A GUIDE FOR Teens WITH IBD
Facts About IBD

QUICK TIPS

www.ccfa.org
888-694-8872
info@ccfa.org

For More Information:

IBD = Inflammatory Bowel Diseases

Two major types

Crohn's disease (CD)
• Inflammation anywhere in the gastrointestinal tract

Ulcerative colitis (UC)
• Inflammation limited to colon and/or rectum

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Statistics

1.4 million affected in the USA
70,000 new IBD cases per year
Often diagnosed between ages 15–35

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Disease Info

Common symptoms
• Diarrhea
• Weight loss
• Feeling tired

Things that can trigger or boost symptoms
• Not taking and missing medication
• Use of nonsteroidal anti-inflammatory drugs (NSAIDs)
• Eating certain foods that make existing symptoms worse
• Ongoing stress that makes existing symptoms worse

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Treatment Options

Prescription medication (Rx)
Over-the-counter (OTC) medication
Surgery
Nutritional support therapy
Remember to take medication even when you don’t feel like it or you feel ok

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Diet and Nutrition

Maintain a healthy diet (www.MyPlate.gov)
Keep a food journal (www.ccfa.org)
Avoid high-fiber foods during a flare-up like popcorn, seeds, and nuts
Get enough calcium
• Ages 9–18yrs, 1200–1500 mg/day

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Things You Can Do

Ask for school accommodations
• “Stop the clock” testing
• Unlimited bathroom breaks
Regular exercise
• At least 1 hour each day
Get enough sleep
• 7–9 hours each night

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Coping Options

Join a support group
www.ccfa.org/chapters/
Connect with college students at www.ccfa.org/campus-connection
Relax and destress with
• Yoga
• Tai Chi
• Meditation
Attend Camp Oasis
www.ccfa.org/kidsteens/camp

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Use CCFA Tools and Resources

GI Buddy for iPhone and Android
www.ccfa.org/gibuddy
Download free brochures
online.ccfa.org/brochures
Teen website www.ccfa.org

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Look for this handy quick reference on important IBD information you should know. Included is a journal to write down answers to questions. Take it with you to your doctor visits or to school to help educate your teachers or friends about IBD.
Your doctor has just told you and your parents or guardians that you have inflammatory bowel disease (IBD).

To start, you probably have a lot of questions. Some of the most commonly asked ones are:

- What is IBD?
- How did I get it?
- Is there a cure?
- Is IBD deadly?
- Will I be able to go to school, hang out with my friends or play sports?

Learning more about IBD can help you get through the day, even when part of you is not feeling so well.

Inside this booklet is an insert with a list of questions you may want to ask the doctor or nurse. We also included some blank pages so you can write down your own questions as well as information about how you feel.

We wrote this booklet for teens 13–18 to answer these and other questions and to provide you with important information and support that can help you manage and live well with IBD.

Throughout this booklet are italicized and bolded words. Click on these words to find the definitions in the glossary on page 34.
Inflammatory bowel disease (IBD) is a chronic (lifelong) disease that causes inflammation of the gastrointestinal (GI) tract. The two main types of IBD are Crohn’s disease and ulcerative colitis.

The GI tract is responsible for digestion of food, absorption of nutrients, and elimination of waste from the body. The GI tract includes all of the parts of the body that digest food. It starts with your mouth (oral cavity) and continues down your throat into your esophagus, and through your stomach, small intestine, large intestine, rectum, and ends with your anus (Figure 1). Inflammation impairs the ability of affected GI organs to work properly.

Crohn’s disease and ulcerative colitis are very similar, but there are important differences. A third type of IBD, indeterminate colitis can sometimes be diagnosed.
## WHAT IS IBD?

### Crohn’s Disease
- Affects any part of the GI tract, from the mouth to the anus
- Often affects the end of the small intestine (the ileum) where it joins the beginning of the colon
- May appear in “patches,” affecting some areas of the GI tract while leaving other sections completely untouched
- Inflammation may extend through the entire thickness of the intestinal wall

### Ulcerative Colitis
- Limited to the large intestine (colon) and rectum
- Can involve the entire colon, or may be limited to the lower colon
- May spread continuously to involve the entire colon
- Inflammation occurs only in the innermost layer of the lining of the intestines

### What are the symptoms of IBD?
Inflammation can prevent your GI tract from working normally, which can lead to IBD symptoms. The symptoms you have depend on the disease, its location, and how severe it is. They may change over time or even disappear for a while. Keep in mind that you may not have every symptom and that symptoms are not the same for everyone. They often go away once the inflammation is under control. When symptoms return, it is called a **flare**.

