Inside this Newly Diagnosed Kit, get the facts that will help you manage your disease. Learn the top things you need to know, get advice from experts, and find out where to go from here.
About the Crohn’s & Colitis Foundation of America

The Crohn’s & Colitis Foundation of America (CCFA) is the largest voluntary nonprofit health organization dedicated to finding cures for inflammatory bowel diseases (IBD). CCFA’s mission is to cure Crohn’s disease and ulcerative colitis, and to improve the quality of life of children and adults who suffer from these diseases. The Foundation works to fulfill its mission by funding research; providing educational resources for patients and their families, medical professionals, and the public; and furnishing supportive services for those afflicted with IBD.

This IBD Newly Diagnosed Kit was reviewed by CCFA staff and members of CCFA’s National Scientific Advisory Committee for scientific and clinical accuracy.

For more information on the Crohn’s & Colitis Foundation of America, visit www.ccfa.org, call 888-694-8872, like us on Facebook (www.facebook.com/ccfafb), or follow us on Twitter (@CCFA).
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I’ve just been diagnosed. What’s next?

Introduction

Facing a lifelong disease can be a lot to take in. Perhaps your mind is filled with questions and concerns. It is entirely normal to have these feelings, but there is help. This Newly Diagnosed Kit will help you and your family understand what is going on.

Let’s start with the basics: Crohn’s disease (CD) and ulcerative colitis (UC) are chronic (lifelong) inflammatory diseases that affect the digestive system. Together, they are known as inflammatory bowel diseases (IBD). Crohn’s disease can affect any part of the gastrointestinal (GI) tract from the mouth to anus, while ulcerative colitis is associated with inflammation in the large intestine. About 10%-15% of people with inflammation of the colon have indeterminate colitis, which means it is difficult to determine whether they have CD or UC. IBD is often confused with irritable bowel syndrome (IBS), but they are different conditions.

There is much to learn in the orientation process, and getting started on that journey is what this kit is all about. Here you will find an introduction to your disease, treatments, tests to expect, and everyday living strategies. By the end of this disease orientation, you should be more knowledgeable and better prepared to move forward. You’ll also have the tools to find additional information and gain some ideas on how to start managing your disease.

Here are the critical steps you’ll want to take as you navigate this process:

1. Learn About IBD
   Educate yourself about the disease and how to treat it. Use this kit as a starting point and take advantage of the additional resources listed inside.

2. Develop and Implement a Disease Management Plan
   A variety of strategies to manage your disease are outlined in this kit. The main steps are assembling your healthcare team, gathering information and advice, and building a plan to make it all work together and keep you as healthy as possible.

3. Build a Support Team of Family and Friends
   This may be a combination of people you already know and those you will meet throughout your journey. The people around you can offer a great deal of help along the way.
4. Find Your Personal Balance
This is a combination of your medical approach, the support you get from others, the coping skills you develop, and what you learn about yourself. It’s the recipe for what you truly need to stay happy and healthy.

Finally, there is a lot of information available to you here and in the other materials we will mention. Be sure to pace yourself. You may be eager to learn more, but don’t forget to take care of yourself in the process.
Learning as much as possible about your disease and educating your family and friends will help you manage your health. The more you are aware of what to expect, the more prepared you can be to meet any challenges along the way.
How Did I Get This?

We are not exactly certain what causes Crohn’s disease (CD) and ulcerative colitis (UC), or how to predict or prevent these diseases. Scientists suspect that a combination of four factors leads to IBD: a genetic component, an environmental trigger, the balance of intestinal bacteria, and an inappropriate reaction from the immune system.

It is not yet completely understood how or why certain genes or changes in genes seem to be associated with CD or UC, but it is a major focus of current research. The disease likely starts when the body is exposed to an environmental trigger (possibly an infection). Your immune system usually plays a protective role in fighting infections, but in IBD, it reacts inappropriately to your intestinal bacteria. This leads to continued inflammation—an immune response to tissue injury that causes redness, swelling, and pain.

You may hear that IBD is related to stress or diet. It is important to note that while stress may play a role in the symptoms, it does not cause the disease. Similarly, while maintaining a proper diet and ensuring good nutrition are important to managing IBD, your disease was not caused by something you ate.

Approximately 1.4 million Americans are living with IBD, split evenly between CD and UC. Men and women are equally affected. Although IBD can occur at any age, most people are diagnosed in their teens or early twenties, and 5% of patients are children. Studies have shown that 5%-20% of people with IBD come from families where more than one person has the disease. IBD tends to be more common in developed countries, particularly the United States, Canada, and in Europe, but it is increasing worldwide.

What Are Common Symptoms?

The symptoms of IBD vary from person to person, and may change over time. The most common symptoms for both CD and UC are:

- Frequent and/or urgent bowel movements
- Diarrhea
- Bloody stool
- Abdominal pain and cramping

Although diarrhea is the most common symptom of IBD, other people may experience constipation. People with IBD may also report symptoms such as fatigue, lack of appetite, and weight loss. It is important to keep track of your symptoms and share them with your healthcare provider to determine the appropriate treatment.
What Is A Flare?

