










# A guide for teens with IBD

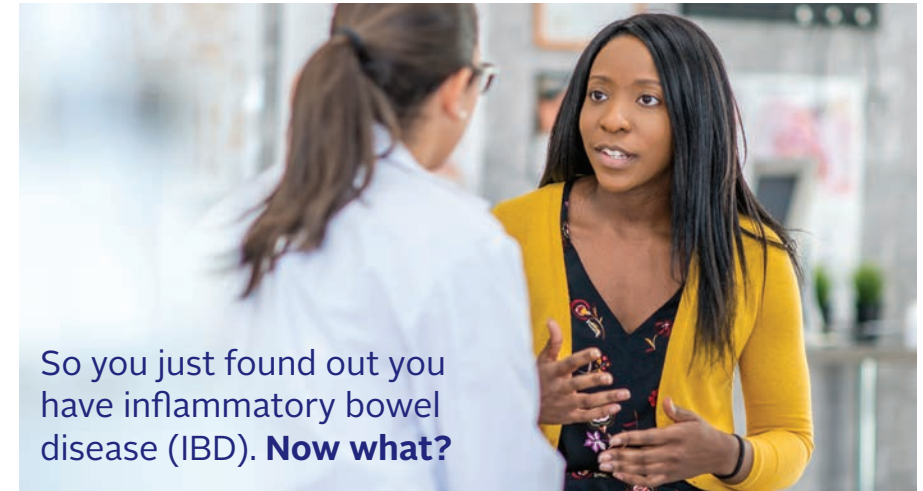


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Look in the center of this booklet for this handy quick-reference pullout on important IBD information you should know. On the back is a journal to write down answers to questions. Take it with you to your doctor visits or to school to help educate your teachers or friends about IBD.




It's normal to feel overwhelmed with this new diagnosis. We know it sounds scary, and you probably have a lot of questions. Some of the questions newly diagnosed patients ask are:

- What is IBD?*
- How did I get it?*
- Can my disease be cured?*
- How will IBD change my life?*
- Will I be able to go to school, hang out with my friends, or play sports?*

That's why we wrote this booklet—to help you and other teens find the answers to your questions, access important information, and get support to help you as you get used to living with IBD.

On the following pages, you'll find some worksheets and discussion guides to help you talk about your disease with your healthcare team. We encourage you to take these materials with you when you see your healthcare providers and use them to help educate your teachers or friends about your disease. Parents and caregivers, these resources will also help you discuss IBD with your teen!

 You'll also see some italicized and bolded words throughout this brochure. You can find the definitions of these words in the glossary on page 36.





## What is IBD?

**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 the parts of the body that take in and digest food. It begins with your mouth, continues down your throat into your **esophagus**, through your **stomach**, **small intestine**, **large intestine**, **rectum**, and ends with your **anus** (Figure 1). Inflammation impairs the ability of your affected organs to work correctly.

Crohn's disease and ulcerative colitis are very similar, but there are important differences. For some, their IBD has features of both Crohn's disease and ulcerative colitis. Sometimes, it's hard to clearly distinguish between the two. When this happens, it is called **indeterminate colitis (or IBD unclassified)**.

### What are the symptoms of IBD?

Inflammation can prevent your GI tract from working normally, which can lead to IBD symptoms.

#### THE GASTROINTESTINAL (GI) TRACT

- 1 Oral Cavity (mouth)
- 2 Esophagus (throat)
- 3 Liver
- 4 Stomach
- 5 Small Intestine
- 6 Large Intestine/Colon
- 7 Rectum
- 8 Anus

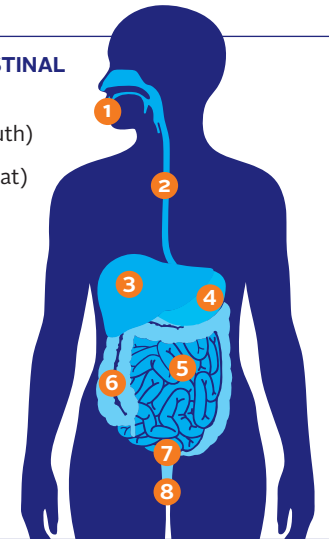


Figure 1

Your symptoms will depend on which disease you have, where it's located within the GI tract, and how severe it is. Your symptoms may change over time or even disappear for a while. Keep in mind that you may not have every symptom, and IBD is not the same for everyone. Symptoms often go away once the inflammation is under control and you enter a period called **remission**. When symptoms return, it is called a **flare**.



Crohn's Disease	Ulcerative Colitis
<ul style="list-style-type: none"> <li>• Affects any part of the GI tract, from the mouth to the anus</li> <li>• Often affects the end of the small intestine (the ileum) where it joins the beginning of the colon</li> <li>• May appear in “patches,” affecting some areas of the GI tract while leaving other sections completely untouched</li> <li>• Inflammation may extend through the layers of the intestinal wall</li> </ul>	<ul style="list-style-type: none"> <li>• Limited to the large intestine (colon) and rectum</li> <li>• Can involve the entire colon or can be limited to the lower colon</li> <li>• Usually starts at the end of the colon (rectum) and can spread upward to other areas of the colon</li> <li>• Inflammation occurs only in the innermost layer of the intestinal wall</li> </ul>

Common symptoms/signs of IBD are:

- An urgent need to go to the bathroom
- Frequent **diarrhea**, sometimes bloody
- Poor growth
- Lack of appetite
- Nausea
- Weight loss
- **Fatigue** (extreme tiredness and low energy)
- Abdominal pain
- Mouth **ulcers** (canker sores)

Sometimes symptoms of IBD occur outside the GI tract and include:

- Joint pain and stiffness
- 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 active symptoms of IBD, it may happen later. It's important that you and your

parents discuss your development with your healthcare providers (HCP).