Common symptoms of IBD are:
- An urgent need to go to the bathroom
- Frequent **diarrhea**, sometimes bloody
- Poor absorption of nutrients
- Poor appetite
- Nausea
- Weight loss
- Feeling tired
- Pain in the abdominal area

[Check out a more detailed explanation of these illnesses at online.ccfa.org/crohnsdisease or online.ccfa.org/ulcerativecolitis.](#)
WHAT IS IBD?

Sometimes IBD causes symptoms outside the GI tract:

- Joint pain and stiffness
- Mouth **ulcers**
- Fever (indicates inflammation somewhere in the body)
- Eye irritation
- Skin rash

IBD and its symptoms can affect other parts of your life, too. They can affect your growth and can even delay **puberty**. Puberty happens at different times for different people, but for people with IBD, it often happens later. Discuss your growth and development with your health care providers (HCP).

**How did I get IBD?**
More than 1.6 million people in the United States have IBD. People of any age, from infants to older adults, can develop IBD. It most often starts in people between the ages of 15 and 35. It is not contagious, so no one gave it to you and you can’t pass it on to anyone else.

We don’t understand exactly what causes IBD, or how to prevent it. Scientists suspect that a combination of four factors lead to IBD:

- **Genes**: certain genes (family traits) make it more likely you will get IBD.
- **Environment**: something that your body comes in contact with, such as bacteria, certain medications, smoke, or toxins.
- **Intestinal bacteria**: the good and bad bacteria in the body are not balanced.
- **Immune system** response: the immune system mistakes something like helpful bacteria for something harmful and attacks it, causing inflammation.

IBD is not caused by stress or diet, but once you have IBD, both stress and diet affect your condition.

**Is There a Cure?**
There is currently no cure for IBD. It is a chronic (long-term) disease with no known cause or cure, but there are many effective treatments that can control your disease symptoms. Research is making incredible progress and many new treatments have been developed.

**Is IBD deadly?**
No. IBD is a chronic, long-term disease, but not a fatal one.

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WEB HELP

Sign up for CCFA’s app, **GI Buddy**, at [www.ccfa.org/gibuddy](http://www.ccfa.org/gibuddy). Use it to track your symptoms and the foods you eat, and to generate reports between doctor’s visits so you can see what trends are happening.
TREATMENTS

WHAT ABOUT Treatments?

Treatment for IBD can include a variety of prescription medicines (Rx) and over-the-counter medications (OTC) that you can buy without a prescription.

Doctors and other HCPs will try one or a combination of medications to see what works best for you. Which medications are used will be different for each person. If you know someone else with IBD, their medication will not likely be exactly the same as yours.

There are five different classes of prescription medications that your health care provider may try. Each type works in a slightly different way. See Figure 2 on page 8. Medicine can be taken:

- orally (medicine in pill or liquid form taken by mouth)
- rectally (medicine in a suppository or as an enema and inserted into your anus)
- intravenously (liquid medicine put directly into your bloodstream)
- as an injection (liquid medicine is given as a shot)
- topical (medicine is spread on skin)

It is important to discuss and understand the side effects of your medication. Discuss them with your nurse or doctor. If you experience side effects, let your parents and health care professionals know immediately.
<table>
<thead>
<tr>
<th>Drug category*</th>
<th>Purpose*</th>
<th>Some Possible Side Effects*</th>
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| **Aminosalicylates** | • Reduces intestinal inflammation  
• Used to maintain remission | • Diarrhea  
• Headaches  
• Nausea |
| **Antibiotics** | • To fight infection  
• To maintain balance of good and bad bacteria in intestines | • Some allergic reactions  
• Other side effects depend on specific drug used |
| **Biologic Therapies** | • To block proteins that cause inflammation  
• To reduce signs and symptoms  
• To induce and maintain remission | • Allergic reactions  
• Reduced ability to fight infections  
• Risk of malignancy (rare) |
| **Corticosteroids** | • To suppress the immune system  
• To control flares  
• To reduce inflammation | • Weight gain  
• Face swelling  
• Difficulty sleeping  
• Mood swings  
• Infections  
• Acne |
| **Immunomodulators** | • To suppress the immune system  
• To achieve remission  
• To maintain remission | • Nausea  
• Inflammation of some organs  
• Reduced ability to fight infections  
• Risk of malignancy (rare) |
| **Over-the-counter medicine** | • To control symptoms of IBD, like diarrhea, constipation, and pain. | Specific to each medication |