A flare is a set of IBD symptoms that occurs after a period of relief (remission). After being diagnosed, people who improve with treatment should watch for warning signs of a flare. Although symptoms do not always mean that inflammation is present, they often suggest that inflammation has returned or is becoming more severe. You will need to follow up with your healthcare provider to determine what is causing the symptoms and if treatment needs to be adjusted or changed. Newly diagnosed patients often ask how to tell the difference between a severe flare and an emergency. If you experience any of the following, you should be evaluated by a doctor immediately:

- Fever (above 100.5 degrees Fahrenheit)
- Severe difficulty eating or drinking, causing symptoms such as nausea, vomiting, or pain
- Abdominal pain that you cannot tolerate or is constant
- Large amounts of diarrhea leading to dehydration, causing symptoms such as dry mouth, extreme thirst, dizziness, or decreased urine production
- Heavy rectal bleeding

These are only a few of the possible emergency conditions. Other severe situations may also require immediate attention.

How Do I Know How Severe My Disease Is?

The severity of your disease depends on several factors, including where the disease is in your body, how much of your digestive tract is affected, the amount of inflammation, and any complications that arise.
Is There A Cure?
While research has led to the development of many effective treatment options, there are currently no cures for IBD. For some people with UC, there are surgical options involving the removal of the large intestine. This essentially cures the disease for those patients. However, inflammation in people with CD often returns after surgery, so CD is not considered curable.

What Is My Life Going To Be Like?
Although CD and UC are considered chronic diseases, many people find that with proper treatment and lifestyle changes, they can live normal lives like they did before experiencing symptoms. Death resulting from CD or UC is extremely rare, and most people with IBD can expect to live long, fulfilling lives. Some people have more difficult challenges than others, however, and that depends on their disease and how responsive they are to treatment. Many people actually find that their lives improve, because with diagnosis and treatment they are finally able to address the problems they were experiencing.

Your healthcare provider will likely recommend regular testing and checkups to monitor your disease. Treatment varies and may include a combination of medication, surgery, diet modifications, and lifestyle changes to minimize symptoms and help you feel well.

In addition to the ongoing need for tests and treatment, you may face some challenges with everyday living and social issues. For example, patients who experience frequent bowel movements may need to plan ahead to make sure there will be restrooms nearby. Learning to accommodate that, along with other difficulties of living with chronic disease, will require some adjustments to your lifestyle. You may need to make special arrangements at work or school. You may have to change some of your routines.

There will be times of difficulty and times of relief, but with appropriate medical care and healthy coping skills, you can make the most of your situation. Living with a chronic disease is a path in life, not an event. Your job now is to learn about the disease and to develop a way of life that works for you.

KEY TAKEAWAYS

IBD are chronic diseases that involve a genetic predisposition, an environmental trigger, an alteration in the composition of intestinal bacteria, and an inappropriate reaction from the immune system.

With proper treatment and lifestyle changes, you can live a long, fulfilling life.
Though it can be overwhelming at first, learning about treatment options is an important step in being a proactive patient. Every patient is different, and keeping yourself informed about treatments and how they affect you will help you and your doctor decide on the best approach.
The overall goals of treatment are to:

1. **Achieve remission** (elimination or significant reduction of symptoms)
2. Control inflammation
3. **Prevent symptoms from returning** (maintain remission)
4. Prevent and manage complications
5. Maximize quality of life

The primary treatments for IBD are medication and surgery. Nutritional methods and alternative therapies can also play a role in managing your disease. Each case of IBD is different, so there is not a single solution. Each person’s treatment strategy will be unique.

All treatments have potential side effects and risks. You will need to weigh those risks against the benefits of each treatment. However, it is important to realize that the most risky situation is uncontrolled inflammation. The risks associated with nearly all treatments are quite small in comparison to the dangers of living with untreated disease.
Medications
The table below is a summary of the most common medications for IBD. Taking your medications as prescribed is very important. There are many tools, such as pill boxes and smartphone apps, to help remind you to take them. Keep in mind that new therapies may have been approved by the Food and Drug Administration since this document went to print. Be sure to visit www.ccfa.org for the latest information on available treatment options and clinical trials.

**Antibiotics**

**OVERVIEW**
Researchers believe that antibiotics help control symptoms of IBD by reducing bacteria in the intestine and by indirectly reducing activation of the immune system. Antibiotics are most commonly used in the treatment of CD. They are also used in patients with complications of CD such as infection in the abdomen. Antibiotics are generally not considered useful for UC.

**EXAMPLES**
- Metronidazole (Flagyl®)
- Ciprofloxacin (Cipro®)

**SIDE EFFECTS**
Side effects of antibiotics vary, and can include nausea and headaches. Talk with your doctor if you experience increased severity of symptoms while on antibiotics.

**Aminosalicylates (5-ASAs)**

**OVERVIEW**
These medications are used primarily to treat UC, both to reduce symptoms and to maintain remission. They work by decreasing the inflammation in the lining of the colon. The choice of aminosalicylate is often determined by the location of the disease. Some people take a combination of enemas or suppositories and pills.

**EXAMPLES**
- Mesalamine (Apriso®, Asacol HD®, Canasa®, Delzicol™, Lialda®, Pentasa®, Rowasa®)
- Sulfasalazine (Azulfidine®)
- Olsalazine (Dipentum®)
- Balsalazide (Colazal®, Giazo®)

**SIDE EFFECTS**
Since aminosalicylates have few side effects, the dosage can be increased when necessary. Headache, heartburn, and nausea can occur. Some people experience increased severity of colitis symptoms, but this is uncommon.