### How did I get IBD?

Millions of people in the United States live with IBD. People of any age can develop IBD, and it is most often diagnosed 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're learning more every day about why people develop IBD and how to prevent it. Scientists suspect that a combination of four factors leads to IBD:

- **Genetics:** There are certain **genes** (family traits) that make it more likely for some individuals to get IBD. However, some people may carry these genes but never develop the disease themselves.
- **Environmental triggers:** Coming in contact with certain bacteria and other microbes, medications, cigarette smoke, and toxins can trigger an inflammatory response and the onset of IBD.
- **Gut bacteria:** Inflammation can occur if there are too many bad bacteria in the intestine, making the good and bad bacteria unbalanced.

- **Immune system response:** Inflammation can occur if the **immune system** mistakes something helpful (like good bacteria) for something harmful (like bad bacteria) and attacks it, causing inflammation.

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

### Can IBD be cured?

There are currently no cures for IBD, and it is a lifelong, chronic disease. This might sound scary, but we are making great strides every day toward finding cures for Crohn's and colitis. Until there are cures, there are many effective treatments that can control inflammation and the symptoms it causes. Researchers are making incredible progress, and many new treatments and technologies are being developed as you read this!

Check out a more detailed explanation of these illnesses at [www.crohnscolitisfoundation.org/what-is-crohns-disease](http://www.crohnscolitisfoundation.org/what-is-crohns-disease) or [www.crohnscolitisfoundation.org/what-is-ulcerative-colitis](http://www.crohnscolitisfoundation.org/what-is-ulcerative-colitis)







## What about treatments?

You'll want to talk with your doctor about what treatment(s) might be right for you and your disease. Treatment for IBD typically includes a combination of prescription medications and over-the-counter medications that you can buy without a prescription.

It's important that you be open with your care team about your symptoms, concerns, and what you hope to get out of your treatment. Your doctors and other healthcare providers will recommend one or a combination of medications to see what works best for you. Living with IBD is a very individual

experience, and treatments can be different for everyone. Therefore, the medication plan will be different for each person. If you know someone else with IBD, their treatment plan will likely not be the same as yours.

There are five different types of prescription medications that your healthcare provider may recommend for your IBD. Each type works in a slightly different way. Medication to treat IBD can be taken in a few ways:

- Oral medications are tablets or liquids that are taken by mouth
- Rectal medications are **suppositories** or **enemas** that can be inserted into your anus



Figure 2

Drug Category*	Purpose*	Some Possible Side Effects*
<b>Aminosalicylates</b>	<ul style="list-style-type: none"> <li>• Reduce intestinal inflammation</li> <li>• Induce and maintain remission</li> </ul>	<ul style="list-style-type: none"> <li>• Diarrhea</li> <li>• Headache</li> <li>• Nausea</li> </ul>
<b>Antibiotics</b>	<ul style="list-style-type: none"> <li>• Fight infection</li> <li>• Maintain the balance between good and bad bacteria in the intestines</li> </ul>	<ul style="list-style-type: none"> <li>• Allergic reactions</li> <li>• Drug-specific side effects</li> <li>• Diarrhea</li> </ul>
<b>Biologic Therapies</b>	<ul style="list-style-type: none"> <li>• Block proteins that cause inflammation</li> <li>• Reduce signs and symptoms of IBD</li> <li>• Induce and maintain remission</li> </ul>	<ul style="list-style-type: none"> <li>• Allergic reactions</li> <li>• Reduced ability to fight infections</li> <li>• Infusion reaction pain at the injection site</li> </ul>
<b>Biosimilar Therapies</b>	<ul style="list-style-type: none"> <li>• Nearly identical copies of other already approved biologic therapies</li> </ul>	<ul style="list-style-type: none"> <li>• Specific to each medication, usually very similar to the side effects seen with biologic therapies</li> </ul>
<b>Corticosteroids</b>	<ul style="list-style-type: none"> <li>• Suppress the immune system</li> <li>• Control flares</li> <li>• Reduce inflammation</li> </ul>	<ul style="list-style-type: none"> <li>• Weight gain</li> <li>• Face swelling ("moon" face)</li> <li>• Difficulty sleeping</li> <li>• Mood swings</li> <li>• Infection</li> <li>• Acne</li> <li>• Risk of osteoporosis</li> </ul>

\*This list is not a complete description of medications, purposes and side effects. Some of these medications may cause other adverse reactions and in rare cases increase risk of cancer. Be sure to speak with your healthcare provider regarding your individual benefits, risks, and side effects. For more information about IBD medications, check out our IBD Medication Guide at: [www.ibdmedicationguide.org](http://www.ibdmedicationguide.org)



