



IBD AND OLDER ADULTS

Inflammatory bowel diseases (IBD), such as Crohn's disease and ulcerative colitis, are traditionally diagnosed in younger people. However, the fact that they are life-long diseases means that there are many older people who have lived with IBD for many years. Patients can put themselves into a position to have a high quality of life and enjoy their golden years by adopting a strategy for managing their disease that is compatible with their short and long-term goals.

Overview

IBD, including Crohn's disease and ulcerative colitis, are a group of inflammatory diseases that primarily affect the gastrointestinal (GI) tract. Approximately 1.4 million Americans have been diagnosed with IBD, and up to 16 percent were diagnosed at age 60 or older.

The exact cause of IBD is currently unknown, but it is believed to be due to several factors including: genetics, the immune system, and one's environment. It is unclear why IBD may not develop in some individuals until later in life. Symptoms vary from person to person, even from disease flare to disease flare. The disease may be limited to the GI tract and include symptoms such as persistent diarrhea, abdominal pain, and bloody stool, or it may affect the whole body and include symptoms such as fever, weight loss, and fatigue.

At this point in time, no cure exists for IBD, but there are treatment options to manage the symptoms and disease to improve or maintain patients' quality of life.

Managing Your Care

Studies suggest that the course and recommended treatment of IBD on its own does not vary greatly from that of a younger patient. However, a patient's overall health at the time of diagnosis plays a large role in determining both how the disease affects him or her and how aggressively the physician may treat the disease.

The length of time between initial symptoms and diagnosis may be longer for older adults than for younger patients for various reasons. These include the fact that IBD presents with different symptoms in older patients than in younger ones, and a patient's physician must rule out other possible diseases. Should this lead to more serious symptoms or complications, a patient may require more aggressive treatment.

In addition, while the nature of a patient's response and tolerance for specific IBD medications is not that much different than in a younger patient, response time to the medications may not be as quick. This is important for a patient's physician to consider when determining course of treatment.

Finally, special considerations must be taken into account, such as a patient's ability to live independently, other diseases or illnesses that require attention, and the medications the patient is taking for these other conditions. For example, biologic therapy, which is one of many treatments for IBD, may have adverse effects if a patient has congestive heart failure, or if used with certain medications, such as some for rheumatoid arthritis because they may increase the risk for infection. It is increasingly important that patients discuss their medical needs with their healthcare professionals, closely monitor the progression of their disease, and make preparations for unforeseen issues.





Here is a broad, but certainly not complete list of options for patients to consider when developing a plan to take charge of their IBD treatment:

Health Care

- **Affording Care:** Between co-pays for doctors' appointments, medications and various testing, and travel expenses for these visits, paying for health care can be costly. It is important to note that:
 - The new health care legislation prohibits insurance companies from denying coverage based on pre-existing conditions, such as IBD.
 - The new legislation will also prohibit lifetime caps on all private insurance plans and provide financial assistance for Medicare recipients who are faced with the prescription drug coverage gap, "the doughnut hole."
 - Beginning in September 2010, new insurance plans were required to provide a number of preventive services free of charge, including colorectal cancer screenings.
 - At any age, a patient may be eligible for Social Security disability benefits or Supplemental Security Income depending on their disease's impact on their ability to work and overall financial situation, respectively.
 - Even if a patient is under the age of 65, he or she may be eligible for Medicare benefits if he or she received Social Security disability benefits for 24 months.
 - IBD patients may also be eligible for Medicaid coverage.
 - Many sponsored patient assistance programs exist to assist patients in affording care. See the "Resources" section for details.
 - If a patient does not have employer-sponsored health insurance and is ineligible for Medicare and/or Medicaid coverage, individual plans are available.
- **Doctors and Treatment Facilities:** The ideal gastroenterologist and his or her affiliated treatment facilities and hospitals are partners with their patients in managing the treatment of the disease. All should provide features such as close proximity, the latest in diagnostic and treatment technologies, and give patients the time and attention they require.
- **Preventive Care:** In addition to regular screenings advised for all seniors, gastroenterologists may recommend more frequent colonoscopies, as individuals with IBD involving the colon have an increased risk of developing colon cancer.

