

Welcome to Week 4 of the Crohn's & Colitis Foundation of America (CCFA) Online Support Group.

Last week's material focused on diet and nutrition and how they relate to inflammatory bowel diseases. This week we will focus on living well with IBD and the next steps you can take to best manage your disease. We will cover coping techniques, including how to maintain a positive attitude and what physical activity may be beneficial; tips for handling flare-ups; how to treat signs of depression or anxiety; ways to find support; and a look at the latest research that is being done to find new treatments and cures for IBD.

Let's first discuss the importance of overall well-being.

An excellent quality of life is one of the main goals of medical treatment for people with either Crohn's disease or ulcerative colitis. By following your doctor's advice and taking your prescribed medications, you may be able to go into and prolong remission. It is also important to continue general health maintenance for your overall well-being. Remember to speak with your primary care provider about other important issues, including vaccinations, oral health, colonoscopy screening, mammogram screening, and periodic blood testing. Remember also to eat well. Proper nutrition

can lead to feeling better and having more strength, so discuss your diet with your doctor and a nutritionist.

HEALTH MAINTENANCE CHECKLIST

- Vaccinations, including flu vaccine
- Routine dental care for oral health
- Blood testing
- Tobacco cessation
- Osteoporosis monitoring
- Blood pressure screening
- Eye exam
- Age appropriate cancer screenings

Accepting a diagnosis

Learning that you have Crohn's disease or ulcerative colitis may be difficult and stressful. As time goes on, this will not always occupy the top spot in your mind. In the meantime, try not to hide your condition from people in your life. Discuss it with them and help them understand what kind of support you need. It is also important to know that life stress can have a negative impact on the course of your IBD so make sure that you

are getting proper social and emotional support during periods of increased life hassles or major stressful life events.



How did you react when you learned you had IBD? Can you identify any times of stress in your life that you can monitor to make sure you are taking extra good care of yourself during those periods?

What are the best ways to cope with IBD?

- 1 Seek effective treatment.** As we reviewed in Week 2, for most people, IBD can be managed very well by means of various treatment options. As active partners in the treatment of your illness, you and your doctor should discuss, in detail, all of the medical and surgical options available to you and determine which treatment plan is best for your particular condition. A good patient-physician relationship makes it possible to deal effectively with almost any complication. And if you have any misgivings about a provider or facility, seek a second opinion and keep looking.
- 2 Maintain a positive outlook.** That's the basic—and best—prescription! An optimistic attitude about having a chronic disease has been associated with improved coping and outcomes. While Crohn's disease and ulcerative colitis are serious chronic diseases, they are not fatal illnesses. There's no doubt that living with this illness can be challenging at times—you have to take medication and, occasionally, make other adjustments. But it's important to keep in mind that most people with IBD are able to lead rich and productive lives. For instance, taking maintenance medication can significantly decrease disease flare-ups and, in between flares, most people are free of symptoms and feel well.
- 3 Try to go about your daily life as normally as possible,** pursuing activities as you did before your diagnosis. There is no reason for you to sit out on things that you have always enjoyed or have dreamed of doing one day.

What about exercise?

Physical activity is important to people with IBD, since it helps keep a person in good shape. Discuss any program that you may want to undertake with your doctor. Be sure that it is not too difficult, since it may tire you out. But generally any activity practiced to a moderate degree will be a good way to deal with stress. For instance, yoga is an excellent way for people with IBD to exercise and also learn relaxation techniques. For those who are at a risk of osteoporosis, physical activity is a must-have since it helps to keep bones strong.

If having IBD limits the amount and intensity of exercise you can take on, keep in mind that even low-intensity activities, like taking a 30-minute walk three times a week, can produce results. If your symptoms make mobility difficult, find ways to be active at home.