Drug Category*	Purpose*	Some Possible Side Effects*
<b>Immunomodulators</b>	<ul style="list-style-type: none"> <li>• Suppress the immune system</li> <li>• Induce remission</li> <li>• Maintain remission</li> </ul>	<ul style="list-style-type: none"> <li>• Nausea</li> <li>• Inflammation of the liver (hepatitis) or pancreas (pancreatitis)</li> <li>• Reduced ability to fight infections</li> <li>• Immunomodulators may take a few months before they start working</li> </ul>
<b>Janus Kinase (JAK) Inhibitors</b>	<ul style="list-style-type: none"> <li>• Suppress the immune system</li> </ul>	<ul style="list-style-type: none"> <li>• Common cold symptoms</li> <li>• Headache</li> <li>• Diarrhea</li> <li>• Blood clots</li> </ul>
<b>Over-the-Counter Medicine</b>	<ul style="list-style-type: none"> <li>• Control symptoms of IBD, like diarrhea, constipation, and pain</li> </ul>	<ul style="list-style-type: none"> <li>• Specific to each medication</li> </ul>

- **Intravenous** medications are delivered directly into your bloodstream through insertion of an IV
- **Subcutaneous** medications that are given through a shot
- Topical medications that are applied directly to areas of inflammation including the mouth, eyes, or skin

Every medication comes with potential benefits and side effects. Figure 2 shows you the purpose and side effects of different types

of drugs typically prescribed to IBD patients. You'll want to discuss what to expect from your medications with your healthcare team. If you experience side effects, let your parents and healthcare professionals know immediately. Do not stop taking your medication without talking to your healthcare provider first. If you are experiencing any severe reactions, or changes in symptoms, you and your parent(s) should be sure to consult with your healthcare provider.





How do I keep track of my medicine?

The best way to get control of your symptoms and get into remission is to follow the treatment plan your healthcare provider has prescribed. This is called **adherence**, and it is your responsibility to stay on top of your health. Even if you are feeling great, it is very important to continue your treatment. If you stop taking your medication, you risk a flare.

Some strategies that patients find useful to stay on top of medications include:

- Using a reminder app or an alarm clock on your phone.
- Making a chart that lists your medicine, and checking it off when you've taken it (see next page).
- Sorting a whole week's pills into a pillbox; it will be easy to see what you've taken (as well as any missed medications).



Purpose (why do you take it?), Comments, or Special Instructions									
Symptoms or Side Effects									
Times Taken Daily									
Dosage/Strength									
Stop Date									
Start Date									
Form (pill, liquid) and/or Method Taken (oral, rectal)									
Name of Medication									



## Surgery

Surgery may be suggested if medication is not working to control your symptoms or address your disease adequately. Although it is common among patients with IBD, it's important to remember that not every patient will require surgery.

The type of surgery you might have depends on your disease type, location of disease in the GI tract, response to medications, and symptoms. After surgery, your healthcare provider may recommend that you continue medication. Even with surgery, it's possible that your IBD symptoms will reoccur. That's why continuing your treatment plan, as prescribed by your healthcare provider, is important.

## Tests and procedures

You probably had several tests before your final diagnosis of IBD, but the testing doesn't stop there. Throughout your disease journey, you'll likely need to have follow-up blood, stool, and imaging tests, such as **colonoscopy**, **upper endoscopy**, **video capsule endoscopy** (pill camera), **computerized tomography (CT)**, or **magnetic resonance imaging (MRI)**. These tests help your healthcare provider monitor your progress and/or make changes to your treatment.

## Managing uncomfortable symptoms

While they will treat many of your symptoms, the medications that are prescribed for you may not get rid of all your symptoms. Sometimes your healthcare provider may recommend using over-the-counter products to help address:

- Diarrhea
- Bloating and gas
- Joint pain and fever
- Irritation of the skin around the anus and other uncomfortable symptoms

If you experience symptoms or discomfort, be sure to write them down and let your parents and healthcare provider know about them.

## Nutritional support therapy

IBD can affect the digestion of food. Sometimes the food we eat normally (by mouth) is not digested well, so we don't get the nutrients we need. IBD can also decrease your appetite so you don't feel like eating, even when you need to.

In these cases, your healthcare provider or dietitian may suggest that you use nutritional support therapy. There are a few types that can be prescribed based on your **disease activity** and nutritional needs:

## Parenteral and Enteral Nutrition

### PARENTERAL NUTRITION

Feeding intravenously, bypassing the usual process of eating and digestion.

- A Feeding through the central vein
- B Feeding through peripheral veins

### ENTERAL NUTRITION

Liquid supplemental nutrition is either taken by mouth or is given via a feeding tube.

- Nasal or oral feeding tube terminates at, either:
  - C Stomach (Nasogastric)
  - D Duodenum (Nasoduodenal)
  - E Jejunum (Nasojejunal)
- F Feeding tube that leads through an artificial external opening into the stomach (Gastrostomy)
- G Feeding tube that leads through an artificial external opening into the small intestine (Jejunostomy)

• **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

- › There are two types of enteral nutrition:
  - › Partial enteral nutrition, which will deliver 30-50% of your calories from formula and the remainder from regular food.
  - › Exclusive enteral nutrition, which will deliver all the calories, vitamins, and minerals you need through a prescription formula, and you do not eat regular food.

• **Parenteral nutrition** delivers necessary nutrients and calories directly into your bloodstream through a thin intravenous tube called a catheter that is inserted directly into a large vein in the chest, arm, or neck.

Using nutritional support therapy allows your body to get healthier and gives your GI tract a chance to heal. In some pediatric patients with Crohn's disease, exclusive enteral nutrition can actually lead to remission.







## How does food affect my IBD symptoms?

**Diet** (what you eat) and **nutrition** (absorbing food and staying healthy) are important parts of managing your IBD. Since IBD affects the organs responsible for absorbing vitamins, nutrients, and water, it is important that you maintain a healthy diet and get proper nutrition.

