

MANAGING INFLAMMATORY BOWEL DISEASES AS A YOUNG ADULT

Inflammatory bowel diseases (IBD) are challenging to manage at any age, but as a young adult between the ages of 18 and 25 years, you may find it particularly demanding. This is a period of life that involves significant maturation and adjustment to your changing environment, and can be further complicated by IBD. However, by adopting a comprehensive strategy for managing your disease, you are putting yourself in a position to optimize your quality of life and to make the most of these formative years.

Overview

IBD, including Crohn's disease and ulcerative colitis, is characterized by inflammation of the gastrointestinal (GI) tract. Approximately 1.4 million Americans have IBD, and 30,000 new cases are diagnosed every year.

The cause of IBD is currently unknown, but it is believed to be due to multiple factors, including genetics and one's environment. Physical and psychological symptoms vary from person to person, and range from within the GI tract, such as persistent diarrhea, abdominal pain and bloody stool, to outside the tract, such as fever, weight loss and fatigue.

At this point in time, no cure exists for IBD, but there are many therapies that have been proven to effectively reduce the disease activity and prevent symptoms and improve or maintain your quality of life.

Transitioning Into Adulthood

Whether you're taking the next step in your education, starting out on a career path, or taking on any host of new ventures, young adulthood is defined by your ever-expanding independence. With this new freedom comes the responsibility of managing your health, including your IBD.

Here is a broad, but certainly not exhaustive list of considerations as you begin to formulate a plan for taking charge of your IBD care:

Health Care

- **Affording Care:** Between doctor's office visits, labs, and medication, paying for your health care can be costly. It is important to note that:
 - New health care legislation makes you eligible for coverage under your parent's health insurance policy until your 26th birthday.
 - If you are a full-time college student, you are protected by Michelle's Law. This provides for continued medical insurance under your parent's policy in the event that you need to take up to 12 months medical leave of absence and/or reduction of your course load to part-time.
 - New legislation also bars insurance companies from denying coverage based on pre-existing conditions, such as IBD.
 - Some employers offer a range of insurance plans. Be sure to realistically 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.

- Individual plans are available to those who do not otherwise have access to a group plan. They tend to be more expensive, but opting for a plan that meets all your needs far outweighs saving money on the front end.
- Various educational scholarships are available to lighten the burden of affording medical and tuition costs.
- **Doctors:** You are no longer a pediatric patient. If you are still followed by a pediatric GI group, you should discuss transferring 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.
 - Your primary care physician (PCP) and pediatric GI physician may be two of your best resources for narrowing down the initial list.
 - Look for a GI physician who specializes in IBD, or treats a significant number of IBD patients.
 - The ideal GI physician is 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 his/her staff, and given the attention you require.
- **Treatment Facilities:** Even when you do your best to manage your disease, it may be necessary to undergo hospitalization for medical or surgical intervention. Selecting a facility for these instances before they arrive ensures you have a constant voice in your treatment. Here is a short checklist for selecting a treatment facility:
 - Consult your health insurance plan for a list of approved facilities in your area.
 - Ask your GI physician for recommendations, and confirm he or she is affiliated with the facility to ensure more seamless treatment.
 - Consider their location in relation to where you live, 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, critique your experience. If it did not meet your expectations, seek a second opinion and consider a new location.

Self-Care

- **Alcohol and Drugs:** Alcohol affects each IBD patient differently. The 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 with your doctor whether or not it is safe for you to consume limited quantities.
- **Smoking:** Tobacco use should be limited because of its potential for making your symptoms worse, damaging your overall health, and interfering with your medications.
- **Diet:** Your doctor or nutritionist will outline a diet that meets your specific needs. It is important to stick to this plan to ensure your nutritional and caloric needs are met and symptoms are kept to a minimum.
- **Exercise:** As long as you are feeling well enough to exercise and have clearance from your physician, athletics are encouraged. From the maintenance of muscle mass, to a healthy outlet for letting off steam, exercise can be a major contributor to your overall health.
- **Medication:** One of the easiest ways to manage your IBD is by keeping a strict medication regimen. Unfortunately, it's just as easy to forget. Establishing a routine and using personal reminders are two ways to ensure you take every dose.

- **Journals:** Keep a daily journal, including meals and activities, along with the “what,” “when,” and “where” for each flare. Over time, patterns may emerge that help you and your doctor understand “why” they happen and “how” to avoid them.
- **Medical Knowledge and Records:** Maintaining a complete and current file of your medical records and understanding of your disease is imperative for successful management. Along with hard copies of doctor’s and laboratory reports, you should intimately know:
 - Disease location
 - Disease history
 - Past and current medications, their respective dosages and their interactions and side effects
 - When to follow up with your GI physician
 - When to have labs checked
 - How to follow up on test results
 - If you are transitioning to a new doctor, how to contact your previous one
 - Your home doctor’s name and contact
 - If you have a temporary residence, your local doctor’s name and contact

Mind and Body

The public may see IBD as nothing more than a set of physical symptoms, but anyone living with one of these diseases knows that the emotional impact is sometimes more profound. Recent research has demonstrated that, in addition to the toll of having a chronic condition and the symptoms it may bring, gastrointestinal inflammation can have a direct effect on the brain. Accordingly, IBD patients are at risk for a number of debilitating psychological problems, including depression, anxiety, social isolation and altered self image.