**Corticosteroids**

**OVERVIEW**
Corticosteroids have powerful anti-inflammatory properties. Steroids work by suppressing the immune system throughout the body and are generally used as a short-term solution to induce remission.

The goal is to quickly reduce inflammation so that another medication can then be used to control the disease over the long term.

**EXAMPLES**
- Prednisone
- Budesonide (Entocort®, Uceris®)
- Hydrocortisone (Cortenema®, Cortifoam®)

**SIDE EFFECTS**
Steroids increase the risk of certain infections as well as skin, eye, bone, and muscle disorders, weight gain, and diabetes.

The table below is a summary of the most common medications for IBD. Taking your medications as prescribed is very important. There are many tools, such as pill boxes and smartphone apps, to help remind you to take them. Keep in mind that new therapies may have been approved by the Food and Drug Administration since this document went to print. Be sure to visit www.ccfa.org for the latest information on available treatment options and clinical trials.
Immunomodulators

OVERVIEW
Immunomodulators suppress the immune system, and can be used to replace steroids, or to achieve or maintain remission on their own. Immunomodulators can take several months to start working. They are commonly used along with other medications, at least at the beginning of treatment.

EXAMPLES
• Azathioprine (Imuran®, Azasan®)
• 6-mercaptopurine (6-MP) (Purinethol®)
• Methotrexate (MTX) (Rheumatrex®, Mexate®)

SIDE EFFECTS
While immunomodulators have a relatively low risk of long-term side effects, they require periodic blood tests. Immunomodulators can reduce the ability of your immune system to fight infections. There is also an increased risk of lymphoma (cancer of the lymph nodes) with immunomodulators, but it is considered to be very low.

Biologic Therapies

OVERVIEW
Biologic therapies, or biologics, are one of the newer types of IBD medications. These medications are antibodies grown in a laboratory that stop certain proteins in the body from causing inflammation.

EXAMPLES
Administered by infusion intravenously:
• Infliximab (Remicade®)
• Natalizumab (Tysabri®)

Self-injectable by the patient, loved one, or healthcare provider:
• Adalimumab (Humira®)
• Certolizumab (Cimzia®)
• Golimumab (Simponi®)

SIDE EFFECTS
Biologic therapies can cause allergic reactions in some people, such as an irritation or rash at the injection site. In some cases, these reactions can be severe. Allergic reactions can usually be prevented by giving the patient an antihistamine like Benadryl®, acetaminophen (Tylenol®), and/or steroids before the infusion or injection.

There are several other potential side effects and risks of biologics which your doctor can explain. These include rare but serious infections, lupus-like reactions, and psoriasis. Like immunomodulators, there is an increased risk of lymphoma with biologics, but it is very low.

Other Medications

While the therapies above are aimed at stopping the inflammation of IBD, patients often find that additional medications can be helpful in managing their symptoms. These include anti-diarrheal medications, laxatives, bile acid binders, and pain relievers. Nonsteroidal anti-inflammatory medications (NSAIDs), such as ibuprofen (Advil®, Motrin®) and naproxen (Aleve®), should be avoided because they can irritate the intestines. Discuss all medications with your healthcare team.
Surgery
While medications are typically the preferred initial treatment approach, especially with CD, many people will require surgery at some point. The purpose of surgery is usually to relieve severe symptoms or to repair or remove damaged portions of the intestines. The most common surgical treatments are described below.

**Proctocolectomy**
Removal of the colon and rectum is the most common surgical procedure for UC. This is known as proctocolectomy. It is also performed for some patients with CD.

When an ileostomy is performed as part of the proctocolectomy, the lower end of the small intestine (ileum) is routed through the abdominal wall to an opening in the skin. The opening is known as a stoma. An external ostomy bag is attached to the stoma to collect stool, which is emptied by the patient. In some cases, the ostomy is permanent. Although it may seem like an undesirable result, many people find it a welcome relief from the difficulties of living with IBD.

In most cases of UC, a restorative proctocolectomy can be performed. This typically requires two or more surgeries. In the first operation, the surgeon removes the colon and most of the rectum, then uses the lower portion of the ileum to make a pouch which can perform some of the duties of the removed rectum (primarily to store bowel waste). The ileum is folded over itself and sewn together to create a larger storage area. The patient typically has a temporary ileostomy for several months to divert stool away from the pouch while it heals. In a later surgery, the ileostomy is closed and the pouch restores relatively normal bowel function. This procedure is called an ileal pouch-anal anastomosis (IPAA), also known as a j-pouch.

While the restorative proctocolectomy can lead to permanent relief, some people with a j-pouch experience pouchitis, or inflammation of the pouch. There are several treatments for pouchitis, including antibiotics.

**Resection and strictureplasty**
Many people with CD have inflammation in the small intestine, and sometimes the damaged tissue needs to be removed or repaired. Resection and strictureplasty are two common surgeries performed in these cases.

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**ON THE DVD**
Hear what gastroenterologist Dr. Eugene Yen has to say about IBD treatments, and watch fellow patients talk about their own treatment journeys.
“My doctor wants what’s best for me. We’re always evaluating the situation at hand.”

JONATHON, Living with IBD
Resection is typically performed to remove a portion of the small intestine that has been damaged. This is typically the result of a stricture (narrowing of the intestine), an abscess, or severe inflammation. The affected portion is removed and then the two ends are reattached. Strictureplasty is performed to widen a portion of intestine that was narrowed by a stricture.

