

# Fact Sheet

## News from the IBD Help Center

### MANAGING IBD AS A YOUNG ADULT

We know that living with inflammatory bowel disease (IBD) at any age can be challenging. As a young adult between the ages of 18-25, you may find it particularly demanding. Moving from childhood to adulthood is a big change, especially when you have a chronic illness, but you can help make the transition into adulthood easier and improve your quality of life by adopting a strategy for managing your disease.

As a young adult, you are expanding your independence and facing a lot of big decisions—the next step in your education, starting your career, or taking on other new adventures. If you have IBD, in addition to these big life decisions, you are also taking on the responsibility of managing your health. Here are some things to keep in mind as you begin to come up with a plan for taking charge of your IBD care:

#### Managing Your Own Care

During your teens to early 20s, you'll likely begin the process of **transitioning** to adult care. During this time, you will gain skills and knowledge to help you begin independently managing your own care. When you are finally ready to make the switch, you will **transfer** your care to an adult gastroenterologist. Here is a short checklist for selecting and transitioning to a new physician's care:

- Consult your health insurance plan for a list of approved gastroenterologists in your area.
- Seek help from your primary care physician (PCP) and pediatric gastroenterologist in narrowing down your options.
- Look for a gastroenterologist who specializes in IBD or treats a significant number of IBD patients.
- The ideal gastroenterologist is someone who will be a good partner in managing the treatment of your disease. That means you need to feel comfortable engaging in open dialogue with your doctor and their staff.

As you transfer your care, make sure you have a complete and current file of your medical and laboratory reports. You should know:

- Disease location and history, including any surgeries
- Past and current medications, their respective dosages, and their interactions and side effects
- When to follow up with your new gastroenterologist and/or have labs checked
- How to follow up on test results
- The names and contact information of both your previous and new doctor

#### Treatment Facilities

From time-to-time, you'll need a place to get scopes, infusions, or other procedures. And, even when you do your best to manage your disease, it may be necessary to be hospitalized for medical or surgical treatment. That's why it's important to be prepared before issues happen. Here is a short checklist for selecting a treatment facility:

- Consult your health insurance plan for a list of approved facilities in your area. Just like certain doctors are in or out of network, certain labs, infusion centers, emergency rooms, and hospitals can also be in or out of network.
- Ask your gastroenterologist for recommendations

- When selecting the facility, consider their geographic location and how far you are willing to travel for treatment.
- Look for a facility with a range of services, including the latest diagnostic and treatment technologies, clinical trials, an on-site pharmacy, and a full range of support services.

After receiving care, make sure you evaluate your experience. If it did not meet your expectations, seek a second opinion and consider a new location.

## Disease Management

In addition to finding a doctor and treatment facility covered by your insurance, here are a few tips to help you maintain a manage your disease:

**Medication:** Taking your medication as prescribed is one of the easiest ways to keep your disease symptoms under control and avoid flares. Establishing a routine and using personal reminders are two ways to ensure you take every dose. Consider reminders on a cell phone or using a pill box to help you stick to your medication schedule.

**Journals:** Keep a daily journal, including meals and activities, along with the **what**, **when**, and **where** for how you are feeling. Over time, patterns may emerge that help you and your healthcare team understand **why** flares happen and **how** to avoid them.

**Diet:** What you eat can have an impact on how you feel! There is no one diet that works for all patients with IBD. It's important to work with your healthcare team to find a diet that meets your nutritional and caloric needs, and helps keep your symptoms under control.

**Time Management:** Good stress management is often related to good time management. It is helpful to aim for a balanced scheduled and to make time to take care of your physical health.

## Mind and Body

We know that having IBD affects more than just your physical health—it can also have a profound impact on your mental health and emotional wellbeing. Recent research has demonstrated that, in addition to the toll of chronic symptoms, gastrointestinal inflammation can have a direct effect on the brain. In fact, patients with IBD are at an increased risk for developing depression, anxiety, social isolation, and altered self-image.

It is important that you monitor your emotional health and reach out for help when needed. Your mind and body impact each other—if you manage one and ignore the other, you likely will not be able to take care of either well. Here are some suggestions:

- **Join a support group:** Whether online or face-to-face, talking with others in the IBD community can help you cope with your disease. Support groups can provide a social network that has an intimate understanding for how difficult it can be to have IBD.
- **Make special accommodations:** Planning ahead can help alleviate some of the anxiety associated with IBD. You may choose to disclose your disease and needs to your college's disability services department, employer's human resources department, or others who can help formulate a plan for accommodating your needs. Please note that it is illegal for a potential or current employer to discriminate against you based on your disease. Be mindful when you share health information and know your rights.
- **Work with a professional:** When family and friends aren't enough to combat an emotional problem, seeking the help of a professional isn't a sign of weakness; rather it's one of personal insight and commitment to your health. Ask your healthcare provider for a mental health professional recommendation, or call your insurance company to see who in your area takes your insurance.