As part of your “self care,” it is important that you monitor your emotional health, and reach out for help when times get too tough to handle on your own. Remember, your mind and body impact each other, so managing one without the other is really not managing either at all. Here are some suggestions:

- **Support Groups:** Whether online or face-to-face, joining with other IBD patients in your community or at the national level may be one of your best tools for coping with your disease. They provide a social network that has an intimate understanding and profound respect for how difficult it can be to have IBD. In addition, they provide an opportunity to share your feelings and experiences, which may help you validate your emotions and realize you are far from alone.
- **Special Accommodations:** Planning ahead can help alleviate some of the anxiety associated with IBD. Disclose your disease and needs to your college residency and disability services departments, employer’s human resources department, or anyone else who can help formulate a plan for accommodating your needs.
 - Please note that while it is illegal for a potential or current employer to discriminate against you based on your disease, this may still occur. Be mindful of with who and when you share health information. See the “Resources” section of this guide to learn more about your rights.
- **Therapists:** When family and friends aren’t enough to combat an emotional problem, seeking the help of a therapist isn’t a sign of weakness; rather one of personal insight and commitment to your health.

Educating Others

Friends, colleagues, teachers, and anyone else with whom you come into contact may not understand IBD and may not know how to react. At these moments, you can help to educate others about the disease. While this may appear intimidating at first, consulting others within your IBD community and formulating a strategy may provide you with the courage to take this important step.

Here are some strategies for educating others about IBD:

- **Know Your Disease:** You can't educate others if you aren't knowledgeable about IBD yourself. Familiarize yourself with available information and resources, and know how to point others in the right direction.
- **Rise Above:** Recognize that what you find offensive may not seem so to others. You have the right to be upset, but also know that inappropriate responses often stem from naiveté, not necessarily hostility.
- **Teach Others:** People are much more receptive to criticism when it comes from an equal. Be mindful of your end-goal, and that will help guide your response.
- **The Policy of Honesty:** Be truthful when sharing 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

Going out in public means losing some control over your environment, and the fear of gastrointestinal symptoms drives some into isolation. However, by planning ahead and making smart decisions that may limit the manifestations of your disease, you can be as social as you would like, and vastly improve your overall quality of life. Here are some situations for which a little planning can go a long way:

- **Relationships and Sexuality:** You can have a successful and rewarding relationship in spite of your disease. Young adults with IBD may view this to be one of the more daunting challenges, as negative body image, physical symptoms and complications, and side effects of medications may all be obstacles. Speak with your doctor about managing these issues, and be honest with your partner about your feelings and physical limitations. Consult the CCFA guide entitled "*The Intimate Relationship of Sex and IBD*," listed in the "Resources" section of this guide, for a complete overview of this topic.
- **Sports:** As noted earlier, exercise should be a key player in the maintenance of your health. In addition, getting involved in organized sports is as much about the camaraderie as it is about staying fit. Make sure to alert your coach about your needs and scout out bathrooms before practices and matches.
- **Parties:** As noted before, drugs and alcohol can have serious IBD-related consequences. Know your limits, plan for the worst, and you're a lot more likely to have a great time.
- **Traveling:** This may be the most important activity for which planning is an utmost priority. 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 an emergency situation.



Resources

The insights and suggestions listed in this fact sheet only begin to scratch the surface of managing IBD as a young adult. There is an array of resources available to you, from information on legal protections, to educational scholarships, to health insurance assistance programs. Below are just a small handful of available resources. For a more inclusive list, please visit <http://www.ccfa.org/info/links>.

General

IBD University: <http://www.ibdu.org/>

Living with Crohn's Disease:

<http://www.ccfa.org/frameviewer?url=/media/pdf/livingwithcd52010.pdf>

Living with Ulcerative Colitis:

<http://www.ccfa.org/frameviewer?url=/media/pdf/livingwithuc52010.pdf>

Health and Self Care:

General Health Care: <http://www.ccfa.org/media/pdf/FactSheets/healthmaint.pdf>

Managing Flares: http://www.ccfa.org/frameviewer?url=/media/pdf/flares_brochure_web.pdf

Diet and Nutrition: <http://www.ccfa.org/frameviewer?url=/media/pdf/diet.pdf>

Emotional Factors: <http://www.ccfa.org/frameviewer?url=/media/pdf/emotional.pdf>

Sexuality: <http://www.ccfa.org/frameviewer?url=/media/pdf/ibdsexuality.pdf>

Pregnancy: <http://www.ccfa.org/media/pdf/FactSheets/pregnancyfactsheet.pdf>

Women: <http://www.ccfa.org/media/pdf/FactSheets/womenfactsheet.pdf>

CCFA Community: <http://www.ccfacommunity.org/>

CCFA Chapters and Events: <http://www.ccfa.org/chapters/>

Finding a Specialist: <http://www.ccfa.org/media/pdf/Finding%20a%20Specialist.pdf>

JCQC: <http://www.qualitycheck.org/consumer/searchQCR.aspx>

JCAHO: www.jointcommission.org

Legislation and Legal Protections

Health Care Legislation: <http://healthreform.kff.org/>

Michelle's Law: <http://www.michelleslaw.com/>

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

Educational Scholarships: <http://www.ccfa.org/about/news/scholarships>

Medicare: <http://www.medicare.gov>

Medicare and Medicaid: <http://www.cms.gov/>

Social Security: <http://www.ccfa.org/living/disability>

Travel

General Guide: <http://wwwn.cdc.gov/travel/>

CCFA Guide: <http://www.ccfa.org/living/travel>

Mobile Bathroom Locator: <http://www.sitorsquat.com/sitorsquat/home/map>

Domestic Bathroom Locator: http://www.imodium.com/page.jhtml?id=/imodium/include/3_5.inc

International Bathroom Locator: <http://www.thebathroomdiaries.com/>

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