While both of these surgeries can relieve symptoms and improve bowel function, there are a number of potential complications. The most common concern is that CD tends to come back near the resection site. Short bowel syndrome, while very rare, can occur in cases where a significant portion of the small intestine has been removed or damaged. This syndrome is associated with several symptoms, and can interfere with proper nutrition. A fact sheet on short bowel syndrome is available at www.ccfa.org.

Fistula and abscess repair
Surgery can be helpful to remove or repair an abscess or fistula. An abscess is an infected fluid collection caused by a leak in the intestine. A fistula is an unnatural channel that forms between portions of intestine and other parts of the gut, the abdominal cavity, vagina, or out through the skin. There are a variety of surgeries to treat these complications.

Nutritional Therapy
When the gastrointestinal tract is severely inflamed or damaged, people with IBD sometimes have trouble eating or digesting foods properly. In these cases, a feeding
tube can be placed through the nose and into the stomach, or directly through the abdominal wall into the stomach. A nutrient-rich liquid formula is fed to the patient through the tube to provide nourishment, usually at night. This is called *enteral nutrition*. Enteral nutrition therapy is not commonly used long term. In the United States, it is used more frequently in children, along with medications, to treat IBD and ensure good nutrition.

**Complementary And Alternative Medicine**

**Probiotics**
Certain bacteria that naturally live in the bowel play a critical role in digestion and gastrointestinal health. Inflammation, illness, antibiotics, and other factors can influence the bacterial mixture in the digestive system. **Probiotics** are sometimes used to change or replace the existing bacteria in an effort to restore a healthy balance. Studies have shown that probiotics can be helpful for IBD, particularly UC and pouchitis. Probiotics occur naturally in some foods like yogurt (only the kind with “active cultures”) and supplements can usually be found at a pharmacy or health food store. Your doctor can provide recommendations on which probiotics may be helpful.

**Vitamins and supplements**
Getting enough of the vitamins and minerals that the body needs is critical to healthy nutrition. While a well-balanced diet often provides the necessary nutrients, some people with IBD may need additional sources due to appetite loss or poor absorption of nutrients from active inflammation or surgery. Vitamins and other supplements can be useful to ensure your body gets what it needs. Talk to your doctor about any nutrients that you need to pay special attention to, and be sure to tell your doctor about any supplements you are taking.

**Additional therapies**
Studies on other complementary and alternative therapies for IBD are limited, but many people with IBD use these approaches to help manage symptoms. Acupuncture, meditation, yoga, massage, and a variety of other remedies have all been reported as helpful.

**KEY TAKEAWAYS**

- There are many treatment options. Work with your healthcare team to decide on the best approach for you.
- Taking your medications as prescribed helps make your treatment more effective. Get a pill organizer, use your cell phone’s alarm as a reminder, or download an app for your smartphone to help remind you to take your medications.
As someone who has been newly diagnosed, you’re probably familiar with a variety of procedures. However, your ongoing treatment will require follow-up tests. You can familiarize yourself with these procedures in this section.
After you are diagnosed, your doctor will work with you on a treatment plan. Once you begin treatment, there may be regular follow-up appointments to monitor your disease, watch for signs of a flare, address any changes in symptoms, and identify possible side effects of treatment. As your symptoms change or improve, the medical team will adjust your treatment program accordingly. Any time you have questions or concerns about your symptoms or treatment, call your medical team.

**Testing And Screening**

**Periodic blood and stool tests**
You may have undergone several lab tests as part of your initial diagnosis. Periodic blood and stool tests may be performed in the future to:
- Check medication levels in the blood
- Test the function of various body systems and how they respond to treatment
- Monitor white blood cells to watch for risk of infections
- Look for any other abnormalities

Routine blood tests include *complete blood count* (CBC) to detect infection and anemia as well as to monitor drug toxicity, and tests for inflammatory markers such as *C-reactive protein* (CRP) and *erythrocyte sedimentation rate* (ESR).

**Endoscopic procedures**
The following procedures are performed to both diagnose IBD and to monitor your disease and potential complications. You may already be familiar with some of them.

*Endoscopy* refers to procedures where a flexible tubular camera system is used to look at the inside of the digestive tract by entering through the mouth or anus. The scope also has other tools that may be used for additional purposes, including collection of tissue samples for biopsies.

*Colonoscopy*: Typically this procedure is performed at a special endoscopy center, or sometimes in an operating room. A gastroenterologist (or in some cases, a surgeon) inserts the scope through the anus and into the colon. The scope has a light which allows the doctor to see the internal walls of the rectum, colon, and lower end of the small intestine (ileum). The procedure is very safe and generally does not cause significant pain or discomfort. The American College of Gastroenterology (ACG) website ([www.gi.org/media/colonoscopy](http://www.gi.org/media/colonoscopy)) offers a video about the effectiveness,
“I bring somebody with me to procedures. Your friends, your loved ones... ask them for help.”

SABRINA, Living with IBD
safety, and importance of a colonoscopy. Featuring the experience of a female patient, the video reviews all clinical information on the procedure.

**Sigmoidoscopy**: A shorter endoscope can be used to inspect the lower portion of the colon in a flexible sigmoidoscopy. This is often referred to as a “flex-sig” procedure.

