



Inflammatory Bowel Disease

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Inflammatory Bowel Disease (IBD): Navigating Evolving Therapies In An Evolving Disease

Frequently Asked Questions about IBD for Patients

Does stress cause IBD?

- ▶ Many have considered that stress in some way causes IBD. Some of this has arisen from instances where patients present for the first time with their IBD after a major stressful life event or present with a flare of disease after a major life stress. There is, however, no evidence that stress actually causes IBD. On the other hand there is an emerging consensus that a person's perception of how stress affects them affects any chronic illness. This is true in IBD. Hence if a patient feels chronically stressed or has difficulty with stress management, this requires as much attention as physical symptoms.

Is IBD caused by some type of infection?

- ▶ No specific bug has been shown to cause IBD. The current thinking about the cause of IBD is that people with a genetic predisposition to the disease respond in an abnormal way to the bugs present in the individual's gut. Our bowels contain several times as many microbes (bugs) than we have cells in our body. It has been very complicated to study the different bugs in the bowel of persons with IBD. There are thousands of types or species of bacteria in the human bowel and also thousands of different viruses and fungi. Thus, it is hardly surprising that probiotics that have a few types of bacteria types are minimally effective in IBD. There are many factors that can impact on the bugs in one's bowels. Diet is one such factor. Use of antibiotics is another. If a bug or several bugs prove to be critical in initiating or perpetuating IBD it doesn't seem to be something you can "catch" from a family member or other close contact. Some researchers have found specific types of bugs, like a type of E coli that may be associated with Crohn's disease or other types of bugs like *Fecalobacterium prauznitzii* that may protect from Crohn's disease. If ongoing research confirms these types of findings it may lead to novel antibiotics or probiotics to be used as treatment. Stool transplants have also been used on the premise of transferring bugs from a healthy donor to someone affected with IBD will reduce inflammation. So far this has been studied in ulcerative colitis with mixed results.

Is there something in my diet that caused IBD and now that I have it should I change my diet?

- ▶ It is possible that there is something in the diet that triggers IBD. It may be that certain diets predispose to the overgrowth of certain microbes (bugs) in the bowel.

However since there is no consistent evidence, doctors generally do not make specific dietary recommendations for Crohn's disease or ulcerative colitis. When a patient has Crohn's disease and small bowel strictures doctors may recommend a low residue or low fiber diet to lessen the likelihood of an obstruction from fiber getting "stuck" at the strictures. Patients with Crohn's have a higher likelihood of having lactose intolerance. It is also important to remember that patients with IBD may also have IBS (irritable bowel syndrome). Dietary modification, often to reduce the intake of certain types of carbohydrates, can help symptoms of IBS, such as bloating.

Will I get cancer because of having IBD?

- ▶ In general, persons with IBD are not at increased risk of cancer; however there are certain types of cancer that are a concern. Patients with colitis are at an increased risk of getting colorectal cancer but the actual risk is relatively low. Patients with proctitis (colitis confined to the rectum) are at no increased risk. Patients with longer duration disease (longer than 20 years) and with more extensive colitis (the whole colon rather than just the left colon) are at increased risk. Isolated small bowel disease is a risk for small bowel cancer, but this is so rare compared to colon cancer that the absolute risk is very small. Dysplasia is a change in the bowel that can be a predictor that cancer is already present or is coming. Colonoscopy surveillance is recommended, but it is worth discussing with your IBD specialist the optimal frequency of colonoscopy for you. This will be based on the duration and extent of your disease but also on other factors like your family history and what other health issues you might have. If colonoscopy surveillance is undertaken and dysplasia is found your doctor may discuss with you having more frequent colonoscopy surveillance or even having your colon removed.

Is there a cure for IBD?

- ▶ Sadly, there is as of yet no cure either for ulcerative colitis or Crohn's disease. These are lifelong diseases and until we find the causes we are not likely to find the cures. Nevertheless, with regular medications and sometimes with surgery, most patients can remain in excellent health. In ulcerative colitis having the colon removed 'cures' the disease (there is no more colon to express colitis), but the patient is not left in a completely normal state.

