

**Understanding**

**Ulcerative Colitis (UC)**

**Disease Activity...**

**ABOVE and**

**BELOW the Surface**

## **A Planning Guide to Help You Optimize Your Treatment for UC**

The information contained in this handbook 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 in this handbook, please discuss them with your healthcare provider.

This has been produced as a patient education resource by Pfizer Inc.

# 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.<sup>1</sup> 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.**<sup>2,3</sup>

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, treatment 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 treatment. Empowerment means gaining control over your medical well-being and acting on the medical issues that *you* define as important.

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

HCP=healthcare professional.

# What You Will Learn

## Important things you may not know—but should know—about UC and your treatment

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 medical 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 treatment** and the main treatment options
- 5. Understand the risks of developing other medical conditions**, 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 treatment 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 you when discussing your medical condition and treatment plan with your healthcare professionals (HCPs)

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

2

Various clinical tools and techniques are used to diagnose UC.

HCPs use various techniques to diagnose UC.<sup>7</sup> Diagnosis typically begins with an understanding of your symptoms and confirmation of inflammation in the lining of your colon. Your gastroenterologist will check for signs of diseased tissue or underlying inflammation using an endoscope—a flexible, lighted tool. Lab tests may also be used to ensure that other causes of inflammation and diarrhea are ruled out.<sup>6</sup> Your HCP will monitor your UC symptoms regularly to note any changes over time. You can assist in this process.<sup>8</sup> You may be asked to complete a questionnaire that is derived from a research instrument used in clinical studies.<sup>9</sup> The questionnaire asks you to provide information about the frequency of your bowel movements and the level of rectal bleeding. This information is then reviewed by your HCP to determine how your UC symptoms vary over time.

HCP=healthcare professional.

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. Together, these issues can affect quality of life. Physical challenges include abdominal pain, bowel-related problems, such as urgency (ie, the sudden or uncontrollable urge to go to the bathroom), and the potential for hospitalization. Urgency is particularly problematic with patients in one study ranking urgency as more bothersome than pain, frequency, and rectal bleeding.<sup>10</sup> Emotional issues facing patients with UC may involve depression, fear, and worry.<sup>11</sup> The potential for developing other physical conditions—including colorectal cancer—is another source of emotional distress. In fact, one study involving 451 patients with UC found that 84% of them worried more about the long-term effects of the disease in comparison to patients with other types of chronic conditions.<sup>12</sup> Unfortunately, some patients with UC report that not feeling well has become the norm. Others feel that UC has taken control of their lives.

Now that you know the key facts about UC, check your understanding by answering the following multiple-choice 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

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

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 can UC negatively affect patients? (Circle your answer)
- A. It hinders intellectual development

B. It may affect your physical and emotional well-being

C. It leads to hair loss

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

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.





4 The goals of UC treatment and main treatment options

There are several goals of UC treatment. These include achieving remission (eg, few or no symptoms), managing potential complications associated with UC, and improving quality of life.<sup>6</sup> Several medications are prescribed for UC. These medications have anti-inflammatory properties. Such medications work by reducing inflammation in the colon.<sup>13</sup> UC medications may be taken orally, by suppository or enema, or by injection or infusion.<sup>13,14</sup> 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.<sup>15,16</sup> Your HCP may specify medications with or without alternative therapies.

5 UC and the risk of developing other medical conditions

Taking your UC medicines exactly as prescribed by your HCP is important.<sup>17</sup> UC is a type of inflammatory bowel disease, but the condition may lead to medical complications that affect more than your digestive system. For example, UC may affect the joints, skin and eyes, lungs, heart, and vascular system.<sup>18,19</sup> Many factors can cause other medical conditions to arise. These include your immune system, inflammation in your body outside the digestive system, or genetics.<sup>19</sup> Adhering to your treatment program may potentially help manage comorbidities associated with UC, such as colorectal cancer.<sup>20</sup>



**A Tip From the UC Iceberg**  
*Effective two-way communication between you and your HCP can help you focus on important treatment issues and, in turn, help you best cope with your condition.*

HCP=healthcare professional.