During a colonoscopy or sigmoidoscopy, the doctor can inspect for early signs of colorectal cancer. Some IBD patients are at a slightly higher risk for colorectal cancer, particularly those with uncontrolled inflammation who have had the disease for a long period of time. However, cancer can often be discovered at earlier stages because of the regularity of IBD-related tests.

**Esophagogastroduodenoscopy (EGD)**: Also known as an upper GI endoscopy, EGD is similar to a colonoscopy, but it is performed on the upper end of the digestive tract. A similar scope is used, entering through the mouth and esophagus. The doctor can inspect the inside of the stomach and upper end of the small intestine (duodenum).

**Endoscopic ultrasound (EUS)**: Is a technique that combines an endoscopic camera and ultrasound to evaluate lesions beneath the inner-most surface of the intestinal tract.

**Enteroscopy**: Similar to an upper endoscopy, an enteroscopy is performed to look deeper into the small intestine. The doctor may be able to reach as far as the jejunum, the middle section of the small intestine.

**Capsule endoscopy**: In cases where the affected area of the bowel cannot be reached with traditional scopes, a capsule endoscopy may be performed. This involves swallowing a capsule that’s equipped with a camera—a “pill camera” (PillCam®, Endo Capsule®). As it travels through the intestines, the capsule automatically takes pictures. The images are wirelessly sent to a receiver worn by the patient. The capsule is expelled during a bowel movement, usually within a day.
Your doctor may order tests or procedures periodically for a variety of reasons, including monitoring your progress, looking for complications, and determining how well you are responding to treatment.

Logging your symptoms and diet can help you keep track of your disease management. This information may also be beneficial to your healthcare team.
“Being honest about your symptoms and medications you’re taking or not taking is very important.”

DR. YEN, Gastroenterologist
With your diagnosis behind you, it’s time to begin the journey of learning to live well with your condition. This section provides some tools to manage everyday life with a chronic illness, and offers a variety of coping methods that may simplify your life.
Ensuring Care

Building an effective medical team

One of the most important things you can do is develop a collaborative relationship with your healthcare providers. Most people already have a primary care physician. By the time they have an IBD diagnosis, most have a gastroenterologist (GI) as well. If you don’t have a gastroenterologist, it’s a good next step. These doctors specialize in digestive health, and some focus specifically on CD and UC.

Along the way you may seek the help of additional specialists, especially if you develop complications or have other conditions that are not typically treated by a gastroenterologist.

Working with multiple caregivers has a tendency to get complicated. Keeping open lines of communication by letting each of your providers know who you are seeing and encouraging them to share information, reports, and test results with each other will help them care for you better as a team.

And don’t forget yourself in this equation. You are the most important caregiver on your team. As the one person who is involved in every doctor-patient interaction, you act as the hub of your treatment process. It may be helpful to take notes at each appointment and keep them in one notebook or binder. You need to be your own advocate when necessary. Don’t be afraid to ask for what you want. And if one of your providers is not working out for you, it’s okay to find a new one. Your goal is to put together the best team that is right for you.

How to find a doctor

Finding healthcare providers is not always an easy task, but there is plenty of help out there. CCFA maintains a database of professional members at www.ccfa.org who have expressed an interest in treating IBD, so the website is a good place to start. The American College of Gastroenterology also maintains a database of gastrointestinal specialists at www.patients.gi.org. Your health insurance provider may have a list of suggestions as well. Support groups are a good way to learn about the local resources available in your area. Asking people you trust for recommendations is another effective route.

As part of your process, don’t forget to look at the details in your health insurance plan, such as which doctors are in or out of network, and how your choices will impact you financially.
Special Populations

Pregnancy and IBD

Many women who are newly diagnosed with IBD are concerned about the impact of the disease on having children. Most women with IBD can have a healthy pregnancy. If you are planning to become pregnant, it is a good idea to talk to your healthcare team. Most doctors emphasize the importance of getting IBD under control before trying to conceive, so your providers can help you determine if it is the right time to consider a pregnancy. Some of the medications used for IBD, such as methotrexate, cannot be used when pregnant, so it will be important to discuss treatment as well.

While most medications do not affect male reproductive health, men should also consult their doctor when considering a potential pregnancy with their partners (especially if taking methotrexate or sulfasalazine). Children of parents with IBD are at a greater risk than the general population for developing the disease, but there is no test to predict if a child will have CD or UC.

Regardless of the particular situation, good coordination between the obstetrician and other members of your healthcare team is critical.

Children with IBD

Living with IBD is difficult for everyone, but there are some special challenges for children. Children have unique medical, psychological, and social concerns.

One of the most important factors is nutrition. Proper nutrition is very important for growth and development. Special attention must be paid to ensuring that children with IBD are well nourished and get enough calcium and vitamin D for bone growth.

Treatments also present some challenges. Since many of the medications used to treat IBD alter the way the immune system works, additional considerations may be necessary. For example, certain immunizations may need to be given before particular medications are used, or the patient may need to wait until the medicine is stopped before the immunization is given.

Because of these special concerns, if possible, children with IBD should be treated by a pediatric gastroenterologist.