*This list is not a complete description of medication purpose and side effects. Be sure to speak with your health care provider regarding your individual benefits, risk, and side effects.
How do I keep track of my medicine?
The best way to get control of your symptoms and get to remission is to follow the treatment plan your doctor has ordered. This is called adherence, and it is your responsibility. No matter how you are feeling, you should continue your doctor’s plan. If you stop taking your medication, you risk a flare. Create an adherence plan for yourself that you follow faithfully:

• Use a reminder system like www.mymedschedule.com or an alarm clock.
• Use a chart listing your medicine and put a check on it when you’ve taken it (see page 11).
• Sort a whole week’s pills into a pillbox. It will be easy to see what you’ve taken.
• Use GI Buddy to help keep track of your medication at www.ccfa.org/gibuddy.

Surgery
Surgery is another treatment for IBD. It is used when medication does not work to control your symptoms or if the medication cannot solve the problems in your intestines. The type of surgery you have depends on your disease and symptoms.

After surgery, your doctor may recommend that you continue to take medication. It’s possible, even with surgery, that your symptoms from Crohn’s disease or ulcerative colitis will reoccur after a few months or years.

Ongoing Testing
You probably had several tests before your final diagnosis of IBD, but the testing doesn’t stop there. Sometimes you will need to have follow-up blood tests and imaging tests such as colonoscopy, Barium x-ray, video capsule endoscopy (pill camera), or magnetic resonance imaging (MRI). All of these tests help the doctor monitor your progress and/or adjust your treatment.
Managing Symptom Discomfort

The medications that are prescribed for you may not get rid of all your symptoms. Sometimes your health care provider may recommend an over-the-counter (OTC) product. These OTCs can help:

- Relieve diarrhea
- Reduce bloating and gas
- Reduce joint pain and fever
- Relieve irritation of the skin around the anus and other uncomfortable symptoms

When you have symptoms or discomfort, be sure to write them down and let your parents and doctor know about them.

Nutritional Support Therapy

IBD can affect the digestion of food. Sometimes the food from normal eating (by mouth) is not digested well, so important nutrients are not absorbed. IBD can also decrease your appetite so you don’t feel like eating, even when you need to. In these cases, another method to get the nutrients is used.

Your HCP or dietitian may prescribe a nutritional supplement. This nutritional support therapy uses drinks that are very nutrient-rich.

Sometimes a doctor might recommend enteral nutrition to give your GI tract a chance to rest and heal. Enteral nutrition is a form of liquid nutrition that can be taken by mouth, or delivered directly to your stomach or small intestine through a tube.
<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Form (pill, liquid) and/or Method Taken (oral, rectal)</th>
<th>Start Date</th>
<th>Stop Date</th>
<th>Dosage/Strength</th>
<th>Times Taken Daily</th>
<th>Symptoms or Side Effects</th>
<th>Purpose (why do you take it?), Comments, or Special Instructions</th>
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Diet and nutrition are important parts of IBD management. “Diet” refers to the foods we eat. “Nutrition” is a term that refers to properly absorbing food and staying healthy.

Since IBD affects the organs responsible for absorbing vitamins, nutrients, and water, it is important that you maintain a healthy diet with proper nutrition.

IBD tends to increase the body’s need for calories, nutrients, and energy. During IBD flares, it may be difficult to maintain adequate nutrition.

Although what you eat won’t trigger a flare, it could make you feel worse during one. However, if you maintain good nutrition, it will improve your overall wellness, promote healing and immunity, increase your energy levels, and may lessen some gastrointestinal symptoms. Once you have your symptoms under control, you may be able to eat the foods you want once again.

A well-balanced diet with an adequate intake of protein, carbohydrates, fats, vitamins, and minerals is necessary for proper nutrition. This can be achieved by eating a variety of foods from all the food groups. Figure 3 shows the healthy balance of food that should be eaten at each meal. Meat, fish, poultry, and dairy products are sources of protein. Bread, cereal, starches, fruits, and
vegetables are sources of carbohydrates. Butter, margarine, and oils are sources of fat.

With IBD, you’ll need to pay more attention to what you eat than you ever did before. There is no evidence to suggest that any particular food or diet causes, prevents, or cures IBD.