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

For many people, talking about their UC is difficult.<sup>21</sup> Symptoms, such as bowel movement urgency, may pose personal and bothersome challenges.<sup>10</sup> 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 treatment 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.<sup>10</sup> Unfortunately, poor communication between HCPs and patients may lead to misunderstandings and cause HCPs to overlook patient expectations with their treatment goals.<sup>21</sup>

**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. Be sure to keep your HCP informed about your symptoms.<sup>22</sup>*



- 4. What are the main goals of UC treatment?** (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
  - 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 treatment option for UC
  - C. A medical condition associated with UC

**Say it in your own words...**Why is it important to take your UC medicine 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 treatment program
  - 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.



# Completing the Clinical Picture of UC Disease Activity

## Common UC Signs and Symptoms<sup>5,11,23,24</sup>

Urgency to defecate

Blood in stool

Diarrhea

Abdominal pain

Weight loss/avoidance  
of certain foods

Psychosocial issues

UC is a chronic inflammatory disease that can progressively worsen over time<sup>17,25-27</sup>

Although effective treatment 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.

## Manifestations of Underlying Inflammation

Blood and fecal biomarkers<sup>18</sup>

Endoscopic activity<sup>18</sup>

Histologic markers  
of inflammation<sup>18</sup>

This is why it is important to continue to follow the treatment plan prescribed by your healthcare professional (HCP).

Patients should always consult their gastroenterologist or other HCP before stopping UC treatment.

## Preparing for Your Next Appointment With Your Healthcare Professional

### Your next appointment:

HCP: \_\_\_\_\_

Date: \_\_\_\_\_ Arrival Time: \_\_\_\_\_

Location: \_\_\_\_\_

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:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

### Answer key to multiple-choice questions:

[1. C] [2. A] [3. B] [4. B] [5. C] [6. B] [7. A] [8. B] [9. C] [10. B]