IBD tends to increase the body's need for calories, nutrients, and energy. During disease flares, it may be hard to maintain adequate nutrition. Although what you eat won't cause a flare, it can make you feel worse during one. However, if you maintain good nutrition, it can improve your overall wellness, promote healing and immunity,

increase your energy levels, and can lessen some gastrointestinal symptoms. Once you have your symptoms under control, you may be able to eat the foods you want once again.

So, you probably want to know what you should eat, or if there is a diet you should follow. Right now, there is no one-size-fits-all approach for diet, though lots of research is happening to better understand how certain diets affect IBD symptoms. In general, you want to make sure you are eating a well-balanced diet with an adequate intake of protein, carbohydrates, fats, vitamins, and minerals. This can be achieved by eating a variety of foods from all the food groups.

Figure 3 shows the healthy balance

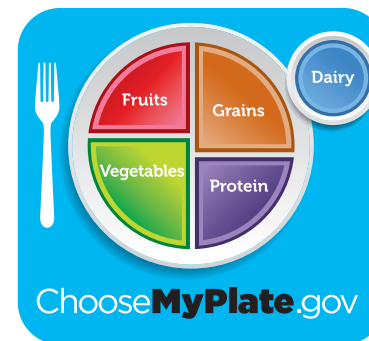


Figure 3



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.

Now, you probably think that there's no way you can eat all these foods, and that might be true. Some patients find it hard to digest certain foods, such as raw vegetables or fruits with skin or seeds. Others have trouble with dairy or meat. It's important to pay attention to what you eat so you can identify what foods work or don't work for you.

Keeping a food diary or journal is a great way to keep track of what you are eating and how your body responds. 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. If you feel the need to limit certain foods, make sure you speak with your healthcare provider or a dietitian to ensure that you are getting those nutrients from another source, such as a vitamin or supplement.

When experiencing symptoms, here are some general tips:

- Eat smaller meals more often.
- Reduce the amount of greasy or fried foods you eat.
- Avoid trigger foods (foods that make your symptoms worse).
- Ask your healthcare provider about limiting certain high-fiber foods, such as seeds, nuts, popcorn, beans, green leafy vegetables, wheat bran, and raw fruits, if these foods make your symptoms worse.
- Limit drinking milk or milk products if you are lactose intolerant (when you can't tolerate the sugar in milk).
- Avoid caffeine in coffee, tea, soda and other beverages. Caffeine can act as a stimulant to "rev" up the bowel, resulting in diarrhea.
- If your healthcare provider approves, consider vitamin and mineral supplements, such as vitamin D and calcium.
- Drink extra fluids. With IBD, it may be easier for you to become **dehydrated**, especially when you are experiencing a flare.



## 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:

- Try not to go out feeling too hungry. You may not make the best food choices if you are being 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 with your favorite drink 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 or asks questions, help educate them about IBD and your diet.







## Life with IBD

Many parts of your life may be affected by your IBD. However, there are things you can do to make your day-to-day life easier. Although people with IBD might have ongoing symptoms and flares, you can still live a successful, productive, and fulfilling life. Here are some answers to questions you might have:

### **Will I be able to go to school, hang out with my friends, or play sports?**

Absolutely! The goal of treating your disease is to get your symptoms under control so you can get back to being a teen. 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 are too tired.

### **How do I cope with symptoms?**

You can't predict when your IBD symptoms may become a problem. There will be periods lasting from weeks to years where you'll feel well, and other times when your IBD symptoms will recur and require some additional attention.

However, you are more than your IBD. It's important to accept your illness and continue to do what you enjoy. Here are some things you can still do, even with IBD:

- Explore the activities you enjoyed before IBD and try new ones. Modify them, if you need to, so you can participate and enjoy fully.
- Form friendships with people who understand and support you.
- Participate in a regular exercise routine, with your healthcare provider's approval. Exercise can improve overall health, reduce stress, and help to maintain and improve bone strength.

Please let your parents or healthcare provider know if your symptoms are making it difficult to live your life, as there may be changes to your medications, or other treatments that can help.





## What about my emotional health?

Living with a lifelong disease can affect your mental health and emotional well-being. It's normal to feel anxious, depressed, or stressed throughout your disease journey. Coping with the emotional burden of your disease can be hard, but it's important to remember that you aren't alone. Making sure you are getting help and support for your mental health and emotional well-being is just as important as treating the physical symptoms of your disease.

Talking with your parents, friends, and other people with IBD can be helpful. If you need more help, talk to your healthcare provider or another professional, like a teacher or guidance counselor. These professionals have a lot of experience helping kids and teens with IBD and can discuss some coping strategies with you.

Stress is part of everyone's life, and you can't always avoid it. It's important to find ways to manage it because it can make symptoms worse and even cause more stress.

Learning stress reduction techniques can be helpful if you're finding it hard to manage your stress. There are many stress

management methods, and no one method has been proven to be more effective than any other. Try an approach that you like. If it doesn't work, try another. Here are some techniques you can try to help manage your stress:

- Relaxation and breathing exercises
- Meditation and mindfulness
- Reading books or listening to podcasts and music
- Practicing yoga, or other low-impact movements

You might also want to try attending a support group where you can connect with other teens who understand what you're going through. You can find a local support group in your community by going to:

[www.crohnscolitisfoundation.org/community-support](http://www.crohnscolitisfoundation.org/community-support)

## How can I be prepared?

There will be times when your disease is in deep remission and you feel great. But at other times, your IBD symptoms might be unpredictable and happen at the most inconvenient times. Just in case you need it, be prepared with emergency supplies. It can also help to obtain a Foundation "I Can't Wait" card and download a bathroom locator app to your phone.

