Understanding Ulcerative Colitis (UC) Disease Activity... ABOVE and BELOW the Surface

A Planning Guide to Help Optimize Disease Management of UC

The information contained in this educational resource is intended to reinforce and supplement information you receive from your healthcare team. It is not a substitute for medical advice from your physician. If you have questions about the information you read in this educational resource, please discuss them with your healthcare provider.

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How to Use This Planning Guide

The Iceberg

It's a commonly used image to help explain situations where what you see doesn't tell the full story.[1] Consider the popular phrase, the tip of the iceberg. This means that only part of an iceberg is visible above the surface of the water, yet below the surface lies a much larger piece of the iceberg that cannot be seen.

The iceberg is a useful metaphor to explain what's happening inside your body when you're living with ulcerative colitis (UC). **That's because the signs and symptoms of UC—increased stool frequency and urgency, abdominal pain, and rectal bleeding—are just the tip of the iceberg; chronic inflammation may still be occurring below the surface.**[2,3]

This is just one of several tips from the UC iceberg that appear throughout this piece.

Understanding Ulcerative Colitis Disease Activity... ABOVE and BELOW the Surface contains information to help advance your understanding of UC. It includes tips, disease management strategies, and quizzes. While the exercises are intended to be useful and interesting, they're specifically designed to reinforce the educational information in each section.

Use this planner as a guide to learn more about UC and to become empowered to support your own disease management. Empowerment can mean taking a more active role in the management of your medical condition with your healthcare provider.

This planning guide can arm you with the information you need to team up with your healthcare provider (HCP) to design a disease management plan that's right for you.

What You Will Learn

Important things you may not know—but should know—about UC and your disease management.

By using this guide, you will be able to:

1. **Describe UC,** including common signs and symptoms
2. **Explain how UC is diagnosed** and the tests used as part of the examination process
3. **Describe how UC can affect your quality of life,** including the physical and emotional challenges associated with the condition
4. **Detail the goals of UC disease management** and the main disease management options
5. **Understand the risks of developing other medical conditions related to UC,** as well as the importance of taking your UC medication as prescribed
6. **Explain the importance of two-way communication** between you and your HCP to support your UC disease management program

A Tip From the UC Iceberg

It's important to take your UC medicines exactly as prescribed by your HCP to control the underlying inflammation associated with UC.

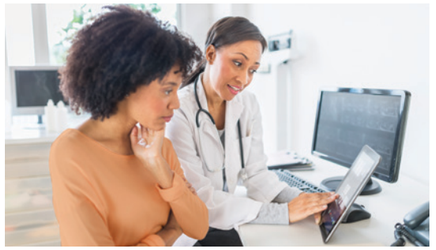
Need-to-Know Information About UC

Understand these key facts about UC…then expand your understanding by completing some exercises to help when discussing your disease management plan with your HCP.

1 UC is a chronic, inflammatory disease that affects the colon and rectum and is marked by a range of signs and symptoms.

UC is a chronic, inflammatory medical condition that affects the colon and rectum.[4,5] Symptoms of UC are long-lasting, tend to come and go, and are marked by episodic flares.[6] Inflammatory means that UC is marked by reddened, swollen tissue.[4,5] The severity of your UC is evaluated based on your symptoms and the affected areas of your rectum and colon.[5] UC has a defining symptom—that is, the presence of bloody diarrhea that may or may not have mucus in it.[4,5] But the symptoms of UC may go beyond the digestive system.[5,7] If you have UC, you may also experience issues affecting your skin, eyes, and musculoskeletal system (eg, joints, ligaments, muscles, nerves, and tendons). UC may also be accompanied by more general symptoms including fever, loss of appetite, weight loss, or fatigue.[7]

2 Various clinical tools and techniques are used to diagnose UC.



HCPs use various techniques to diagnose UC.[7] Diagnosis typically begins with an understanding of your symptoms and confirmation of inflammation in the lining of your colon.[7,8] Your gastroenterologist will check for signs of diseased tissue or underlying inflammation using an *endoscope*—a flexible, lighted tool that can allow for biopsies.[9] Lab tests may also be used to ensure that other causes of inflammation and diarrhea are ruled out.[6] Your HCP will monitor your UC symptoms regularly to note any changes over time. You can assist in this process.[10] Your HCP may ask questions about your condition, such as the frequency of your bowel movements and level of rectal bleeding.[11] Symptom-related information that you share with your HCP may be used to help assess UC disease activity.

3 UC may have different effects—both physically and emotionally—on your quality of life.

UC may pose physical and emotional challenges to patients struggling with the condition.[12] Together, these issues can affect quality of life. Physical challenges include abdominal pain and bowel-related problems, such as urgency (ie, the sudden or uncontrollable urge to go to the bathroom).[13,14] Urgency is particularly problematic, with patients in one study ranking urgency as more bothersome than pain, frequency, and rectal bleeding.[15] Emotional issues facing patients with UC may involve depression, fear, and worry.[16] The potential for developing other physical conditions—including colorectal cancer—is another source of emotional distress.[14] In fact, one study involving 460 patients with UC found that their greatest concerns were the potential risk of developing colon cancer and a need for surgery. Unfortunately, many patients with UC report that it is a mentally exhausting condition.[17] Others feel that UC has taken control of their lives.