Tips for handling uncertainties of flare-ups or accidents

Attacks of diarrhea or abdominal pain may make people fearful of being in public places. But that isn't necessary. All it takes is some practical, advanced planning. Here are a few tips:

- Find out where the restrooms are in restaurants, shopping areas, theaters, and on public transportation.
- Carry extra underclothing, toilet paper, or moist wipes when traveling as needed.
- When venturing farther away or for longer periods of time, speak with your doctor first to address any additional considerations.
- Travel plans should include a long-term supply of your medication, its generic name in case you run out or lose it, and the names of doctors in the area you will be visiting.

- Find ways to keep anxiety levels low, as this can increase bowel frequency, even when you are not experiencing an active IBD flare. Some examples include identifying what triggers are associated with anxiety so you can avoid them or using relaxation techniques, such as imagining a positive or calming place or diaphragmatic breathing, to reduce its effect.
- Get an "I Can't Wait" card from CCFA, which provides help with restroom access.

Learning more about how your body reacts to certain food groups, if any, also may be a big help. You might want to try an elimination diet, in which you stop eating certain foods, and then gradually reintroduce them to see how your body reacts to each one. Avoiding foods that your body cannot tolerate may help keep you well.



How do you manage flare-ups in public? Do you have any other tips to share with others?

The role of emotional factors on IBD

Although the disease occasionally recurs after a person has been experiencing emotional problems, there is no proof that stress causes Crohn's disease or ulcerative colitis. It is much more likely that the emotional distress that people sometimes feel is a reaction to the symptoms of the disease itself. With active inflammation, some of the symptoms can look like depressive symptoms such as fatigue, sleep disturbance, decreased appetite, decreased concentration and loss of motivation. These symptoms, if they persist, can lead to more imposing symptoms of depression with impairment of functioning and may require extra attention. This is especially important as untreated depression has been shown to lead to increased risk of relapse of IBD.

Individuals with Crohn's disease or ulcerative colitis should receive understanding and emotional support from their families, friends and healthcare team. Because more severe or sustained depression can be associated with chronic illness, a doctor may recommend an

anti-depression or anti-anxiety medication and/or a referral to a mental health professional.

Although formal psychotherapy usually isn't necessary, some people are helped considerably by speaking with a therapist who is knowledgeable about IBD or about chronic illness in general. Learning coping skills, disease self-management skills, self-hypnosis, and/or addressing depression or anxiety through psychotherapy can be an important adjunct to medical treatment. These therapy techniques as well as certain non-opiate medications can also be helpful in coping with persistent abdominal pain. In addition, CCFA offers local in-person support groups to assist patients and their families in coping with ulcerative colitis and Crohn's disease.



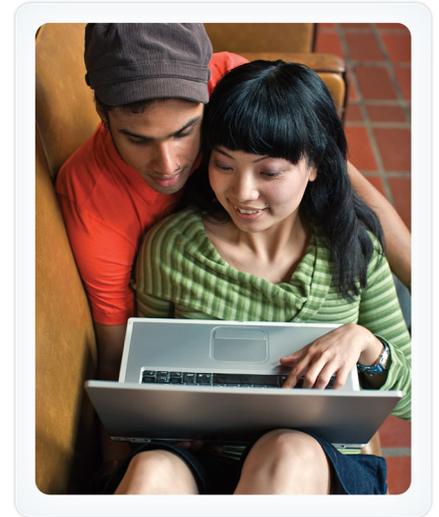
Who do you count on for support? Do you sometimes become depressed about your condition? If so, have you mentioned this to your doctor?

Where can you find support?

As we hope you've experienced from your time in our Online Support Group, support groups can be especially helpful. The best help, advice, and understanding will come from interacting with people who know what you are going through from personal experience. Peers with IBD also can be a great source of information. You can also continue connecting with others on CCFA's Online Community to continue to get the support you need through participation in discussion boards, personal stories, and much more.

