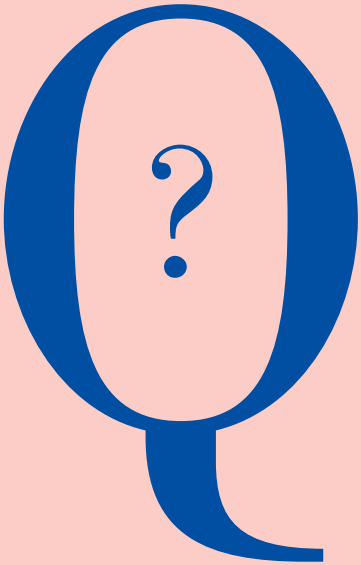
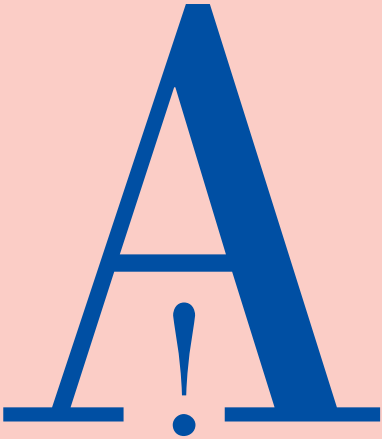


Crohn's Disease and Ulcerative Colitis:

Women's Issues



CCFA

CROHN'S & COLITIS FOUNDATION OF AMERICA

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.

Crohn's disease and ulcerative colitis are chronic digestive diseases of the small and large intestines, collectively known as inflammatory bowel disease (IBD). Crohn's disease causes inflammation in the lower part of the small intestine (ileum), the large intestine (colon), or any part of the digestive tract. Ulcerative colitis causes ulceration of the inner lining of the colon and rectum. If you have IBD, you may suffer from diarrhea, abdominal pain, rectal bleeding, and fever. Loss of appetite and weight are common. If medications fail to control the symptoms of the disease, or if certain complications occur, surgery may be required. Yet, in spite of the physical and emotional demands of coping with IBD, most patients are able to lead full, satisfying lives.

Crohn's disease and ulcerative colitis are primarily diseases of young people, and women are as likely to be affected as men. If you are a woman with IBD, it is important to understand how the events in a woman's life—menses, pregnancy, and menopause—can affect the course of your disease, and how your disease, in turn, can affect these milestones. The questions in this brochure are those asked most frequently by patients and their physicians. The answers are based upon available data from studies in women with IBD.

Why Are My Periods Irregular With This Disease?

Many factors contribute to regular menstrual periods, including hormone levels, adequate nutrition, and amount of stress. When a woman has active disease, the inflammation itself can cause the body to shut down normal hormone function. Restoring health is the mechanism to restore regular periods.

My Disease Always Seems to be Worse the Week Before or the Week of My Period. Is This Common?

Yes, this pattern is common for many diseases, actually. It is important to appreciate the fluctuation in symptoms that may be associated with menses, so that you are not over-treating your disease when symptoms may wax and wane based on your cycle.

Is The Pill Safe To Use If I Have IBD?

There is no evidence to suggest that the pill causes either ulcerative colitis or Crohn's disease. It is regarded as safe in ulcerative colitis. There are some studies that suggest that being on the pill can make Crohn's worse, but most of the women in these studies were also smokers, a habit we know makes Crohn's disease worse.

Is It Safe To Have A Colonoscopy During My Period?

Yes. There are no increased risks to the procedure associated with menstrual flow.

Is It Common To Have Pain During Intercourse If I Have Crohn's Disease Or Ulcerative Colitis?

There is no reason that ulcerative colitis should cause dysparuneia (the medical term for painful sexual intercourse). For women with Crohn's disease, dysparuneia may signal active disease in the perianal region or a fistula in the vagina. Although this may be embarrassing to talk about, you should discuss this symptom with your gastroenterologist and/or gynecologist.

Are My Chances Of Having Iron Deficiency Higher With IBD?

Yes, the chances are higher for you than for women of the same age who do not have IBD. Not only is there the normal loss of iron from menstrual flow, but also the increased chance of bleeding, and the decreased absorption of iron from inflamed small intestine make the chances higher.

Can Women With Crohn's Disease or Ulcerative Colitis Conceive As Easily As Other Women?

Generally, yes. Studies have shown that women with ulcerative colitis have the same rate of fertility as women without IBD. Studies of the fertility rates of women with Crohn's disease are conflicting. One large study showed no difference in fertility rates, but older studies and a more recent one show a slightly decreased rate of conception in women. This is true for active Crohn's disease, not quiescent disease, where the rate looks to be the same as in the normal population.