4 The goals of UC disease management and main disease management options.

There are several goals of UC disease management.[18] These include achieving remission (eg, few or no symptoms), managing potential complications associated with UC, and improving quality of life.[6] Several medications are prescribed for UC.[19] These medications have anti-inflammatory properties. Such medications work by reducing inflammation in the colon.[13] UC medications may be taken orally, by suppository or enema, or by injection or infusion.[19,20] Other multidisciplinary care options may be considered to help lessen the potential burdens of UC, such as herbal therapy, yoga (for stress management), and acupuncture.[21,22] Medications and/or alternative therapies may be used to help manage your UC.[19,23] You should work with your HCP to identify your personalized disease management goals.

A Tip From the UC Iceberg

Sometimes, your UC symptoms may decrease or be absent. When there are no symptoms, UC is considered in *remission*. However, symptoms may reappear with relapses known as *flares*.[13] Be sure to keep your HCP informed about your symptoms.

Need-to-Know Information About UC, *continued*

5 UC and the risk of developing other medical conditions.

Taking your UC medicines exactly as prescribed by your HCP is important.[24] UC is a type of inflammatory bowel disease, but the condition may lead to medical complications that affect more than your digestive system.[8,25] For example, UC may affect the joints, skin and eyes, lungs, heart, and vascular system. Many factors can cause other medical conditions to arise.[25] These include your immune system, inflammation in your body outside the digestive system, or genetics. Adhering to your disease management program may potentially help manage comorbidities—conditions associated with UC—such as colorectal cancer.[26-28]

6 The importance of two-way communication between you and your HCP.

For many people, talking about their UC is difficult.[12] Symptoms, such as bowel movement urgency, may pose personal and bothersome challenges.[15] But keeping the lines of communication open with your HCP is important. When you speak openly and honestly with your HCP, you can help pinpoint the disease management areas of greatest concern. However, there may be obstacles to physician-patient communication. Research involving 775 patients with UC showed that 21% are open about their symptoms and suffering in discussions with their HCP—and only when actively questioned about their condition; another 10% of patients admitted to secretly withholding information about their UC issues. Unfortunately, poor communication between HCPs and patients may lead to misunderstandings and cause HCPs to overlook patient expectations with their disease management goals.[12]

A Tip From the UC Iceberg

Effective two-way communication between you and your HCP can help you focus on important disease management issues and, in turn, help you best cope with your condition.

Now that you know the key facts about UC, check your understanding by answering the following questions:

1. Which parts of the body are mainly affected by UC? (Circle your answer)
- **A.** Throat, nose, and mouth
- **B.** Bladder, urinary tract, and kidneys
- **C.** Colon and rectum[4,5]

Say it in your own words... What are some of the main signs and symptoms of UC?

2. Why might your HCP ask you to complete a questionnaire? (Circle your answer)
- **A.** To have you provide information about your UC symptoms[11]
- **B.** To avoid the need for laboratory tests
- **C.** To measure how long you have had UC

Say it in your own words... Why is it important to monitor your own UC symptoms?

3. Generally, how does UC negatively affect patients? (Circle your answer)
- **A.** It hinders intellectual development
- **B.** It may affect your physical and emotional well-being[12]
- **C.** It leads to hair loss

Say it in your own words... Name the potential quality-of-life challenges posed by UC.

4. What are the main goals of UC disease management? (Circle your answer)
- **A.** Increase your visits to your HCP; decrease the time you spend with your family
- **B.** Achieve remission (eg, absence of UC symptoms); attain mucosal healing (eg, lessening the inflammation in your body); restore quality of life[3,6]
- **C.** Increase the amount of medication you take; decrease the amount of food you eat

Say it in your own words... Describe how the different types of UC medication work.

5. What is a comorbidity? (Circle your answer)
- **A.** Another person who has UC
- **B.** A disease management option for UC
- **C.** A medical condition that exists at the same time as another[26]

Say it in your own words... Why is it important to take your UC medication exactly as prescribed?

6. What is the main goal of improving communication with your HCP? (Circle your answer)
- **A.** To spend less time in the doctor's office
- **B.** To focus on the disease or treatment-related issues of greatest importance to your disease management program[12]
- **C.** To eliminate the need to see other healthcare specialists for your UC

Say it in your own words... Explain the benefit of effective two-way communication between you and your HCP.

A Tip From the UC Iceberg

Your gastroenterologist and other HCPs are ready to help you address the quality-of-life challenges associated with UC. You should share your concerns with your HCPs. They can help you cope with disease-related obstacles that may be interfering with your daily activities.

Completing the Clinical Picture of UC Disease Activity

Common UC Signs and Symptoms[5,16,29,30]

- Urgency to defecate
- Blood in stool
- Diarrhea
- Abdominal pain
- Weight loss/avoidance of certain foods
- Psychosocial issues

Signs of Underlying Inflammation[8]

- Blood in stool
- Endoscopy findings (eg, ulcers) in the colon and rectum
- Tissue damage

UC is a chronic inflammatory disease that can progressively worsen over time[4,5,31]

Although effective disease management for UC can help alleviate UC symptoms, the underlying inflammatory process can continue, possibly leading to flares, loss of colon function, and increased risk for colon cancer.[13,31] This is why it is important to continue to follow the disease management plan prescribed by your healthcare provider (HCP).[24] Patients should always consult their gastroenterologist or other HCP before stopping UC treatment.

Preparing for Your Next Appointment With Your HCP

Your next appointment:

HCP: _____

Date: _____ Appointment Time: _____

Location (HCP office/telehealth visit): _____

List the questions, issues, or concerns you would like to discuss with your HCP (gastroenterologist, nurse practitioner, physician assistant, or pharmacist) during your next visit:

_____

_____

Answer key to multiple-choice questions:
[1. C] [2. A] [3. B] [4. B] [5. C] [6. B]

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