Below are a few other options for finding support:

- 1 Local chapters:** Local programs are provided through more than 40 staffed and volunteer CCFA chapters and affiliates nationwide. To find programs, support groups, and events in your area, visit our Web site at www.ccfa.org/chapters, or call CCFA's Information Resource Center at 888.MY.GUT.PAIN (888-694-8872).
- 2 Power of 2** is a peer-to-peer support program for individuals seeking to talk by phone, email, or video chat to other patients or caregivers with IBD. To learn more, contact your local CCFA chapter.
- 3 Information Resource Center (IRC)** Information Specialists at CCFA's Information Resource Center offer help through phone, e-mail, and online chat. The IRC is here to help you understand IBD from diagnosis to treatment and living with IBD. Call us at 888.MY.GUT.PAIN (888-694-8872) Monday through Friday, 9 a.m. to 5 p.m. Eastern Time, or email us at info@ccfa.org.
- 4 Referrals:** Your healthcare team can provide referral information for a mental health or pain specialist.



Your healthcare team can make a difference.

By learning all you can and working as a team with your family, friends, and healthcare team, you, too, can take charge of your illness and enjoy all that life has to offer.

Remember that there is no "one size fits all" treatment for everyone with Crohn's disease or ulcerative colitis. The approach must be tailored to the individual because each person's disease is different. Medical treatment can bring about remission, which can last for months to years, but the disease will flare up at times from the reappearance of inflammation or from a particular trigger.

It is important to stay in communication with your healthcare team. Keep a journal to write down questions for your doctor to ask during your visits. If you use any complementary and alternative medicines (CAM), be sure to discuss these with your healthcare team as well. Finally, consider bringing a family member or friend to the doctor with you! Then they can ask questions about your condition that you might not have thought about.

What about the future of IBD and current research efforts?

Investigators all over the world are devoted to research for patients with IBD. For instance, with many experimental treatments for IBD in clinical trials, experts predict that a wave of new therapies for Crohn's disease and ulcerative colitis are on the way. With an ever-increasing number of clinical trials of potential new IBD therapies, there is an even greater need for patient participation to see if these experimental therapies work. To learn more about what participation entails or locate clinical trials in your area, visit the CCFA web site at <http://www.cdfa.org/research/participate-in-research/find-studies-and-clinical-trials/>.

CCFA has also launched an ambitious program called CCFA Partners, which is designed to improve the quality of life for patients with IBD through research and education. Patients can enroll in this online registry to further our understanding of issues facing IBD patients, how they are functioning, what they eat, and how they receive treatment in different areas of the country. To learn more or register, visit <http://www.ccfapartners.org>.



CCFA-sponsored research has led to huge strides in the fields of immunology (the study of the body's immune defense system); microbiology (the study of microscopic organisms with the power to cause disease); and genetics. Through CCFA's continuing research efforts, much more will be learned and eventually cures will be found.

We hope this week's material on the medical management of IBD has been informative. In preparation for this week's live online support group session, consider the following:

- What did you learn from this material?
- What do you still want to learn?
- What coping strategies have you tried or do you plan to try?
- What questions do you have for your doctor?

We are happy that you are participating in our online support group and hope you have found the experience beneficial.

To join this week's support group, visit:
<http://ccfacommunity.org/chatseries.aspx>

Additional Resources

CCFA offers many resources and services to provide you with accurate, current, disease-related information. Check out the resources below for more information on living well with IBD.

CCFA's Information Resource Center (IRC) is a support line for patients and caregivers living with IBD. We can help guide you in the right direction—whether you need to locate a doctor, find financial resources, or have questions about your disease. Specialists are available Monday-Friday, 9 AM to 5 PM Eastern time. Call 1-888-MYGUTPAIN (1-888-694-8872) or email info@ccfa.org.

CCFA's website (www.cdfa.org)

is a great place to continue your research on IBD and connect with your local chapter to learn more about programs in your area. Additionally, you can:

- View free educational webcasts on a variety of topics at www.cdfa.org/resources/webcasts.html.
- Visit www.IBDetermined.org to learn more about quality of life through videos, interactive quizzes, and more!
- Learn more about emotional wellness at <http://www.cdfa.org/resources/emotional-wellness-and-ibd.html>