If the male partner is taking sulfasalazine (Azulfidine®), temporary male infertility may occur because this drug decreases sperm production, a reversible side effect. Before attempting conception, the male partner should stop the sulfasalazine and/or change to a 5-ASA compound, such as Asacol®, Canasa®, Colazal®, Dipentum®, Pentasa®, or Rowasa®, which has not been shown to interfere with sperm production.

Will Pregnancy Harm A Woman With Crohn's Disease Or Ulcerative Colitis?

Any woman contemplating pregnancy should consider the state of her health before conceiving. It is a good idea for a woman to have her disease in remission before pregnancy. According to recent studies, women with either illness should do well

during the pregnancy if disease was inactive at the time of conception. If a pregnancy occurs during a period of active disease, however, either disease is likely to remain active or to worsen. This worsening generally occurs during the first trimester (three months) in ulcerative colitis, and during the first trimester or the few months immediately after delivery in Crohn's disease. There is also a subset of women whose disease will actually get better. One study has suggested a relationship between the amount of shared genetic information between mother and child; the more alike they are, the worse the disease will be.

Can Crohn's Disease Or Ulcerative Colitis Affect the Pregnancy And Delivery, Or Cause Harm To The Newborn?

Most pregnant women with these illnesses have normal deliveries and healthy babies in roughly the same proportions as healthy women in the general population. If there is a problem affecting the pregnancy, it generally occurs in women with active Crohn's disease. These women run a greater risk of premature delivery, stillbirth, or spontaneous abortion. If the symptoms become severe enough to require surgery, the risk to the fetus becomes even greater. There are a few studies that show that the rate of C-section is higher in women with IBD, but this is due to physician preference, and not any scientific fact.

Do These Diseases Ever Begin During Pregnancy?

There are many reports of ulcerative colitis starting during pregnancy, but recent studies suggest that this time of onset makes the condition no worse than at any other times of symptom onset. Crohn's disease may also begin during pregnancy. Both diseases may begin during the postpartum period (the weeks immediately following delivery), but this is very rare.

Is It Safe To Take 5-ASA Compounds Such As Sulfasalazine, Or Mesalamine, Or Prednisone (Corticosteroids) During Pregnancy?

It is only natural for the pregnant woman and her obstetrician to want to restrict all medications during pregnancy to avoid possible harm to the fetus. Sulfasalazine, prednisone and the 5-ASA compounds (Asacol®, Canasa®, Colazal®, Dipentum®, Pentasa®, Rowasa®) are the drugs used most commonly to control the symptoms of Crohn's disease and ulcera-

tive colitis. A national study has found no evidence that the fetus is harmed by sulfasalazine or prednisone taken by the mother during pregnancy. Another study done in a prospective manner showed the safety of 5-ASA during pregnancy, with no increase in adverse events. (In this type of study, researchers follow a patient population over a period of time, in order to compare specific data from the beginning of the study to the end.)

Because the major threat to the pregnancy appears to come from the active disease itself and not from the medication, these drugs should not be discontinued just because a woman becomes pregnant. If either disease worsens severely during the pregnancy, prednisone, sulfasalazine, or a 5-ASA compound may be introduced or increased. Sulfasalazine or a 5-ASA compound may also be used to maintain a remission for the remainder of the pregnancy and after.

Are The Side Effects Of These Drugs Greater When They Are Taken During Pregnancy?

No. But sulfasalazine may cause nausea, which adds to the nausea commonly experienced in early pregnancy. The drug also may cause heartburn very much like the heartburn sometimes experienced in pregnancy.

Should A Woman Taking Sulfasalazine Or Prednisone Nurse Her Baby?

Yes, if she wants to. Although some sulfasalazine does pass into the breast milk, its concentration is much reduced, and it has not been shown to harm the newborn. Five-ASA compounds and immunomodulators, such as 6-MP and azathioprine (Imuran®), have not been shown to harm the newborn during nursing. However, there is one report of a nursing baby developing diarrhea following the mother's administration of a 5-ASA rectal suppository. The baby's diarrhea stopped when the mother's therapy stopped. When clinically feasible, the dosage of prednisone should be reduced and the drug discontinued as quickly as possible in any patient, whether pregnant or not. If a mother wishes to nurse her baby while still taking a moderate or high dose of prednisone, the baby should be monitored by the pediatrician.