## Health Insurance

Between doctors' visits, labs, procedures, and medication, paying for your healthcare can be costly. It is important to know that:

- Under the Affordable Care Act, you are:
  - Protected from being denied insurance coverage based on pre-existing conditions, such as IBD.
  - Eligible for coverage under your parent's health insurance policy until you turn 26, regardless if you are married, a dependent, or a student. Be sure to check with your parent's employer or plan, since some states and plans have different rules.

- Eligible to purchase a plan through a health exchange if you do not have access to a group plan. Exchange plans may be pricey, but opting for a plan that meets all your needs far outweighs saving money on the front end.
- If you are a full-time college student and need to take a leave of absence or reduce your course load, you are protected by [Michelle's Law](#). Michelle's Law allows you to take up to 12 months medical leave of absence and/or reduce your course load to part-time. It also provides for continued medical insurance under your parent's policy.
- For young adults in the workforce, some employers offer a range of insurance plans. Be sure to evaluate your medical needs and select the one that meets them.
- Regardless of age, you may be eligible for Medicare, Medicaid and/or Social Security benefits.
- There are educational scholarships available to lighten the cost of medical care and tuition.

## Educating Others

Friends, colleagues, teachers, and anyone else with whom you interact may not understand IBD and may not know how to react. At these moments, you can help to educate others about the disease by sharing your story. While this may appear intimidating at first, connecting with others in your IBD community may help in the long term.

Here are some strategies for educating others about IBD:

- **Know your disease:** To educate others, it's best to make sure you have a good understand of IBD yourself. Familiarize yourself with information about your disease and know some resources you can share with others.
- **Rise above:** Recognize that everyone has a different comfort level when discussing IBD. Remember that inappropriate responses often stem from lack of knowledge or understanding, not necessarily hostility.
- **Honesty is the best policy:** Be truthful when discussing your experiences. The impact of words can be a powerful tool in breaking through to others. By doing so, you are changing your acquaintance's notion of IBD from an obscure disease to a personal one.

## Social Settings

Because of the unpredictable nature of IBD, it's common to avoid going out or to isolate yourself. Planning ahead and making smart decisions can help you be social, enjoy time with friends and family, and vastly improve your overall quality of life. Here are some situations for which a little planning can go a long way:

- **Alcohol and drugs:** Alcohol affects each patient differently. The abuse of alcohol or other drugs, either illicit or over the counter, can have damaging effects on your gastrointestinal tract, including your liver, and may interfere with your medications. Discuss with your healthcare provider whether it is safe for you to consume alcohol or over the counter drugs.
- **Smoking and vaping:** Tobacco use should be limited because of its potential for making your symptoms worse in Crohn's disease. The risks of tobacco use outweigh the benefits and can be damaging to your overall health. Tell your healthcare provider if you smoke and discuss options for smoking cessation.
- **Relationships and sexuality:** Young adults with IBD may experience negative body image, physical symptoms, complications, and side effects of medications which may affect their relationships. You can have a successful and rewarding relationship by sharing your concerns with your healthcare provider and being honest with your partner about your feelings and physical limitations.
- **Sports and exercise:** Being physically active is important, even though it might seem daunting when you are feeling unwell. From the maintenance of muscle mass to a healthy outlet for reducing stress, exercise can be a major contributor to your overall health. In addition, getting involved in organized sports is as much about the camaraderie and social benefits as it is about staying fit. Whatever physical activity you're involved in, consider alerting your team leader about your needs and scouting out bathrooms before practices and matches.
- **Traveling:** You can travel with IBD – it might just take some planning. From locating physicians domestically or abroad, to getting through security with prescription medications, to avoiding traveler's diarrhea, compiling resources before you travel can help avoid inconvenience and emergency.

## Resources

This fact sheet only begins to scratch the surface of managing IBD as a young adult. There are many resources available to you, from information on legal protections, to educational scholarships, to health insurance assistance programs. Below are some available resources.

### Foundation Resources

- Patient Brochures: <https://www.crohnscolitisfoundation.org/brochures>
- Local Support Groups – Contact Your Local Chapter: <http://www.crohnscolitisfoundation.org/chapters/>
- Campus Connection page for college students: <https://www.crohnscolitisfoundation.org/campus-connection>

### Transition to Adult Care

- Finding a Physician: <https://www.crohnscolitisfoundation.org/living-with-crohns-colitis/find-a-doctor/>

### Legislation and Legal Protections

- Health Care Legislation: <https://www.crohnscolitisfoundation.org/get-involved/be-an-advocate>
- Michelle’s Law: <https://www.congress.gov/bill/110th-congress/house-bill/2851>
- Employment Discrimination: <http://www.eeoc.gov/laws/types/disability.cfm>
- Family and Medical Leave Act: <http://www.dol.gov/whd/fmla/index.htm>

### Financial Support

- Medicare and Medicaid: <http://www.cms.gov/>
- Social Security: <http://www.crohnscolitisfoundation.org/resources/applying-for-social-security.html>

### For additional resources, contact our IBD Help Center:

888-MY-GUT-PAIN  
(888-694-8872)

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

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

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