You might want to keep a kit on you that includes the following:

- Toilet paper
- Wet wipes
- Hand sanitizer
- Small can of air freshener
- Disposable gloves (to handle any soiled clothes)
- Large-sized freezer bags (for the soiled clothes) or garbage bags
- Clean underwear
- Clean shorts, pants, or leggings (anything that you can wear until you get home)
- Cleaning supplies

## What will happen as I get older?

As you get older, you will begin to take more responsibility for managing your treatment. That way, by the time you are in college or living on your own, you will be able to take full control of your medical needs. If you can answer yes to the below questions, you're doing great!

### Younger Teens

- Can you describe your IBD?
- 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 that you have taken?
- Do you speak up when you're not feeling well?

### Older Teens

- Can you describe what will happen if you don't follow your treatment plan?
- Do you understand the impact that drinking alcohol and smoking can have 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?
- Do you carry your insurance card with you at all times?

Visit [www.crohnscolitisfoundation.org/campus-connection/managing-your-care](http://www.crohnscolitisfoundation.org/campus-connection/managing-your-care) and [naspghan.org/](http://naspghan.org/) for more information about transitioning to adult care.





## Talking about my disease

Talking about your disease to people who are unfamiliar with it can be hard. But the good news is that it's your decision who you tell and how much you share. You may find that it becomes easier over time to share details, but you should not feel pressured to share more than you are comfortable with.

Some people, like your parents, guardians, and the school nurse, might need to know more details about your disease, any symptoms you have been experiencing, and which medications you are taking. If you are away from home, maybe at college, someone needs to be your healthcare point person for when your healthcare provider is not available. They need to know your history, symptoms, and your emergency care plan. Others, like your friends, teachers, or 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 a question that makes you feel embarrassed. Here are some ideas (on page 24). Add your own questions









and think of some good answers (page 25).

### What about school?

You spend a lot of time at school, and IBD is unpredictable. Therefore, it's a good idea to make a plan with someone at school who knows what's going on.

The symptoms of your IBD and IBD treatments might affect your school attendance or performance. You might have to miss school when you have medical appointments or if you're feeling bad during a flare. Remember, you are still responsible for learning the required subject matter, but having a plan for accommodations will help make that process less stressful so you can thrive at school.



Questions I may be asked:	How I can respond:
 What's wrong with you?	 It's a chronic illness called inflammatory bowel disease, where part of my digestive system is inflamed.
 Can I catch it?	 Don't worry, you can't catch it. It's not contagious.
 Are you OK?	 My disease symptoms can come and go, and sometimes I'm in a lot of pain, but I'm okay overall. I might need to rest or take things easy at times.
 Why is your face so puffy?	 It's because of my medicine. It won't be like this for long. It will become less puffy once I finish taking this medicine.

Questions I may be asked:	How I can respond:
Add your own questions and answers below:	



## School accommodations

To help you meet all of your academic requirements, your parents can request a **504 (accommodation) plan**. Once you and your healthcare providers identify how your IBD could affect you in school, a 504 plan is created with school professionals that lists the accommodations, special services, or adjustments you need.

Once an evaluation of your needs is completed, changes to your school activities can be made. These accommodations can include, but are not limited to:

- The freedom to go to the bathroom whenever you need to
- Access to 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
- Help with classwork that you missed and having 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 are going 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 the brochure: A Guide for Teachers and Other School Personnel. It has information to help them understand IBD, its effect on you, and what they can do to help. *Find it and other resources at:* [www.crohnscolitis-foundation.org/brochures](http://www.crohnscolitis-foundation.org/brochures)



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

Travel takes planning, whether it's to the mall, to grandma's house in the next town, or across the country on an airplane. You can do it—just think ahead:

- Know the fastest route to the nearest bathroom.
- On a plane, train, or bus, sit near the restroom.
- Keep your medicine, snacks, and drinks within easy reach.
- Store your extra medicine and emergency supplies with you in your carry-on, just in case there are any airplane delays.
- Carry a letter from your healthcare provider describing your IBD and identifying any specific instructions they may give you.
- 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 health insurance cards and the health insurance company's phone number.



# Preparing for college, work, and more

Your teen years are filled with good, bad, and unexpected things. So how do you deal with all the changes in your life while living with IBD? Here's some information to help you navigate your future:

## College

You can still receive accommodations when you are in college, including undergraduate and graduate school. Section 504 of the Rehabilitation Act of 1973 and the **Americans with Disabilities Act (ADA)** prohibits public colleges, universities, and trade schools from discriminating against students with a disability. Note that if you had an IEP (Individualized Education Plan) or 504 Plan in high school, this does not automatically carry over to college. Although the accommodations you receive may be similar to those you received in the past, you must apply for accommodations through your college's Disability Resource Center (or equivalent department). To register with your school's disability office, you typically must submit acceptable proof of why you need accommodations and meet with the proper staff members to learn what accommodations are available