Transitioning from pediatric to adult care

Many people with IBD are diagnosed as children or teens. As a young patient reaches the transition to adulthood, making the move from pediatric to adult care becomes important. Adult patients have different needs than young people, and adult providers have more experience addressing adult concerns. Your pediatric specialist may have some recommendations for you when the time comes.
It's understandable that you will go through periods of stress.”
Managing Your Disease
Diet and nutrition
Two of the most frequently asked questions from IBD patients are “What can I eat?” and “What shouldn’t I eat?” While dietary choices can certainly have an impact on symptoms, IBD is not caused or cured by any particular food. Because each person’s disease is unique, there is no universal solution. Generally, people with IBD should aim to have a nutrient-rich, well-balanced diet with plenty of fruits, vegetables, grains, and lean sources of protein. Keeping hydrated with plenty of fluids is also important.

There may be foods that you cannot tolerate. The key is to pay attention to what you eat, and keep track of the results. Using a food diary to log your eating habits and how you’re feeling is a great way to collect information that can be used to identify foods that may trigger symptoms.

Keep in mind that your dietary needs may change over time. For example, many people find that fiber is helpful during remission but problematic during a flare. Sometimes a food that you were not able to tolerate later turns out to be easy to digest. So remember to modify your approach as needed.

Here are a few tips:

1. Experiment with foods several times in different situations before deciding if you can or cannot tolerate them.

2. Make small changes to your diet, one at a time, so you can more easily determine cause and effect.

3. Be careful about “miracle diets.” Many people report success with certain diets, but they have not been scientifically proven to help IBD. No diet should replace the treatment your doctor prescribes.

4. Focus on what you can eat rather than foods you need to avoid.

5. Talk to your healthcare team about any nutritional deficiencies that may require supplementation. You may wish to discuss your needs with a registered dietician or nutritionist.
Coping and managing stress
Living with a chronic disease obviously impacts physical health, but it can also take a
toll on emotional well-being. Learning to cope with challenges and managing stress
are critical components of healthy living.

The most important thing to keep in mind is that there are many other people
experiencing the challenges you face. It is still possible to live a rich, fulfilling life,
despite your condition.

Many people find that connecting with other IBD patients helps them to cope with
their disease. CCFA hosts support groups throughout the country. Other support
programs include the Power of Two (a peer mentorship program), a Community
website, and Camp Oasis (summer camp for kids with IBD). Visit your local CCFA
chapter’s website for more information, or call The Irwin M. and Suzanne R. Rosenthal
IBD Resource Center (IBD Help Center) at 888-MY.GUT.PAIN (888-694-8872).

Getting regular exercise is another great way to keep your spirits up. Physical activity
improves the performance of body systems, and helps the mind as well. Try to stay
active, in whatever way you can. You might be surprised how capable you are, even
with some limitations.

Also remember that you may need to slow down sometimes. You are fighting a
disease, you are under stress, and your life has extra complications. Get plenty of
sleep. Take breaks. Try to keep your daily schedule and calendar as flexible
as possible.

Don’t be afraid to get help if you need it. Seeing a counselor or therapist is a great
way to sort out your challenges, learn new coping methods, and gain perspective
from a professional. Many mental health providers specialize in treating people with
chronic diseases, so be sure to ask your doctor for recommendations.

Lifestyle Challenges

The people in your life
Because IBD includes some potentially embarrassing symptoms and occasional
mishaps, it can be difficult to talk about it with others. It’s common to worry about
whether or not others will understand, or if they will treat you differently. The good
news is that everyone knows what it’s like to not feel well. That said, until someone
has personal experience with chronic disease, it’s difficult to truly understand what
it’s like to face IBD.

For these and other reasons, relationships become an important factor for IBD
“How do I deal with misunderstanding?” Trust and communication are the two keys to approach these common concerns.

To help others help us, we will have to trust them—with personal information and with a willingness to be helped. Inviting people in is a critical step. Clear and honest communication is the other half of successful relationships. Being specific about what you need is the most effective way to get it. This may seem obvious, but it is all too common to assume that subtle clues will do the job, and this is what leads to miscommunication and frustration.

Lastly, you may wonder how you should describe your disease to people in your life that you are not as close to, such as coworkers and acquaintances. Some people with IBD are less willing to share details about their disease with others, and this is perfectly fine. A simple way of telling people about IBD without going into detail is saying, “I have been diagnosed with a digestive disease that can cause pain and other symptoms. There are good treatments and strategies to manage the disease.”

Remember that loved ones will also experience some stress.

Support for caregivers
People with IBD have special needs due to the nature of the disease, but it is important to recognize that people close to you may be working hard and making sacrifices to help you to accommodate those needs. For this reason, it is important to acknowledge their involvement. Everyone wants to be appreciated for what they do to help. Express your gratitude in whatever way you can, and as often as possible.

Remember too that loved ones will also experience some stress in this process. They may need some support or may want to learn more about the disease. Perhaps you could invite them along to an education program or support group meeting, and share your resources with them. Keep the communication open.

Accommodations at work and school
Negotiating the accommodations you need with friends and family is one thing, but it can be even more challenging to do so with supervisors, coworkers, teachers, and other people who you are not as close to. Regardless, there are things that can be done at the workplace or at school to make life a little easier.
Perhaps your desk, office, or locker can be moved closer to the restroom. Maybe you can arrange for access to a private restroom. At some schools, there is one at the nurse’s office. At college (and at larger companies), there is usually an office specifically tasked with arranging accommodations for people with special needs—everything from dorm room selection, to flexibility with schedules, exam-taking, or other concerns. Don’t be afraid to ask for these or other accommodations that can make your life easier.

