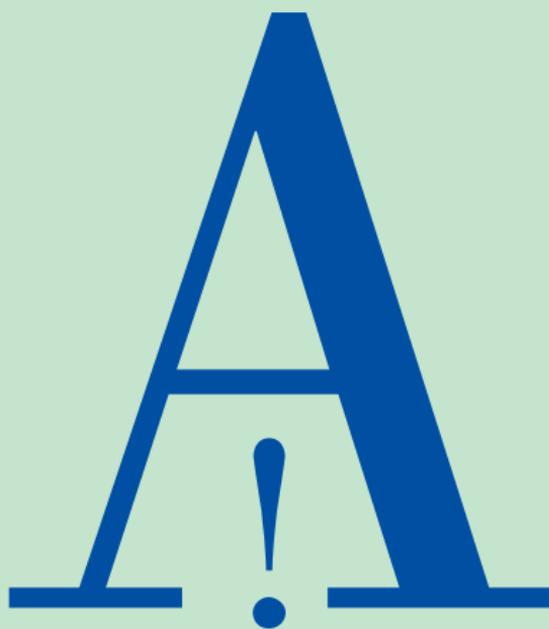


Crohn's Disease and Ulcerative Colitis:

Understanding Colorectal Cancer



CROHN'S
&
COLITIS
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The Crohn's & Colitis Foundation of America is a non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis. CCFA sponsors basic and clinical research of the highest quality. The foundation also offers a wide range of educational programs for patients and healthcare professionals, and provides supportive services to help people cope with these chronic intestinal diseases. CCFA programs are supported solely by contributions from the public.

We hope that this brochure will help you to better understand these illnesses, and to become an active member of your healthcare team.

All of us have reason to worry about cancer. Heredity, smoking, and exposure to asbestos, pesticides and other toxins are only a few of the many factors that have been linked to cancer. But what if we or our loved ones happen to have ulcerative colitis or Crohn's disease? Does that give us additional reason to worry about developing cancer?

To attempt to shed some light on this complicated and already heated issue, here is a list of questions that patients with inflammatory bowel disease (IBD) might have concerning their risk of developing cancer. For each question, we have attempted to supply a balanced, honest, up-to-date answer that a panel of gastroenterologists, statisticians, and pathologists would be likely to provide.

SINCE I HAVE IBD, SHOULD I BE CONCERNED ABOUT CANCER?

Yes. Some studies have shown as much as a five-fold increased risk in the development of intestinal cancer in people with IBD compared to the general population.

THAT IS A SCARY ANSWER.

IS IT MORE LIKELY THAN NOT THAT I WILL GET CANCER?

No, just the opposite: You are much more likely *not* to get cancer. More than 90 percent of patients with IBD never develop cancers.

IS THE INCREASED RISK OF CANCER TRUE FOR BOTH ULCERATIVE COLITIS AND CROHN'S DISEASE?

Until recently, it was felt that the risk was mostly for ulcerative colitis. More recent studies, however, indicate that there is increased risk for Crohn's patients as well. Also, if there is a history of colon cancer in your family members, you may be at further risk.

WHICH IBD PATIENTS SHOULD WORRY ABOUT CANCER?

For ulcerative colitis, the two factors that are associated with increased cancer risk

are disease duration and the extent of the colon that is affected by colitis. The risk of colon cancer doesn't start increasing until eight to 10 years after disease onset. Those with the entire colon involved are at greatest risk; those with inflammation only of the rectum have the least risk; and those with only part of the colon having colitis are at intermediate risk. The factors for Crohn's disease appear to be similar but have not been as well studied.

WHAT IS THE ACTUAL RISK?

While the statistics vary, it is generally felt that the risk of getting colon cancer in patients who have had ulcerative colitis for more than 10 years increases at a rate of approximately 0.5 percent per year. For Crohn's disease of the colon, the statistics appear to be similar.

IF MY DISEASE HAS BEEN QUIET AND I RARELY HAVE ANY SYMPTOMS, AM I AT LESS RISK FOR CANCER?

Unfortunately, no. The cancer risk appears to apply to patients with both active and inactive IBD. The extent of colonic involvement and the length of time since onset appear to be the important factors, not the amount of inflammation.

DO ANY OF THE MEDICATIONS USED TO TREAT IBD CONTRIBUTE TO THE INCREASED CANCER RISK?

No. Sulfasalazine, corticosteroids, antibiotics, immunosuppressives, antidiarrheals, and antispasmodic medications all have been used for many years in a number of diseases, and no convincing association has been found with subsequent cancer development. In fact, some experts believe that taking these medicines might lower your risk of developing cancer.