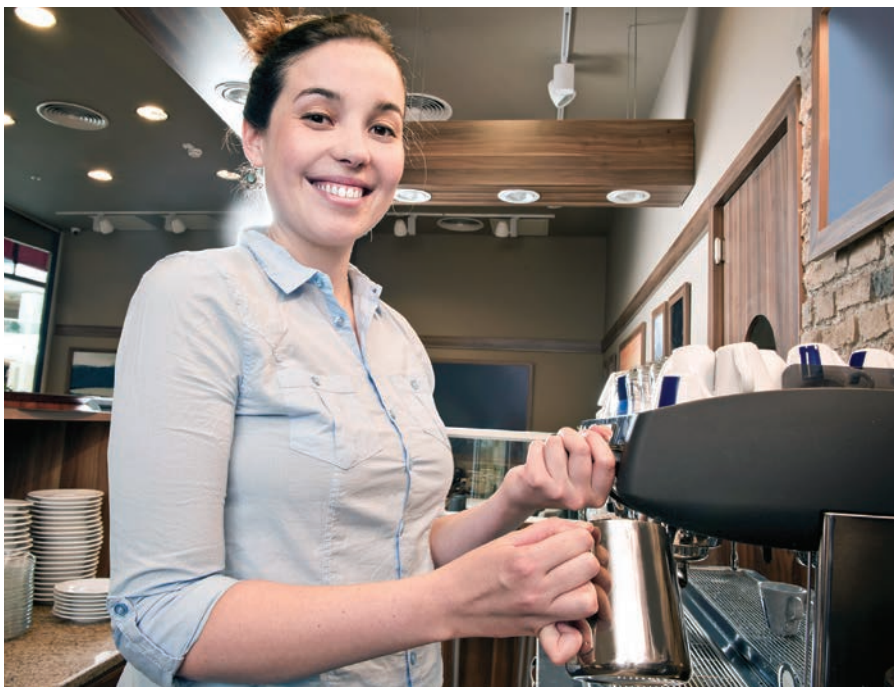
and what may be right for you. In college, these accommodations can also apply to dorm life and not just the classroom. They might include extended time on exams, adjusted deadlines and attendance, note-taking support, priority enrollment, and a private dorm room or bathroom. Talk to your school's disability office to arrange necessary accommodations, and visit the Crohn's and Colitis Foundation's Campus connection website at [www.crohnscolitisfoundation.org/campus-connection](http://www.crohnscolitisfoundation.org/campus-connection) for more information. 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 feel like it's necessary for you to discuss your IBD during 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 period, then you may want to discuss your need for any specific work accommodations. The 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. Smoking can also make IBD symptoms worse and may 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 and drugs

Alcohol affects each patient with IBD differently. The use or abuse of alcohol or other drugs, can have damaging effects on your GI tract and may interfere with your medications. Be sure to discuss your use of alcohol with your healthcare provider.

### Friends and dating

When dating or socializing with your friends, you may need to explain that because of IBD you might not always be able to go out. If you feel like talking more about it, that's up to you. IBD shouldn't prevent you from dating or having a successful and rewarding relationship. Whether you tell your partner about your IBD is up to you. If you're not sure, get some advice from a parent, friend, or maybe another IBD patient.

The bottom line is that you shouldn't feel pressured to share more than you're comfortable with at any time. If you choose to share information and the person doesn't respond well, it may not be healthy to have this person in your life.

### General healthcare maintenance

It's important to stay up to date with health maintenance in addition to staying on track with your IBD treatment. Remember to speak with your healthcare provider about general health issues, including:

- **Vaccinations:** Teens with IBD should generally follow the same vaccination schedules as the general pediatric population. If you are on immunomodulators or biologic therapy, you should avoid live virus vaccines. These live

virus vaccines can include but are not limited to the intra-nasal flu vaccine, measles/mumps/rubella (MMR), and varicella (chicken pox). Be sure you or your parents ask your healthcare provider about flu shots, HPV, pneumococcal and other immunizations.

- **Oral health:** Symptoms of IBD outside the GI tract may include aphthous ulcers in the mouth (commonly called canker sores). These may be caused by the IBD itself, or they might be due to a lack of nutrients that your body needs. These ulcers can be quite painful, and mouth rinses and other topical treatments may help relieve the discomfort. It is important to also see your dentist for routine dental care and checkups.

Visit the website that is specifically for college students with IBD: [www.crohnscolitisfoundation.org/campus-connection/](http://www.crohnscolitisfoundation.org/campus-connection/)

There are several important things to continuously check to ensure your body is healthy. For a full list of healthcare maintenance needs, check out our booklet: *Healthcare Maintenance Discussion Guide*, or share with your parent or caregiver. Find it and other resources here: [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).







## More information and support for IBD patients

The Crohn's & Colitis Foundation has resources and support that can help you manage your life with IBD.

- Contact the IBD Help Center at [info@crohnscolitisfoundation.org](mailto:info@crohnscolitisfoundation.org), 888.MY.GUT.PAIN (888.684.8872), or live chat ([www.crohnscolitisfoundation.org/community-support/ibd-help-center](http://www.crohnscolitisfoundation.org/community-support/ibd-help-center)) available Monday through Friday from 9 a.m.–5 p.m. ET.
- Visit the Foundation's website ([www.crohnscolitisfoundation.org/](http://www.crohnscolitisfoundation.org/)) to access resources for patients, caregivers, and healthcare providers.
- Read or download brochures and fact sheets about a wide array of IBD topics: [www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures).
- Find a list of the Foundation's support services: [www.crohnscolitisfoundation.org/community-support](http://www.crohnscolitisfoundation.org/community-support).
- Attend or volunteer at Camp Oasis, the Foundation's summer camp for kids with Crohn's and colitis: [www.crohnscolitisfoundation.org/camp](http://www.crohnscolitisfoundation.org/camp).
- Connect with and learn from college students with IBD on Campus Connection: [www.crohnscolitisfoundation.org/campus-connection/connect-with-others/](http://www.crohnscolitisfoundation.org/campus-connection/connect-with-others/).
- Find local education events and support programs: [www.crohnscolitisfoundation.org/chapters](http://www.crohnscolitisfoundation.org/chapters).
- Become a Foundation advocate by signing up for the advocacy network—join today at [www.crohnscolitisfoundation.org/advocacy](http://www.crohnscolitisfoundation.org/advocacy).