Self-Care

- **Extra Support:** Depending on your health and mobility, IBD patients may require additional help with medical care and everyday tasks. This may alleviate some of the physical and emotional toll the disease takes on a patient's life.
- **Alcohol and Smoking:** Alcohol and tobacco affect each IBD patient differently. However, its use should be limited because of its potential for making IBD symptoms worse, damaging the patient's overall health and interfering with medications.
- **Diet:** While there is no specific diet that will make the inflammation associated with IBD better or worse, for any individual, certain foods may worsen symptoms. The patient's doctor, nurse, or dietitian may outline a diet that meets his or her specific needs. It is important to stick to this plan to ensure your nutritional and caloric needs are met and flares are kept to a minimum.



- **Hydration:** Seniors are less able to withstand dehydration, which may occur with diarrhea. It is advisable for seniors to drink plenty of fluids, even with infrequent diarrhea.
- **Medication:** One of the easiest ways to manage IBD is by regularly taking prescribed medication. Unfortunately, it's just as easy to forget. Sticking to a routine, setting reminders, and utilizing pill counters are just a few ways of ensuring the patient gets every dose.
- **Preventive Treatments:** In addition to IBD medications, IBD patients may be taking one or more medications to prevent certain illnesses, such as low-dose aspirin or warfarin following a heart attack. These medications may interact with those for IBD, or worsen IBD symptoms. It is important for patients to tell their doctor about all of the medications they are taking, and alert his or her physician if they suspect a problem.
- **Journaling:** Patients may need to keep a daily journal to write down information on items such as meals and activities, along with specific details regarding each flare he or she experiences. In time, patterns may help the patient and their doctor understand why they happen, and how to avoid them.
- **Medical Knowledge and Records:** It is important for patients to maintain a complete and current file of their medical records and understand of all their diseases for successful disease management. Along with copies of doctor's notes and laboratory, endoscopy, pathology, and radiology reports, patients should know:
 - The IBD history and what part of the GI tract is involved
 - All other diseases and illnesses
 - Past and current medications, their interactions, and any side effects experienced
 - Regular doctor's name and contact information
 - Local doctor's name and contact information if traveling or living in a temporary residence,

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 toll can be even more challenging. IBD patients are at risk for a number of psychological problems, including depression, anxiety, social isolation, and negative self image.

As part of "self-care," it is important for patients to monitor their emotional state, and reach out for help when times get too tough to handle alone. Remember, the mind and body interact with each other, so managing one without the other is really not managing either at all. Here are some suggestions:

- **Special Accommodations:** Planning ahead can help ease some of the anxiety associated with IBD. It is important for patients to share information about their disease with special needs coordinators at places they frequent to make a plan for unexpected problems.
- **Support Groups:** Whether it is online by computer or face-to-face, joining with other IBD patients to share feelings and experiences may help patients validate their emotions and realize they are not alone. CCFA has more than 40 chapters and affiliates nationwide. Find a local support group and other events in your area by visiting <http://www.ccfa.org/chapters/> or calling our Information Resource Center at 1-888.MY.GUT.PAIN (1-888-694-8872).
- **Therapists:** When family and friends aren't enough to help the patient deal with an emotional problem, seeking the help of a therapist isn't a sign of weakness, but rather one of wisdom and commitment to his or her health.



Educating Others

Family, friends, and acquaintances may not understand IBD and may not know how to react. At these moments, the patient can help to educate others about the disease. While this may appear intimidating at first, speaking with others within the IBD community and creating a strategy may be enough to build up the courage to take this important step.