The best way to figure out what foods are causing problems is to keep a food diary or journal like the one shown in Figure 4. Identify what you eat and when you feel worse. You may have to use trial and error to see what reduces your symptoms. If you cut a certain food out of your diet, do you feel better? You will probably see a pattern and notice which foods are affecting you and should be avoided. When experiencing symptoms, it may help to follow some of the food tips below:

- Eat smaller meals more often
- Reduce the amount of greasy or fried foods you eat
- Avoid trigger foods (foods that make your symptoms worse)
- Limit eating certain high-fiber foods such as seeds, nuts, popcorn, beans, green leafy vegetables, wheat bran, and raw fruits and vegetables
- Limit drinking milk or milk products if you are lactose intolerant
- Avoid caffeine in coffee, tea, soda, and other beverages (caffeine can act as a stimulant to “rev” up the bowel resulting in diarrhea)
- Consider vitamin and mineral supplements, such as vitamin D and calcium, if your HCP approves
- Sometimes during a flare you will become dehydrated and need to drink extra fluids

Keep a food diary online or with your smartphone using CCFA’s GI Buddy app. Also download a copy of the brochure Diet, Nutrition and Inflammatory Bowel Disease at online.ccfa.org/dietbrochure.
Eating Out
Here are some tips to keep in mind if you are eating in the school cafeteria, at a restaurant, or at a party:
• Don’t go out feeling too hungry. You may not make the best food choices as you will be driven by hunger and the desire to feel full.
• Eat smaller portions, perhaps an appetizer or a half-size portion.
• When in doubt, keep it simple. Go for boiled, grilled, broiled, steamed, poached, or sautéed, and limit sauces and spices.
• When going to a party, bring an item you know you can eat and bring enough for the group.
• If you can’t eat, hold a glass in your hand. There is nothing wrong with drinking liquids if you can’t find a meal that will work for you.

If your friends make comments, help educate them about IBD and your diet.
LIFE WITH IBD

School and work, doing what you enjoy, and keeping healthy are all affected by IBD. You can do things to make your life easier.

- Most people with IBD need to take medication for the rest of their lives.
- You may have symptoms that range from mild to severe.
- You will have times when you have flares with active symptoms.
- You will have times of remission and good health.

Will I be able to go to school, hang out with my friends, or play sports? Yes. You will be able to do many of the same activities that you did before. However, you may need to take certain precautions and rearrange your plans when you are not feeling well or you are too tired.

Coping with IBD
Your IBD symptoms may disappear at times, but you never know when they’re going to become a problem. If you are prepared and take care of yourself, these symptoms won’t limit your life.

Since you haven’t changed, remember who you are.
- You are more than your IBD. Accept your illness and continue to do what you enjoy.
- Explore the activities you enjoyed before IBD and try new ones. Modify them, if you have to, so you can participate fully.
- Form friendships with people who understand and support you.
- Participate in a regular exercise routine, with your doctor’s approval. Exercise can improve overall health, reduce stress, and help to maintain and improve bone strength.

Emotional Help and Support
You might feel anxious or depressed. IBD patients may have more stress than others. This is common because they have to deal with problems related to their IBD.
Talking with your parents, friends, and other people with IBD can be helpful. If you need more help, talk to your doctor or another professional, like a teacher or guidance counselor, about how you feel. They can help you to cope with your feelings and those of the people around you. They’ve learned what works by talking to many people.

Stress is part of everyone’s life. You can’t avoid it. You need to manage it because it can make symptoms worse and even cause more stress. Of course, avoiding all stress is impossible.

Stress reduction techniques can help you to stay calm, stay focused, and break this anxiety cycle. There are many stress management methods, and no one method has been proven to be more effective than another. Try an approach that you like. If one doesn’t work, try another. Here are some techniques to try for managing stress:
- Relaxation and breathing exercises
- Meditation (a state of being silent and calming of the mind)
- Reading books, listening to recordings and music
- Practicing yoga or tai chi (low-impact and slow-moving exercise designed to promote relaxation, balance, and health)

For more help, find a local CCFA support group in your community or log on to CCFA’s teen website at www.ccfa.org or campus connection at www.ccfa.org/campus-connection.

Be Prepared
There will be times when your disease is in deep and durable remission and you feel great. But at other times, IBD symptoms are unpredictable. Just in case you need it, be prepared with emergency supplies. Carry the basics in your purse or backpack.

You might want to include the following:
- Toilet paper
- Wet wipes
- Powder
- Hand sanitizer
- Small can of air freshener

At www.ccfacommunity.org, you can connect with others and learn how they are managing their IBD.
• Disposable gloves (to handle any soiled clothes)
• Large-sized freezer bags (for the soiled clothes)
• Clean underwear
• Clean shorts, pants, or leggings (anything that you can wear until you get home)

What happens as I get older?
As you get older, you need to take more responsibility for managing your treatment. That way, by the time you are living on your own, you will be able to take full control of your medical life. If you can answer yes to the questions for your age group, you’re doing really well!