There are other websites that promise to help you with your IBD. Be careful—make sure they have a good reputation and are not offering a magic cure. A good way to check if they are credible is if they cite or reference research articles and other reputable sources. Always check with your parents or doctor before trying anything you read on the internet.



MORE INFO





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

### Research studies

You can help researchers find cures for Crohn's disease and ulcerative colitis by taking part in IBD Partners Kids and Teens. If you're under 18, your parents will have to join on your behalf and, twice a year, fill out an online survey about your health. Visit [ibdpartners.org](http://ibdpartners.org) to register or learn more.

### Other Ways to Get Involved

- Participate in Take Steps, Team Challenge, or spin4 crohn's & colitis cures. Find a fundraising event in your area:

[www.crohnscolitisfoundation.org/get-involved/fundraising-events](http://www.crohnscolitisfoundation.org/get-involved/fundraising-events)

- The Crohn's & Colitis Foundation has local chapters across the country. Each offers support programs and activities. Find one near you at [www.crohnscolitisfoundation.org/chapters](http://www.crohnscolitisfoundation.org/chapters)



## Final things to remember

We hope you now have a better understanding of your IBD diagnosis. Your journey with your disease will be full of ups and downs. Here are some quick things to remember as you navigate your new normal:

- Nothing you did or didn't do gave you IBD.
- You didn't catch it from anyone else and you can't give it to anyone.
- Most people who live with IBD are healthy more often than they are sick.
- Ask your healthcare provider questions so you can learn more about managing your disease.
- Understand that sometimes the disease might be a hurdle, but overcoming these hurdles will make you stronger.
- Keep working toward your goals. Remember that there is an IBD community of other patients, including doctors, lawyers, celebrities, professional athletes, teachers, and people from all walks of life.
- Keep track of your medication, disease symptoms, and foods that cause you problems using helpful tools like:
  - › Food journal
  - › Medication log
  - › Reminder apps
- You are not alone! Get support from:
  - › Family and friends
  - › Other IBD patients
  - › Healthcare professionals
  - › Crohn's & Colitis Foundation

# Glossary

## **504 (accommodation) plan—**

This act requires organizations and schools that receive federal funding to provide appropriate educational services that support children with special health needs.

**Absorption**—This is when something is incorporated or taken into another, like when lotion is absorbed into your skin, or nutrients are absorbed into your body in the GI tract.

**Adherence**—Taking medications correctly, as prescribed by a healthcare professional.

**Americans with Disabilities Act (ADA)**—A civil rights law that prohibits discrimination based on disability.

**Antibiotics**—Medications that treat infections and slow down the growth of bacteria.

**Anus**—The opening where the rectum ends.

**Biologic Therapy**—A group of medications used in the treatment of IBD. These medicines work to stop certain proteins in the body from causing inflammation.

**Biosimilar Therapies**—Therapies used to treat IBD that are designed to be near-identical copies of approved biologic therapies.

**Chronic**—This is used to describe lifelong illness.

**Colonoscopy**—This test involves using a long flexible tube with a camera on the end, which is inserted into the anus. This procedure is used to take pictures and/or remove a small piece of tissue (biopsy) from the intestines.

**Corticosteroids**—Medication that decreases inflammation by suppressing the immune system. This helps symptoms get better quickly. This is usually not used as a long-term medication.

**Crohn's disease**—One type of inflammatory bowel disease. With Crohn's disease, inflammation and ulcers can be found in any part of the GI tract.

**Computerized Tomography (CT)**—This scan uses X-ray images to create detailed three-dimensional images of the body that can show inflammation. These tests are usually used to understand how IBD has changed in the body over time.

**Dehydration**—This is the loss of water in the body. It often happens to a person when diarrhea continues for a long time or a person isn't drinking enough water.

**Diarrhea**—When bowel movements are too often, too soft, or too loose.

**Diet**—The combinations of foods that you eat.

**Digestion**—The process of breaking down food into substances that can be used by the body.

**Disease Activity**—Disease activity is based on your symptoms, laboratory results and findings on imaging studies, endoscopy, or colonoscopy. Disease activity can impact the way you feel, how well you can participate in daily life activities and your overall health and well-being. When your disease is very active, we often call this a flare. When your disease is quiet, we call this remission.

**Enema**—Medicine that is injected into a person's rectum.

**Enteral Nutrition**—Any method of feeding that uses the gastrointestinal tract. This may include taking nutrition by mouth or using a tube that goes into the stomach or small intestine.

**Esophagus**—A tube inside the body connecting the mouth to the stomach.

**Flare**—When IBD symptoms reappear after a period of low or no activity. The symptoms can get worse over time or get worse suddenly.





**Fatigue**—The feeling of extreme tiredness and exhaustion.

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

**Genes**—These are basic units of heredity that help determine what characteristics a child will develop from parents.

**Immune system**—A system of tissues and cells in the body that works to protect it from foreign substances and disease.