**References:** 1. Goodman M. The iceberg model. [http://www.ascd.org/ASCD/pdf/journals/ed\\_lead/el200910\\_kohm\\_iceberg.pdf](http://www.ascd.org/ASCD/pdf/journals/ed_lead/el200910_kohm_iceberg.pdf). Accessed January 11, 2018. 2. Rosenberg L, Lawlor GO, Zenlea T, et al. Predictors of endoscopic inflammation in patients with ulcerative colitis in clinical remission. *Inflamm Bowel Dis*. 2013;19(4):779-784. 3. Boal Carvalho P, Dias de Castro F, Rosa B, Moreira MJ, Cotter J. Mucosal healing in ulcerative colitis—when zero is better. *J Crohns Colitis*. 2016;10(1):20-25. 4. Ungaro R, Mehandru S, Allen PB, Peyrin-Biroulet L, Colombel JF. Ulcerative colitis. *Lancet*. 2017;389(10080):1756-1770. 5. Danese S, Fioricchi C. Ulcerative colitis. *N Engl J Med*. 2011;365(18):1713-1725. 6. Feuerstein JD, Cheifetz AS. Ulcerative colitis: epidemiology, diagnosis, and management. *Mayo Clin Proc*. 2014;89(11):1553-1563. 7. Bernstein CN, Eliakim A, Fedail S, et al. World Gastroenterology Organisation Global Guidelines Inflammatory Bowel Disease: update August 2015. *J Clin Gastroenterol*. 2016;50(10):803-818. 8. Bewtra M, Brensinger CM, Tomov VT, et al. An optimized patient-reported ulcerative colitis disease activity measure derived from the Mayo score and the simple clinical colitis activity index. *Inflamm Bowel Dis*. 2014;20(6):1070-1078. 9. Lewis JD, Chuai S, Nessel L, Lichtenstein GR, Aberra FN, Ellenberg JH. Use of the noninvasive components of the Mayo score to assess clinical response in ulcerative colitis. *Inflamm Bowel Dis*. 2008;14(12):1660-1666. 10. Schreiber S, Panes J, Louis E, Holley D, Buch M, Paridaens K. Perception gaps between patients with ulcerative colitis and healthcare professionals: an online survey. *BMC Gastroenterol*. 2012;12:108. 11. Devlen J, Beusterien K, Yen L, Ahmed A, Cheifetz AS, Moss AC. The burden of inflammatory bowel disease: a patient-reported qualitative analysis and development of a conceptual model. *Inflamm Bowel Dis*. 2014;20(3):545-552. 12. Rubin DT, Dubinsky MC, Panaccione R, et al. The impact of ulcerative colitis on patients' lives compared to other chronic diseases: a patient survey. *Dig Dis Sci*. 2010;55(4):1044-1052. 13. Mayo Clinic. Ulcerative colitis. Diagnosis & treatment. <https://www.mayoclinic.org/diseases-conditions/ulcerative-colitis/diagnosis-treatment/drc-20353331>. Accessed January 11, 2018. 14. Allen PB, Lindsay H, Tham TC. How do patients with inflammatory bowel disease want their biological therapy administered? *BMC Gastroenterol*. 2010;10:1. 15. Langhorst J, Wulfert H, Lauche R, et al. Systematic review of complementary and alternative medicine treatments in inflammatory bowel diseases. *J Crohns Colitis*. 2015;9(1):86-106. 16. Korzenik J, Koch AK, Langhorst J. Complementary and integrative gastroenterology. *Med Clin North Am*. 2017;101(5):943-954. 17. Steinhart AH, Fernandes A. Clinical practice guidelines for the medical management of nonhospitalized ulcerative colitis: the patient perspective. *Can J Gastroenterol Hepatol*. 2015;29(6):294-296. 18. Mohammed N, Subramanian V. Clinical relevance of endoscopic assessment of inflammation in ulcerative colitis: can endoscopic evaluation predict outcomes? *World J Gastroenterol*. 2016;22(42):9324-9332. 19. Ott C, Scholmerich J. Extraintestinal manifestations and complications in IBD. *Nat Rev Gastroenterol Hepatol*. 2013;10(10):585-595. 20. Higgins PD, Rubin DT, Kaulback K, Schoenfeld PS, Kane SV. Systematic review: impact of non-adherence to 5-aminosalicylic acid products on the frequency and cost of ulcerative colitis flares. *Aliment Pharmacol Ther*. 2009;29(3):247-257. 21. Lönnfors S, Vermeire S, Greco M, Hommes D, Bell C, Avedano L. IBD and health-related quality of life—discovering the true impact. *J Crohns Colitis*. 2014;8(10):1281-1286. 22. Silverberg MS, Satsangi J, Ahmad T, et al. Toward an integrated clinical, molecular and serological classification of inflammatory bowel disease: report of a Working Party of the 2005 Montreal World Congress of Gastroenterology. *Can J Gastroenterol*. 2005;19(suppl A):S4-S6A. 23. Mayo Clinic. Ulcerative colitis. Symptoms & causes. <https://www.mayoclinic.org/diseases-conditions/ulcerative-colitis/symptoms-causes/syc-20353326>. Accessed January 11, 2018. 24. Casanova MJ, Chaparro M, Molina B, et al. Prevalence of malnutrition and nutritional characteristics of patients with inflammatory bowel disease. *J Crohns Colitis*. 2017;11(12):1430-1439. 25. Magro F, Rodrigues A, Vieira AI, et al. Review of the disease course among adult ulcerative colitis population-based longitudinal cohorts. *Inflamm Bowel Dis*. 2012;365(18):573-583. 26. Gupta RB, Harpaz N, Itzkowitz S, et al. Histologic inflammation is a risk factor for progression to colorectal neoplasia in ulcerative colitis: a cohort study. *Gastroenterology*. 2007;133(4):1099-1105, quiz 1340-1. 27. Solberg IC, Lygren I, Jahnsen J, et al. Clinical course during the first 10 years of ulcerative colitis: results from a population-based inception cohort (IBSEN Study). *Scand J Gastroenterol*. 2009;44(4):431-440.