Younger Teens
• Are you able to identify your medical team?
• Can you describe your GI condition?
• Can you name your medications, when you need to take them, and their side effects?
• Can you describe how your IBD affects your daily life, at home, in school, and in the outside world?
• Can you give the name and purpose of each of the medical tests you take?
• Do you share your information during appointments?
• Do you ask questions during appointments?

Older Teens
• Do you take responsibility for renewing prescriptions and keeping track of side effects?
• Can you describe what will happen if you don’t follow your treatment plan, including taking medication?
• Do you understand the impact of drinking alcohol and smoking on your IBD?
• Can you identify people and places you can turn to for support?
• Do you know how to contact your medical team in case of an emergency?
• Can you establish new medical and support arrangements with college or adult providers?
• Do you make your own medical appointments with providers?
• Do you know your health insurance information or carry your insurance card with you at all times?
What do I say to my friends when they ask me what’s wrong? It’s hard to know how to respond to questions. It’s hard to be someplace I don’t know.

Who do I tell about my disease?
The easy answer is “tell whomever you want, whatever you want,” but that isn’t always easy to figure out. You have to decide how much to tell the people around you about your illness.

Some people, like your parents, guardians, and the school nurse, will need to know details. If you are away from home, maybe at college, someone needs to be your health care point person for when your doctor’s not available. They need to know your history, symptoms, and the emergency care that works. Others, like your teachers and your boss, only need to know some details to understand how your IBD symptoms can affect your daily life.

Sometimes it’s hard to know what to say when someone asks an embarrassing question. Here are some ideas. Add your own questions and think of some good answers.
<table>
<thead>
<tr>
<th>Questions I may be asked:</th>
<th>How I can respond:</th>
</tr>
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<tbody>
<tr>
<td>What’s wrong with you?</td>
<td>It’s a chronic illness called inflammatory bowel disease, where part of my digestive system is inflamed (swollen).</td>
</tr>
<tr>
<td>Can I catch it?</td>
<td>Don’t worry, you can’t catch it!</td>
</tr>
<tr>
<td>Are you OK?</td>
<td>I’m gonna be fine. My disease symptoms just come and go.</td>
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<tr>
<td>Why is your face so puffy?</td>
<td>It’s because of my medicine. It won’t be like this for long. It will go back to normal once I finish taking this medicine.</td>
</tr>
<tr>
<td>Questions I may be asked:</td>
<td>How I can respond:</td>
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<tr>
<td>Add your own questions and answers below:</td>
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</table>
What about school?
Whether it’s middle school, high school, college, or a job, you spend a lot of time in these places. Because IBD is unpredictable, you’ll need a backup plan with someone who knows what’s what.

Your IBD and treatments might affect your school attendance or performance. You might have to miss school when you have medical appointments or if you’re feeling really bad during a flare. Remember, you are still responsible for learning the required subject matter. To help you do that, your parents can request a 504 (Accommodation) Plan. Once your health care professionals and the school identify how your IBD could affect you in school, a 504 Plan is created that lists the accommodations, special services, or adjustments that you might need.

School Accommodation
Once an evaluation of your needs is completed, accommodations, special services, or adjustments to your school activities due to your IBD can be made. These accommodations can include, but are not limited to:
• The freedom to go to the bathroom whenever you need to
• Permission to use a private bathroom, like the one in the nurse’s office
• A place to keep your emergency supplies, maybe near that bathroom in the nurse’s office
• Permission to take regularly scheduled and emergency medication at the nurse’s office
• Permission to eat snacks and drink liquids throughout the day
• Get help with classwork that you missed and have quizzes, tests, and projects rescheduled
• “Stop the clock” during tests so you can use the bathroom and not lose any test-taking time
• Excused absences due to illness, medical appointments, and treatments
• A home tutor if you have to be out of school for a while

Even if you are doing well and do not feel like you need a 504 Plan, it is always good to have it in place—just in case.
Ask your teachers and school nurses to download *A Guide for Teachers and Other School Personnel* at online.ccfa.org/teachersguide. It has information specifically to help them understand IBD, its effect on you, and what they can do to help.

**What do I need to do when I travel?**

Travel, whether it’s to the mall, to Grandma’s in the next town, or across the country on an airplane, takes planning. You can do it, just think ahead.