**Immunomodulators**—Medications that change the way the immune system works.

**Indeterminate colitis (IBD-unclassified)**—A type of IBD that shares characteristics of both Crohn's disease and ulcerative colitis but cannot be classified as either.

**Inflammation**—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 chronic inflammation inside the gastrointestinal tract. These include Crohn's disease and ulcerative colitis.

**Intravenous**—Taking place within the vein or veins.

**Janus Kinase (JAK) Inhibitors**—A special class of medications that suppress the immune system by preventing the activation of immune system cells that cause inflammation.

**Large intestine**—The last part of the gastrointestinal tract where water and stool (poop) is stored before leaving the body.

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

**Nutrients**—These are substances that the body needs to live and grow. Examples include vitamins, proteins, and carbohydrates.

**Nutrition**—There are substances like food, vitamins and minerals, needed for health and growth.

**Over-the-counter**—Medications that can be bought at most retail pharmacies without a prescription.

**Parenteral nutrition**—A nutrition method involving delivering nutrients and calories directly into the bloodstream.

**Puberty**—The process of physical changes where a child's body matures into an adult body.

**Rectum**—The last part of the large intestine, just before the anus.

**Remission**—The period of time when inflammation and symptoms from IBD are under control.

**Small intestine**—An organ in the GI tract where most of the digestion of food and absorption of nutrients and minerals takes place.

**Stomach**—The organ where the digestion of food begins after it is swallowed.

**Subcutaneous**—Under the skin.

**Suppository**—A way to deliver a medication into the body. It's often a small, round object that is inserted through the anus and into the rectum. The suppository then melts to release the medicine.

**Symptom**—A change in how you feel or your physical appearance that is a sign of illness or health concern.

**Ulcer**—A break in the skin or lining of the GI tract. In Crohn's disease, ulcers can occur anywhere between the mouth and the anus. In ulcerative colitis, ulcers can occur in the colon.

**Ulcerative colitis**—One type of inflammatory bowel disease in which inflammation and ulcers are found in the large intestine and rectum only.

**Upper endoscopy**—A procedure that uses a small scope with a light and camera to look inside the esophagus, stomach, and first part of the small intestine.

**Video capsule endoscopy**—A procedure that allows your doctor to view areas of the small intestine 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.



## About the Crohn's & Colitis Foundation

Established in 1967, the Crohn's & Colitis Foundation is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn's disease and ulcerative colitis, and improving the quality of life of children and adults affected by these diseases. Since our founding, the Foundation has remained at the forefront of research in Crohn's disease and ulcerative colitis. Today, we fund cutting-edge studies at major medical institutions, nurture investigators at the early stages of their careers, and finance underdeveloped areas of research. In addition, the Crohn's & Colitis Foundation provides a comprehensive series of education programs, printed and online resources, support services and advocacy programs to members of the IBD community, including patients and caregivers.

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# Quick facts about IBD

## For More Information:

 [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org)

 **800-932-2423**

 [info@crohnscolitisfoundation.org](mailto:info@crohnscolitisfoundation.org)

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### Find Tools and Resources

Download free brochures:  
[www.crohnscolitisfoundation.org/brochures](http://www.crohnscolitisfoundation.org/brochures)

Visit our teen website:  
[www.crohnscolitisfoundation.org/justlikeme](http://www.crohnscolitisfoundation.org/justlikeme)

1



### IBD = Inflammatory Bowel Disease

Two major types

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

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

2



### Statistics

Millions affected in the USA

70,000 new IBD cases per year

Often diagnosed between  
ages 15–35

3



### Disease Info

Common symptoms:

- Diarrhea
- Weight loss
- Feeling tired

Things that can trigger or cause symptoms:

- Not taking or 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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### Coping Options

Join a support group:  
[www.crohnscolitisfoundation.org/chapters/](http://www.crohnscolitisfoundation.org/chapters/)

Connect with college students:  
[www.crohnscolitisfoundation.org/campusconnection](http://www.crohnscolitisfoundation.org/campusconnection)

To help relax and de-stress try:

- Yoga
- Breathing exercises
- Meditation

Find a Camp Oasis near you:  
[www.crohnscolitisfoundation.org/campoasis](http://www.crohnscolitisfoundation.org/campoasis)

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### Things You Can Do

Ask for school accommodations

Regular exercise

- At least 1 hour each day

Get enough sleep

- 7–9 hours each night

Participate in research, and visit our  
Clinical Trials Community:

[www.crohnscolitisfoundation.org/clinical-trials](http://www.crohnscolitisfoundation.org/clinical-trials)

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### Diet and Nutrition

Maintain a healthy diet  
([www.MyPlate.gov](http://www.MyPlate.gov))

Keep a food journal

Get enough calcium

Talk to your healthcare team to make  
sure you are getting all the nutrients  
your body needs

4



### Treatment Options

Prescription medication (Rx)

Over-the-counter (OTC) medication

Surgery

Nutritional support therapy



Email us: [info@crohnscolitisfoundation.org](mailto:info@crohnscolitisfoundation.org)  
Call us: 1-888-MY-GUT-PAIN (888-694-8872, extension 8)  
Get answers to your questions. Our helpline is available Monday through Friday from 9 a.m. to 5 p.m. ET

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

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



## My IBD Journal

You might have some questions about your treatment, diet, and living with IBD. Below are some questions you might want to ask your doctor and other healthcare professionals. We left some 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?

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

Other Questions for My Healthcare Team  
If you have other questions for your healthcare providers, write them down and take them with you to your next visit.

**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.

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