, with the choice driven by such things as the nature of your symptoms, your preferences, age, and medical condition.

If you are a candidate for surgery, your surgeon will help you decide which type best fits your needs.

When you see your doctor, remember to:

- Do some research before you go
- Write down questions and answers
- Be specific when describing how you feel
- Don’t be afraid to ask questions—even a lot of questions!
- Speak up if something is confusing—your doctor wants you to understand
- Consider bringing along a trusted family member or friend
Managing Diet

The connections between what you eat and how you feel are complicated. While diet is not thought to cause UC, people react differently to different foods. Some people may be sensitive, or allergic, to certain foods, which may cause symptoms that look like UC. Some foods may make your symptoms worse, while some dietary changes may help reduce symptoms. Writing down exactly what you eat during the day may help you pinpoint foods or drinks that make your symptoms worse.

More studies are needed to determine if there are direct links between diet and UC. Talk to your doctor before making any changes in your diet. If you do try an experiment with diet, change only one thing at a time and keep track of your symptoms.

No matter what, you need to make sure you are eating a healthy, well-balanced diet, so you get all the nutrition you need.
Foods considered part of a healthy diet are:

- Vegetables
- Fruits
- Whole grains
- Fat-free or low-fat dairy (if you are lactose-intolerant and have diarrhea after drinking or eating dairy, you should avoid lactose-containing foods)
- Seafood
- Lean meats and poultry
- Eggs
- Beans and peas
- Nuts and seeds

Here are some tips that may help you during a UC flare:

- Eat smaller amounts of food during the day
- Limit high-fiber foods in favor of cooked or steamed fruits or vegetables
- Drink lots of water—at least 8 cups of water a day can help avoid dehydration

Remember: healthy foods should be eliminated from your diet only when you are certain—after multiple tries, and after consulting with your doctor—that a particular food is a problem for you.
Dealing with UC can be tiring and stressful. It’s also not that easy to talk about, or explain to others. But it’s important that you do talk about it, at least with those closest to you. UC is nothing to be embarrassed about—it’s just another kind of medical condition that needs to be managed. Being open and honest about UC can be a relief, and can allow those around you to be supportive.

You can build a support team of family members, close friends, health care professionals, or others who have dealt with UC. Support groups can be a great way to connect with others. This is easier than ever, thanks to the Internet. You can find information about both online and in-person support groups from some of the organizations listed in the Resources section of this booklet, including the Crohn’s & Colitis Foundation of America (www.ccfa.org).

If you are feeling stressed, here are some tips that might help:

- Use a relaxation strategy like deep breathing. There are different ways to do this. You may try closing your eyes and taking a slow, deep breath in. Hold it for a few seconds and then slowly exhale. Repeat as needed. This may help you feel a little calmer.
• Research shows that physical activity (exercise) can improve mood and mental well being. But always check with your doctor before starting any new type of exercise.

• Sometimes people find that writing down their stressful thoughts helps. You may want to write in a journal where you can collect your thoughts.

Another thing that might help is learning whether the state where you live has laws aimed at providing easier access to bathrooms for those who need that. Some states have passed laws requiring stores to allow customers to use their bathrooms if they have UC, or another medical condition, that makes quick access to a toilet necessary.

It also pays to think ahead. Consider making an emergency kit to keep on hand in your car, desk drawer at work, handbag, or wherever. Things to include could be:

• Extra underclothing
• Toilet tissue
• Wet wipes
• Pocket tissue packs

Pregnancy and UC

Women who have UC may have concerns about pregnancy and breastfeeding. It is important for women with UC to speak with their gastroenterologist, as well as their obstetrician or gynecologist, before becoming pregnant. Together with your doctor or health care team, you can prepare a plan for your pregnancy while managing your UC.
Conclusions

By reading this booklet and watching the DVD, you’ve taken important steps in educating yourself about ulcerative colitis. You’ve learned that this chronic condition can be managed by avoiding triggers and, if needed, taking one of the several types of medicines for UC.

No two people—and no two medical conditions—are exactly alike. But you can use the information in this booklet to begin charting your own course.

By working with your health care team and building your personal support network, you can give yourself the best chance of staying healthy and getting the most from whatever treatments you and your doctor choose.
American College of Gastroenterology
www.gi.org
(search for the term “ulcerative colitis”)

Centers for Disease Control & Prevention
www.cdc.gov/ibd/#aboutUlcer

Crohn’s & Colitis Foundation of America
www.CCFA.org
(search for the term “ulcerative colitis”)

MedlinePlus
www.medlineplus.gov
(search for the term “ulcerative colitis”)

National Digestive Diseases Information Clearinghouse
www.digestive.niddk.nih.gov
(search for the term “ulcerative colitis”)

American College of Gastroenterology

Founded in 1932, the American College of Gastroenterology is an organization with an international membership of more than 12,500 individuals from 86 countries. The College is committed to serving the clinically oriented digestive disease specialist through its emphasis on scholarly practice, teaching and research. The mission of the College is to serve the evolving needs of physicians in the delivery of high quality, scientifically sound, humanistic, ethical, and cost-effective health care to gastroenterology patients. For more information, visit www.gi.org.
FUNDING AND REVIEW

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Casey Abrams
...and the three other UC patients who also share their stories in the DVD

FEATURING

Casey Abrams
Musician, composer, and UC patient
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Ulcerative colitis (UC) causes unpleasant symptoms such as diarrhea with blood or mucus, and abdominal cramping and pain. These symptoms can be uncomfortable and disruptive. Other symptoms can include weight loss or tiredness.

UC affects about 500,000 people in the United States. The good news: UC can be effectively managed by avoiding possible triggers and working with health care professionals to find appropriate treatments.

This program will help you take steps to control your UC symptoms.

You’ll learn about:
- UC and its causes
- Managing the disease
- How to build a support team of family and friends

WITH
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to watch the video, scan the QR code above