**Financial management**
The financial impact of a chronic illness can pose challenges. Medical bills, prescriptions, lost work time, and other hardships tend to have an effect on family finances, and they also contribute to the stress of being sick.

One of the best things you can do is to understand your health insurance plan as thoroughly as possible. Discuss the options with your doctor and pharmacist as part of your decision-making process. Sometimes, simple choices have significant financial consequences. Making those decisions carefully can save a lot of money and time. Insurance companies are sometimes frustrating to deal with, especially when it comes to large expenses. When you have questions, talk to the employer’s benefits advisor. Call the insurance company. Stick up for yourself when necessary, and ask for the help of others if you are not getting fair results.

Planning is also an essential component. This includes things like effectively managing your sick leave, vacation, and other time off from work, as well as balancing income and expenses to accommodate medical costs. Healthcare benefits are an important consideration when discussing employment.

These factors should all be considered together in the financial planning process. Don’t be afraid to see a financial consultant for help with these matters. This person may even be another essential member of your disease management team.

If you encounter difficulty in affording care, don’t be afraid to ask for help. You may be eligible for government assistance or co-pay support. Local social service offices are usually able to help identify programs that offer assistance with medical bills, prescription medications, and legal aid.

**KEY TAKEAWAYS**

- Develop a collaborative relationship with your providers, including your primary care physician, gastroenterologist, dietician, and other specialists.

- Good communication and planning will help things go smoothly along your journey. Don’t be afraid to ask for help when you need it.
What’s next?

Resources from the Crohn’s & Colitis Foundation of America

Now that you have the basic information, it’s time to move forward with your journey. The resources below should be helpful for finding additional information on living well with IBD. You may also want to read portions of this kit again in the future, and share it with your close friends and family.

Be sure to watch the DVD in this kit and complete the self-addressed postcard. If you complete it, you will receive a free one-year membership to CCFA and will be sent a membership card with an “I Can’t Wait” message on the back to help you request restroom access.

Individual Support
The Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center) is a support line for patients and caregivers living with IBD. We can help steer you in the right direction—whether you need to locate a doctor, find an education event in your area, or have questions about your disease. Specialists are available Monday-Friday, 9 AM to 5 PM Eastern time. Call 888-MY.GUT.PAIN (888-694-8872) or email info@ccfa.org.

Online Resources
CCFA’s website (www.ccfa.org) is a great place to continue your research about the disease and treatments, find a doctor or support group, learn about the latest news and research, and connect with your local chapter. The American College of Gastroenterology’s IBD Health Center (www.patients.gi.org) is a multimedia resource center for patients.

CCFA’s interactive “I’ll Be Determined” website (www.ibdetermined.org) is designed to help you take a closer look at IBD management and includes a special module for newly diagnosed patients, a handy disease management tracker, interactive games, and more.

Connect with others on CCFA’s Online Community (www.ccfacommunity.org) and get support in managing your IBD through discussion forums, personal stories, an online support group program, interactive learning opportunities, and more.
Additional brochures and fact sheets on a variety of topics are available at [www.ccfa.org](http://www.ccfa.org). Topics include:

- Medications and side effects
- Surgery
- Managing flares
- Disease complications
- Diet and nutrition
- Social, emotional, and lifestyle factors
- Specialized guides for children, teenagers, parents, teachers, and other school personnel

**Programs**

CCFA offers a variety of programs that provide education and support to IBD patients, and that help people connect with each other by getting involved. Go to the “Get Involved” section at [www.ccfa.org](http://www.ccfa.org) for more information on:

- Online and in-person education programs
- Exciting and rewarding fundraising programs: Take Steps, a family-friendly walk event, and Team Challenge, an endurance training program
- Support groups and our peer mentorship program, Power of Two
- Camp Oasis, a summer camp for kids living with IBD

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**HELP US FIND CURES!**

CCFA Partners is a unique opportunity for you to contribute to advances in your own care. By completing a short, confidential survey about your current quality of life and providing occasional updates on your health, you can shape researchers’ understanding of IBD. Take the survey, see the latest statistics, and learn more at [www.ccapartners.org](http://www.ccapartners.org).
IBD Tracker: With this tracker, you will be able to stay on top of your IBD and share the information with your healthcare team. Remember to make copies!

GI Buddy is our interactive tool that you can access via computer or smartphone and helps you track your IBD over time. It also creates reports that you can share with your doctor. Visit www.IBDetermined.org for details.

Date: / /

**SYMPTOMS**

1. Describe any symptoms you had today.

Bowel movements (examples: number, blood/mucus, urgency):

Abdominal pain:
- [ ] None
- [ ] Mild
- [ ] Moderate
- [ ] Severe

Other symptoms:

2. How do you feel overall?

- [ ] Very well
- [ ] Fair
- [ ] Poor
- [ ] Very poor
- [ ] Terrible

**TREATMENT**

1. List the treatments you’ve taken today and the time, including nonprescription medications:

<table>
<thead>
<tr>
<th>AM</th>
<th>PM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
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</table>

2. List any side effects you have experienced:

3. Have your treatments been effective?

4. If you missed a dose of a prescribed treatment, list when and why:
**DIET**

Write down what you ate, or if you skipped a meal.

