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## EVERYDAY Living

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

# Keeping open lines of communication will help your healthcare team work together.

## Ensuring Care

### Building an effective medical team

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

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

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

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

### How to find a doctor

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

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

## Special Populations

### Pregnancy and IBD

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

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

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

### Children with IBD

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


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

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

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

### Transitioning from pediatric to adult care

Many people with IBD are diagnosed as children or teens. As a young patient reaches the transition to adulthood, making the move from pediatric to adult care becomes important. Adult patients have different needs than young people, and adult providers have more experience addressing adult concerns. Your pediatric specialist may have some recommendations for you when the time comes.



“It’s understandable  
that you will  
go through periods  
of stress.”

MARY, GI Nurse

# Keep in mind that your dietary needs may change over time.

## Managing Your Disease

### Diet and nutrition

Two of the most frequently asked questions from IBD patients are “What can I eat?” and “What shouldn’t I eat?” While dietary choices can certainly have an impact on symptoms, IBD is not caused or cured by any particular food. Because each person’s disease is unique, there is no universal solution. Generally, people with IBD should aim to have a nutrient-rich, well-balanced diet with plenty of fruits, vegetables, grains, and lean sources of protein. Keeping hydrated with plenty of fluids is also important.

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

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

### Here are a few tips:

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

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

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

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

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- 5 Talk to your healthcare team about any nutritional deficiencies that may require supplementation. You may wish to discuss your needs with a registered dietician or nutritionist.**

## **Coping and managing stress**

Living with a chronic disease obviously impacts physical health, but it can also take a toll on emotional well-being. Learning to cope with challenges and managing stress are critical components of healthy living.

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

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

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

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

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

## **Lifestyle Challenges**

### **The people in your life**

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

For these and other reasons, relationships become an important factor for IBD patients. "Who do I tell?" "How do I tell them?" "How do I ask for help?"

“How do I deal with misunderstanding?” Trust and communication are the two keys to approach these common concerns.

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

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

## **Remember that loved ones will also experience some stress.**

### **Support for caregivers**

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

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

### **Accommodations at work and school**

Negotiating the accommodations you need with friends and family is one thing, but it can be even more challenging to do so with supervisors, coworkers, teachers, and other people who you are not as close to. Regardless, there are things that can be done at the workplace or at school to make life a little easier.

Perhaps your desk, office, or locker can be moved closer to the restroom. Maybe you can arrange for access to a private restroom. At some schools, there is one at the nurse's office. At college (and at larger companies), there is usually an office specifically tasked with arranging accommodations for people with special needs—everything from dorm room selection, to flexibility with schedules, exam-taking, or other concerns. Don't be afraid to ask for these or other accommodations that can make your life easier.

### **Financial management**

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

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

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

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

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

### **KEY TAKEAWAYS**

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

**Good communication and planning will help things go smoothly along your journey. Don't be afraid to ask for help when you need it.**