Nonetheless people who have surgery for ulcerative colitis and end up with an ileoanal pouch operation (where the small bowel-the ileum, is made into a pouch and brought down to the anus) usually have a very good quality of life.

Do I need to take drugs forever to treat my IBD?

- ▶ It really depends on the type of IBD you have; where it is located and how active it has been. When IBD is newly diagnosed nearly all patients receive some type of drug therapy. There are some persons with Crohn's disease who get surgery as a treatment early in their disease and do not receive drug therapy. When surgery is not needed as therapy early on, the central approach to treating either Crohn's disease or ulcerative colitis is to use drug therapy to settle active disease and then to use either the same or a different therapy to maintain remission which means the disease is settled over the long term. Certain drugs are intended to be used for short periods such as corticosteroids. Other drugs when started are expected to be used for years such as thiopurines (i.e. azathioprine) or the antibodies to TNF (i.e. infliximab or adalimumab). However, there are some patients after years of drug treatment or a surgery, that can remain drug free for an indefinite period. For most persons with ulcerative colitis who undergo surgery to remove the colon they will not need drug therapy ever again. The decision to discontinue treatment in either Crohn's disease or ulcerative colitis should be made jointly between patients and their doctors.

How serious are the risks for infection if I take drugs that can suppress my immune system?

- ▶ All prescription medications may have some risks although no medications would be approved by drug regulators unless the benefits of taking the drugs far outweighed the risks. Many of the drugs used to treat IBD suppress some aspect of the immune system but in general the immune suppression is mild. IBD drugs do not have strong effects on the immune system as drugs used to treat cancer. Patients on most IBD drugs should not expect to get more infections. However, there are some effects that can be expected and patients should be aware of. For instance, thiopurine drugs like azathioprine can sometimes lower white blood cell counts; these are the main cells that fight infection. So if using a thiopurine, patients should have intermittent blood tests to check the white blood cell count. The antibodies to TNF (i.e. infliximab or adalimumab) have been used for approximately 19 years so doctors are quite comfortable

that they do not pose a big risk for infection. However, if a person using an antibody to TNF gets a fever they should notify their doctor and they may need to delay dosing with the drug. It is rare for persons using antibodies to TNF to get serious infections. Vedolizumab has been used to treat IBD for approximately 3 years and its effects are specific on the gut as opposed to having generalized effects. Hence, concerns for developing infections in users of this drug are generally low. The newest drugs to be used to treat IBD such as Ustekinumab and Tofacitinib are also thought to have low risks for developing infections but experience with using them is not as deep as doctors' experience with using antibodies to TNF. 5-aminosalicylates and sulfasalazine are drugs that have been used for decades and are not associated with any risk for infection. On the other hand, corticosteroids have also been used for decades and are the one type of drug where concerns for infection are well founded. Hence, it should be a main goal of treatment with corticosteroids to use them for short periods.

An additional factor which needs attention during treatment with drugs suppressing the immune system is the possibility of reactivation of viral infections. Reactivation means that the infection flares up. Among viral infections affecting the liver, the risk of reactivation is observed only with hepatitis B virus infection. Hence, before starting immune suppressing drugs especially the anti-TNF drugs it is important to assess if the patient is carrying hepatitis B by a simple blood test. If there is the presence of a hepatitis B infection (and this can occur in the absence of any symptoms so the patient may be unaware) prophylactic treatment with antiviral drugs such as entecavir or tenofovir are used while the anti-TNF is administered. With high dose and prolonged treatment with corticosteroids the risk may actually be higher. Both entecavir and tenofovir have a very good safety profile. Another viral infection to be aware of is herpes zoster. This is a common infection and can reactivate at any time and cause a painful skin rash called shingles. There is an increased risk for this reactivation when treated with immune suppressing drugs. There is a vaccine for herpes zoster that is recommended for administration to the general population if over age 60 (when the risk for shingles is highest), however this vaccine should be considered in younger persons with IBD who are going to receive immune suppressing drugs.

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