- Know the fastest route to the bathroom wherever you are.
- On a plane or bus, sit near the restroom.
- Keep your medicine, snacks, and drinks within easy reach.
- On an airplane, carry on extra medicine and emergency supplies in case there are delays.
- Carry a letter from your doctor describing your IBD and giving instructions.
- Carry a list of your medicines and when you take them.
- Know who you’d call in an emergency and have their number handy at all times.
- Be sure you have your insurance cards and the insurance company’s phone number.
- Request CCFA’s I Can’t Wait card (contact info@ccfa.org). This card can help you explain your IBD to the outside world. Show the card to ask for access to bathrooms in stores, restaurants, and other public places.
With all of the good, bad, and crazy things that happen during the teen years, how do I deal with all the change to my life?

**College**

College students can also get accommodations. The Americans with Disabilities Act (ADA) prohibits colleges, universities, and trade schools from discriminating against students with a disability. You must request these accommodations, submit acceptable proof of having a disability, and meet with the proper people to determine which accommodations will apply to you. In college, these accommodations can also apply to dorm life, not just to the classroom. They might include modifications to testing, seating, absences, and a private dorm room or bathroom. To learn more about the Americans with Disabilities Act, visit [www.ada.gov](http://www.ada.gov).

**Work**

If you are looking for a job, you should consider yourself just another job applicant. Don’t discuss your IBD in your interview. Your interview should focus on your qualifications and suitability for the job. After you land the job, are doing it well, and are through the probationary

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**WEB HELP**

CCFA has a teacher’s guide to help them understand what IBD is and how they can help you succeed in school, download it at [online.ccfa.org/teachersguide](http://online.ccfa.org/teachersguide).
period, then discuss your need for any specific work accommodations. ADA requires that employers provide reasonable modifications, like the frequent use of a restroom or flexible time off for treatments and appointments.

**Smoking**
Smoking carries many health risks, including lung cancer and heart disease. Also, smoking can make IBD symptoms worse. Smoking cigarettes can trigger flares. People with Crohn’s disease who smoke tend to have more recurrences of their disease, more frequent need for surgery, and a greater need for immune-system-suppressing medications. So don’t get started, or get help to stop.

**Alcohol**
Alcohol affects each IBD patient differently. The use or abuse of alcohol or other drugs, either illicit or over-the-counter, can have damaging effects on your GI tract, including your liver, and may interfere with your medications. Discuss the use of alcohol with your doctor or health care provider.
Friends and Dating
When dating or socializing with your friends, you may need to explain that you might sometimes have symptoms and will not always be able to go out, but you don’t have to say any more. If you feel like talking more about it, fine, but that’s up to you.

You can have a successful and rewarding relationship in spite of your disease. Whether you tell your boyfriend or girlfriend about your IBD is up to you. If you are just planning a couple of dates and nothing serious, then maybe not. If it turns out that you plan to spend a lot of time with this person, it may be something to think about. It’s up to you to decide. If you’re not sure, get some advice from a parent, friend, or maybe another IBD patient.

General Health Care Maintenance
It is important to continue general health maintenance. While working with your health care provider for your IBD issues, also remember to speak with your pediatrician about other important issues, including:

- Vaccinations: Kids and teens with IBD should generally follow the same vaccination schedules as the general pediatric population. People on immunomodulators and biologic therapy should generally avoid live virus vaccines. Be sure you or your parents ask your health care provider about flu shots, HPV, and other immunizations.
- Oral health: Among symptoms of IBD outside the GI tract are aphthous ulcers in the mouth, also known as canker sores. These may be caused by the IBD itself, or they might be a secondary symptom due to nutritional deficiencies. Although not serious, these ulcers can be quite painful. Mouth rinses and other topical treatments may help relieve the discomfort. Please remember to also see your dentist for routine dental care.

Visit the websites that are specifically for older teens with IBD. These include www.ccfa.org/campus-connection/ and www.ibdu.org/.
The Crohn’s & Colitis Foundation of America has resources and support that can help you manage and live well with IBD.

- IBD Help Center
  info@ccfa.org
  888.MY.GUT.PAIN (684.8872)
- www.ccfa.org has many IBD resources.
- www.ccfacommunity.org is specifically for support.
- GI Buddy, www.ccfa.org/gibuddy, is a free online tool and mobile app. Log your symptoms, medications, diet, and more.
- Campus Connection (www.ccfa.org/campus-connection/) allows you to connect with other college students and get tips and info.
- Local education and support programs can be found at www.ccfa.org/chapters/.

Camp Oasis’ website (www.ccfa.org/kidsteens/camp) gives information about CCFA’s summer camp programs.