Here are some strategies for educating others about IBD:

- **Know the disease:** Patients can't educate others if they aren't knowledgeable about IBD themselves. CCFA's Information Resource Center (IRC) can be a valuable source of information.
- **Rise above:** Recognize that a comment or interaction that feels hurtful may not have been intended to be that way. It is okay to be upset, but know that this inappropriate comment can stem from a lack of understanding, not necessarily hostility.
- **Teach others:** People are much more open to comments when it comes from an equal. Be mindful that the end-goal is education, and that will help guide the response.
- **Be honest:** Being truthful when sharing an experience can be a powerful tool in breaking through to others. By doing so, it is possible to change someone's notion of IBD from an unknown disease to a personal one.

Social Settings

By planning ahead and making smart decisions that avoid accidents and minimize symptoms, patients can be as social as they like and vastly improve their overall quality of life. Here are some situations for which a little planning can go a long way:

- **Athletics:** It is okay to engage in sports as long as a doctor provides clearance and the patient is feeling well enough. Athletics can be a great way to look and feel young. However, relevant individuals, such as lifeguards, trainers, or other staff, need to be alerted in advance to the patient's needs. Bathrooms should also be scouted out.
- **Outings:** Whether at the movies, a restaurant, or any other location, the key is for a patient to know his or her limits and plan for the worst with appropriate staff members and caregivers. That should relieve some anxiety, allowing the patient to relax and have a great time.
- **Traveling:** This may be the most important activity for which planning is an utmost priority. From locating local physicians and getting through airport security with prescription medications, to avoiding traveler's diarrhea, compiling resources before travel can help avoid an emergency situation.



Sexuality

Any senior can tell you that sex doesn't have to take a back seat once you hit 65. However, IBD may complicate this issue, so special treatment options should be considered when formulating an overall plan.

Women

- While preliminary studies suggest that menopause may begin earlier in IBD patients, this does not appear to have any negative effect on disease progression.
- Having IBD increases patients' risk for osteoporosis during menopause. Patients and their physicians should discuss options for reducing bone loss.
- Some studies suggest Hormone Replacement Therapy (HRT) following menopause may have benefits with regard to IBD. However, due to the controversial nature of this treatment, some doctors may not recommend HRT.

Men

- Aside from methotrexate, IBD medications do not usually cause erectile dysfunction.
- Ileal pouch anal anastomosis (IPAA or J-Pouch) surgery, while occasionally associated with some loss of sexual function, is not associated with erectile dysfunction. In addition, many men find that any experienced change or loss of function is outweighed by the beneficial effect of reducing IBD symptoms.
- There is no known association between IBD and prostate cancer. However, as with all senior male patients, some doctors may deem it important to regularly screen for the disease.

All Seniors

- Just like for any other physical activity, it is important for patients to ask their physicians if they are healthy enough for sex.
- Some IBD patients are prescribed medications for depression and anxiety management. Sexual side effects are common with some of these drugs. Patients should speak with their physician if they experience a reduction in sexual drive or performance after starting these medications.
- Negative body image and physical symptoms of IBD may prove to be challenging in maintaining a sexual relationship. Patients should speak with their doctor about managing these issues and should be honest with their partner.



Resources

To order free brochures and fact sheets and to get information on other resources, please contact our Information Resource Center at 1-888-MY-GUT-PAIN (1-888-694-8872) or visit <http://www.ccfa.org/info/brochures/?LMI=4.4>

Insurance & Financial Support

- HealthCare.gov: <http://www.healthcare.gov/>
- Medicare: 1 (800) Medicare (633-4227) or <http://www.medicare.gov>
- Social Security: (800) 772-1213 or <http://www.ssa.gov/applyfordisability/>
- Patient Advocate Foundation: 1(800) 532-5274 or <http://www.patientadvocate.org/>
- Patient Access Network Foundation: 1(866) 316-7263 or <https://www.panfoundation.org/>
- NeedyMeds: <http://www.needymeds.org/>
- RxAssist: <http://www.rxassist.org/>

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