WHAT CAN I DO BESIDES WORRY?

Discuss your concerns with your gastroenterologist. Also, consult CCFA, which can offer mutual self-help groups and other educational programs and literature. Remember—you are much more likely not to get cancer than to get it.

WHAT KIND OF TESTS CAN I HAVE TO CHECK FOR CANCER?

It is wise to see your gastroenterologist for a general checkup annually, even if you feel entirely well. Of course, any change in your symptoms should prompt at least a telephone call to your gastroenterologist. Symptoms like diarrhea and rectal bleeding, which are early signs of colon cancer in the general population, are difficult to assess in people with IBD, because these symptoms may also

represent a flare-up of IBD. When you come in for your annual exam, your gastroenterologist is likely to obtain an interval history, perform a physical examination, and perhaps some blood tests. If you have had colitis for more than eight or 10 years, your gastroenterologist is likely also to suggest a colonoscopy with biopsies.

WHAT WILL THE GASTRO- ENTEROLOGIST LOOK FOR IN THE COLONOSCOPY?

The appearance of the colon at colonoscopy can help to determine how much colitis you really have, how inflamed it is, and whether you have any bumps, polyps or narrowed areas. Multiple biopsies are likely to be obtained throughout the colon and from anything that looks unusual.

DO BIOPSIES NECESSARILY MEAN CANCER?

No. Taking a biopsy involves obtaining a tiny sample of the lining of your colon, which is then analyzed under a microscope by a pathologist. The biopsy is painless and does not increase the risks of colonoscopy. This too will help to determine how much colitis you really have, how active it is, and whether there are any subtle changes in the direction of cancer.

WHAT ARE POLYPS?

ARE THEY ALWAYS SERIOUS?

Polyps are bumps that form on the usually smooth surface of the colon lining. In colitis, bumps may be just swollen, inflamed tissue, in which case they are called “pseudopolyps.” Patients with pseudopolyps are not at greater risk for cancer than those without. Occasionally, however, the bumps may contain dysplasia or cancer.

WHAT IS DYSPLASIA?

IS IT AS BAD AS IT SOUNDS?

Dysplasia is a term coined by pathologists who specialize in the microscopic analysis of tissue obtained from the intestines of IBD patients. Dysplasia is a pattern of cells that is neither normal nor cancer, but somewhere between the two. Dysplasia is sub-classified as “indeterminate,” “low grade,” or “high grade,” depending on its appearance to the pathologist under the microscope.

IF I HAVE DYSPLASIA,

DO I HAVE CANCER?

Not necessarily. Dysplasia is far from perfect in predicting coexistent or subsequent cancer. It is a subject of active debate and research. The most concern is for “high grade” dysplasia. Most experts

regard high-grade dysplasia as pre-cancer and would recommend surgery.

For low-grade and indeterminate dysplasia, there is considerably more uncertainty as to their importance as markers or precursors of cancer. Dysplasia can sometimes be difficult to prove. Therefore, doctors often request that an experienced pathologist review biopsies with dysplasia to confirm its presence. Of patients who undergo surgery because they had dysplasia, less than 50 percent actually are found to have any cancer at all. The important thing to remember is that dysplasia does not equal cancer, although it does make us want to be more vigilant.

IS COLONOSCOPY PERFECT IN FINDING DYSPLASIA OR CANCER?

Unfortunately, no. We only can sample a small fraction of the lining of the colon, even with multiple biopsies. Thus, tiny areas of dysplasia or cancer could be overlooked. But colonoscopy with multiple biopsies remains the best means we have at this time to detect early, curable cancer.

HOW OFTEN SHOULD I HAVE COLONOSCOPY?

Most gastroenterologists suggest repeating the examination every year or two, depending upon how long you have had

colitis, and on the amount of the colon affected by the colitis.

WHAT ARE THE INDICATIONS FOR SURGERY?

It is impossible to answer this specifically because this big decision needs to be individualized. In broad terms, however, the indications for surgery include: an obstruction in the intestine that does not resolve with medical therapy; very active colitis that is unresponsive to all available medical therapies, or that results in unacceptable side effects from the medications; cancer found on biopsy; or confirmed dysplasia.

ARE THERE OTHER WAYS TO CHECK FOR CANCER?

A tremendous amount of research is directed at improving colonoscopic techniques, improving the microscopic analysis of biopsies, and searching for a noninvasive marker (a blood test) that would detect patients at risk or those who are in the early stages of cancer. So far, none of these is reliable or accurate enough. But stay tuned... There is more good news here than bad. The best advice we can give is to stay in touch with your gastroenterologist and your local CCFA chapter, and to be optimistic!



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