Breakfast:

Lunch:

Dinner:

Snacks:

**LIFESTYLE**

1. Rate the degree to which IBD affected your life today:

☐ Not at all  ☐ Low  ☐ Moderate  ☐ High  ☐ Very High  ☐ Highest

2. Add any details about the impact your IBD has on you:

3. How severely has IBD affected your stress level?

☐ None  ☐ A Little  ☐ Somewhat  ☐ Moderately  ☐ Very  ☐ Extremely

4. Did you have to cancel any plans, skip meals, lose sleep, or otherwise change your behavior due to IBD?

☐ Yes  ☐ No

If yes, explain:
Glossary

A
Abscess—Infected fluid collection in a tissue cavity (usually caused by a leak in the intestines).

B
Bowel—Another name for the intestine. The small and large bowels are the small and large intestines, respectively.

C
Colon—Large bowel or large intestine.
Constipation—Infrequent bowel movements or difficulty passing stools.

D
Diarrhea—Passage of excessively frequent or excessively liquid stools.

E
Endoscopy—Visual inspection of the internal organs using a tubular camera scope.
Enema—Injection of fluid or medication into the rectum.

F
Fistula—Unnatural channel that forms between portions of intestine, or between the intestine and another nearby structure such as the bladder, vagina, or skin.
Flare (or flare-up)—Return of IBD symptoms often caused by increased inflammation in the gastrointestinal tract.

G
Gastrointestinal (GI, or digestive) tract—Collectively referring to the mouth, esophagus, stomach, small and large intestines, and anus.

I
Ileal-pouch anal anastomosis (IPAA)/j-pouch—Surgical construction of a stool storage pouch made from the lower portion of the small intestine and connected to the anus.
Ileostomy—Surgical opening in the abdominal wall allowing for the external passage of stool from the ileum.
Ileum—Lowest portion of the small intestine that connects to the large intestine.
Immune system—The body’s natural defense system that fights against disease.
Inflammation—Immune response to tissue injury that causes redness, swelling, and pain.
Intestine—Long, tubelike organ in the abdomen that completes the process of digestion. It consists of the small and large intestines. Also called the bowel.

L
Lymphoma—Cancer of the lymph nodes.

O
Ostomy bag—External bag that stores stool passed through the abdominal wall, commonly via an ileostomy after a proctocolectomy.

P
Pouchitis—Inflammation of the ileoanal pouch following a restorative proctocolectomy.
Proctocolectomy—Surgical procedure involving removal of the rectum and/or colon.

R
Rectum—Lowest portion of the large intestine that connects to the anus.
Remission—Period in which IBD symptoms disappear or substantially decrease and good health returns.
Resection—Surgical removal of a diseased portion of the intestine.

S
Stoma—Artificial opening on the skin that allows for draining and stool collection into an ostomy bag.
Stricture—Unusual narrowing of the intestine caused by inflammation or scar tissue.
Strictureplasty—Surgical procedure to widen the intestine as a result of a stricture.
Suppository—Medication (pill or capsule) that is delivered by insertion through the anus.
We hope you found the Newly Diagnosed Kit helpful. The Crohn's & Colitis Foundation values your feedback. Please return this brief survey below to CCFA (no postage necessary). All responses are confidential.

If you include your name and address, you will receive a free one-year membership and an I Can't Wait card that will help you request restroom access.*

You can also complete the survey online at www.surveymonkey.com/s/ccfakit

NAME
STREET ADDRESS
CITY STATE ZIP

1. When were you diagnosed with Crohn's disease or ulcerative colitis?

5. After reviewing this kit, I (check all that apply):
   □ Feel comfortable seeking additional information on my disease
   □ Feel that I can live well with my disease
   □ Understand my options for treatment and disease management
   □ Follow up with my doctor or healthcare provider on what I learned
   □ Follow along in the disease management tips discussed.
   □ Ask my doctor or healthcare provider about my treatment plan
   □ Recommend a food or symptom diary

6. After reviewing this kit, I will (check all that apply):
   □ Understand my options for treatment and disease management
   □ Follow along in the disease management tips discussed.
   □ Ask my doctor or healthcare provider about my treatment plan
   □ Follow up with my doctor or healthcare provider on what I learned
   □ Follow up with my doctor or healthcare provider on what I learned
   □ Follow along in the disease management tips discussed.

7. What information or advice was not included that would be helpful to you?

4. Which part of this kit was most helpful?

□ Printed booklet
□ DVD videos
□ IBD tracker (at end of booklet)

3. How would you rate the information in this kit in increasing your understanding of inflammatory bowel disease?

□ Excellent
□ Very good
□ Good
□ Average
□ Poor
□ Very poor

2. How did you receive this kit?

□ From your doctor or healthcare provider
□ From CCFA's Information Resource Center (via mail)
□ At a CCFA education or fundraising event
□ From CCFA's Information Resource Center (via mail)
□ Printed booklet
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7. What information or advice was not included that would be helpful to you?
Now that you have The Facts on Crohn’s & Colitis in hand, make sure to watch our companion videos for candid interviews with a gastroenterologist, a nurse, and patients who’ve been there. Together, these tools will help you start on a positive path toward living well with IBD.

Note: This DVD is intended for use on DVD players and computer disk drives. Use on Blu-ray players may distort the content.
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