Many brochures are available on the website, too. Find all brochures and fact sheets at online.ccfa.org/brochures/.
There are other websites that promise to help you with your IBD, but be careful. Make sure they have a good reputation and are not offering a magic cure. Check with your parents or doctor before trying anything you read on the Internet.

**How can I help myself and others with IBD?**

**Research Studies**
You can also help researchers find cures for Crohn’s disease and ulcerative colitis by taking part in CCFA Partners Kids and Teens. You will join others with IBD who, twice a year, fill out an online survey about their health. Visit [www.ccfapartners.org](http://www.ccfapartners.org) to learn more.

**Other Ways to Get Involved**
- Participate in Take Steps for CCFA. Take Steps is CCFA’s national walk program. It brings together thousands of people who Take Steps to raise money, improve fitness, and increase awareness of IBD. Find a walk in your area at [www.cctakesteps.org](http://www.cctakesteps.org).
- CCFA has 40 local chapters across the country. Each offers support programs and activities. Find one near you at [www.ccfa.org/chapters](http://www.ccfa.org/chapters).
Now that you know what IBD is, remember these important ideas.

- Nothing you ate or did gave you IBD.
- You didn’t catch it from anyone else.
- Most people who live with IBD are healthy more often than they are sick.
- Ask your doctor questions so you can learn more about managing your IBD.
- Understand that sometimes the disease might be a hurdle, but overcoming these hurdles will make you stronger.
- Keep working towards your goals. Remember there are successful doctors, lawyers, business people, celebrities, and professional athletes with IBD.
- To keep track of your medication, disease symptoms, and foods that cause you problems, use helpful tools like:
  - Food Journal
  - Medication Log
  - GI Buddy
  - My IBD Journal
- Don’t go it alone, get support from:
  - Family and friends
  - Other IBD patients
  - Health care professionals
  - CCFA

You’ll have a ton of questions about your illness, many now and many more as time goes on. That’s okay.

You’ll be doing yourself a big favor if you learn as much as you can about your IBD and how it affects your body. Just ask! One place to learn more is www.ccfa.org.

The My IBD Journal pages in the center of this booklet can help you get started. Use them to think and write down what’s important to you as well as what will help you understand your IBD.
Glossary

**Absorption** – This is when something is incorporated or taken into another, like when lotion is absorbed into your skin.

**Barium x-ray** – For this test, you swallow a chalky drink so that your intestinal tract shows up clearly on an x-ray.

**Chronic** – This is used to describe a continuing illness that lasts a long time or frequently reoccurs.

**Colonoscopy** – This test involves emptying out the intestines and then going to sleep so a flexible, lighted viewing tube can be inserted into the anus. It can be used to take pictures or remove a small piece of tissue from the intestines.

**Crohn’s disease** – This is one of the inflammatory bowel diseases. With Crohn’s disease, inflammation and ulcers can be found in any part of the GI tract.

**Dehydration** – This is the loss of water. It often happens to a person when diarrhea continues for a long time or a person goes without drinking enough water to replace what is lost.

**Diarrhea** – This is when bowel movements are too often, too soft, or too loose. They are often very watery and can be a symptom of IBD.

**Flare** – When a disease flares, its symptoms suddenly become worse. This word is short for flare-up.

**504 (Accommodation) Plan** – This plan comes from section 504 of the Rehabilitation Act of 1973. This act requires organizations and schools that receive federal funding to provide children with disabilities appropriate educational services designed to meet their needs.

**Gastrointestinal (GI) tract** – This includes all parts of the body that digest food, including the mouth, throat, stomach, small intestine, large intestine, rectum, and anus.

**Genes** – These are the basic physical unit of heredity and are passed from parent to child. They carry coded instructions and help determine what characteristics a child will inherit from its parents.
Immune system – This network within the body works to protect it from foreign substances and disease.

Indeterminate colitis – A specific condition that involves the colon and can have changes in the terminal ileum as well.

Inflammation – Inflammation is part of the body’s immune response to protect it from harmful irritants, viruses, and damaged cells. Without inflammation, infections and wounds would not heal. Too much inflammation can cause several diseases and conditions.

Inflammatory bowel disease (IBD) – This general label describes several different illnesses that produce inflammation inside the gastrointestinal tract.

Magnetic resonance imaging (MRI) – For this test, you swallow a liquid and then lay down in a machine that uses magnets to map your intestines.

Nutrients – These are substances that a body needs to take in and utilize to live and grow. Examples include vitamins, proteins, and carbohydrates.

Puberty – The process of physical changes where a child’s body matures into an adult body.

Remission – This happens when the inflammation of IBD is under control, allowing control of symptoms.

Symptom – This is a change in your physical condition that is a sign of a specific illness.

Ulcer – This is a break in the skin or lining. With IBD, the break causes a sore anywhere in the lining of the GI tract, from the mouth to the anus.

Ulcerative colitis – This is one of the inflammatory bowel diseases. With ulcerative colitis, inflammation and ulcers are found in the large intestine and rectum only.

Video capsule endoscopy – A procedure that allows your doctor to view areas of the bowel that cannot be reached with traditional scopes or imaging tests. This involves swallowing a capsule that is equipped with a camera—a “pill camera.” As it travels through the intestines, the capsule automatically takes pictures.
Disclaimer: Due to rapid research advances and new treatments, there may be changes to this information over time. You should always check with your health care provider to get the most current information. The Crohn's & Colitis Foundation of America provides information for educational purposes only. This information should not replace the recommendations and advice of your health care provider.

About CCFA

Established in 1967, the Crohn’s & Colitis Foundation of America (CCFA) is a nonprofit, volunteer-driven organization whose mission is to cure Crohn’s disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.

WE CAN HELP!

888.MY.GUT.PAIN (888.694.8872)
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IBD = Inflammatory Bowel Diseases

- Two major types
  - Crohn's disease (CD)
    - Inflammation anywhere in the gastrointestinal tract
  - Ulcerative colitis (UC)
    - Inflammation limited to colon and/or rectum

Statistics

- 1.6 million affected in the USA
- 70,000 new IBD cases per year
- Often diagnosed between ages 15–35

Disease Info

- Common symptoms
  - Diarrhea
  - Weight loss
  - Feeling tired
- Things that can trigger or boost symptoms
  - Not taking and missing medication
  - Use of nonsteroidal anti-inflammatory drugs (NSAIDs)
  - Eating certain foods that make existing symptoms worse
  - Ongoing stress that makes existing symptoms worse

Treatment Options

- Prescription medication (Rx)
- Over-the-counter (OTC) medication
- Surgery
- Nutritional support therapy
  - Remember to take medication even when you don’t feel like it or you feel ok

Diet and Nutrition

- Maintain a healthy diet (www.choosemyplate.gov)
- Keep a food journal (www.ccfa.org)
- Avoid high-fiber foods during a flare-up like popcorn, seeds, and nuts
- Get enough calcium
  - Ages 9–18yrs, 1200–1500 mg/day

Things You Can Do

- Ask for school accommodations
  - “Stop the clock” testing
  - Unlimited bathroom breaks
- Regular exercise
  - At least 1 hour each day
- Get enough sleep
  - 7–9 hours each night

Coping Options

- Join a support group
  - www.ccfa.org/chapters/
- Connect with college students at
  - www.ccfa.org/campus-connection
- Relax and destress with
  - Yoga
  - Tai Chi
  - Meditation
- Attend Camp Oasis
  - www.ccfa.org/kidsteens/camp

Use CCFA Tools and Resources

- GI Buddy for iPhone and Android
  - www.ccfa.org/gibuddy
- Download free brochures
  - online.ccfa.org/brochures
- Teen website www.ccfa.org

For More Information:

- www.ccfa.org
- 888-694-8872
- info@ccfa.org
My IBD Journal

You will have some concerns and questions about your treatment, diet, and living with IBD. Below are some questions you may want to ask your doctor or other health care professional. We left space so you can fill in the answers and keep track of other important information.

Questions to Ask the Doctor

Which type of IBD do I have and where is the inflammation located?

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What medications will I need to take and how often? (Be sure to keep a list of your medications, use the medication log on page 11.)

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Once I start the medication, how long will it take for it to work and for my symptoms to go away?

Will I be able to continue to play sports, dance or other activities that I normally do?

To get the answers to your questions, contact an Information Specialist at the CCFA IBD Help Center at info@ccfa.org, www.ccfa.org, or by calling (888) 694-8872.
Other Questions for My Doctor
If you have more questions for the doctor, write them down and take them with you to your next office visit.

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Important Phone Numbers
Be sure to keep a list of your GI doctor, nurse, pharmacy, and other important phone numbers.

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Foods that are good for me and foods that cause me problems.
With IBD you’ll need to pay more attention to what you eat. Keep track of foods that don’t cause you problems and foods that make your symptoms worse.

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Other Important Information about My Health
Keep track of your symptoms and other important information that will help you and your health care professionals manage your health.

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