Are Immunosuppressive Drugs Such As Azathioprine, Cyclosporine, And 6-Mercaptopurine Safe To Take During Pregnancy?

While some animal studies have shown genetic damage to occur in offspring, these animals

were given very high doses of these medicines, much higher than that used in humans. Our evidence comes from the long experience of women on these medications for transplants who have done well. Talking with investigators who have treated many women with these drugs has failed to show any increase in the number of adverse outcomes. Again, the importance of keeping disease inactive overrides the risk of these medications on the fetus.

Is It Safe To Have A Remicade™ Infusion During Pregnancy?

The effects of Remicade (infliximab) have not been studied on pregnant women. It may turn out that it is safe, but currently the recommendation is to not give it if a woman is known to be pregnant.

Is Therapeutic Abortion Ever Recommended For Any Reason In IBD Patients?

Therapeutic abortion is rarely, if ever, performed for active IBD. Instead, the patient is treated vigorously with drug therapy in an effort to control symptoms. Simply having a diagnosis of IBD is not a reason in and of itself for an abortion.

Which Diagnostic Procedures Are Safe To Perform During Pregnancy?

Abdominal ultrasound, sigmoidoscopy, rectal biopsy, upper endoscopy and colonoscopy are safe in pregnancy if necessary for diagnosing or managing the disease. An MRI scan is probably safe, but more information is needed. Diagnostic x-rays should be postponed until after delivery. If a medical emergency necessitates an x-ray, however, it should be a limited study, and the baby should be shielded.

Is Surgery For IBD Ever Performed During Pregnancy?

Whenever possible, surgery should be postponed until after delivery. If the disease is severe and not responding to drug therapy, however, it may be more dangerous to the patient not to operate. It is a matter of weighing the risks. Although there are reports of intestinal resections and even of ileostomies performed successfully in pregnant women, when any abdominal surgery is performed, the likelihood that the fetus will survive is reduced.

Does Previous Bowel Surgery Affect The Course Of Pregnancy?

In Crohn's disease, previous bowel resection does not appear to affect the pregnancy in any way. In fact, since resection usually results in remission of symptoms, the patient is likely to do better during the pregnancy than she would have with smoldering disease. There is one study in the literature that suggests that pregnancy *protects against further disease and that there may be fewer operations* in women who have been pregnant versus those women who have not been pregnant. The results of this study have yet to be duplicated by other investigators. After ileoanal anastomosis for ulcerative colitis, women have had successful outcomes in pregnancy. Women with ileostomies for ulcerative colitis or Crohn's disease occasionally suffer prolapse or obstruction of the ileostomy during pregnancy. If possible, it is best to postpone pregnancy for one year after the ileostomy is constructed (whether conventional or a newer procedure) to allow the body time to adapt to it. In Crohn's disease complicated by abscesses or fistulas around the rectum and vagina, episiotomy (standard surgery to widen the birth canal during labor) may have to be avoided if involving the diseased perianal area. In these cases, delivery is by Caesarian section.

If One Pregnancy Is Complicated By Active IBD, Are Future Pregnancies Likely To Be Affected In The Same Way?

There is no evidence that the course of either disease during any pregnancy will be the same during subsequent pregnancies.

What Are The Chances That The Child Of A Mother With IBD Will Develop One Of These Diseases?

It is possible, but certainly not inevitable, that the child of a mother with one of these illnesses might develop either illness. Recent studies suggest that the risk to the offspring of developing IBD if one parent has the disease is about nine percent, and if two parents have the disease, as high as 36 percent. When IBD clusters in families, there does not seem to be any clear-cut mode of inheritance. Because of this, the diseases are called "familial" and not "genetic." At present, no one can predict whether a child will "inherit" the disease from his or her parent. If a child is to develop IBD, one cannot predict at what age it will happen.

Do Pregnant Women With IBD Need To Follow A Special Diet?

In general, the pregnant woman with Crohn's disease or ulcerative colitis should follow the same well-balanced diet recommended for all pregnant women. The obstetrician and/or gastroenterologist may recommend the addition of specific foods, vitamins and minerals. It is particularly important that any woman who is on sulfasalazine therapy while pregnant supplement her diet with plenty of folic acid. This is recommended to prevent birth defects seen in any woman with a diet deficient in this nutrient.

Do Emotional Factors Cause Flare-Ups Of The Disease During Pregnancy Or In The Weeks Following Delivery?

Emotional stress may cause symptoms to worsen during pregnancy, just as it can at any other time. But this does not mean that stress plays any role in causing the disease. Similarly, the postpartum period is a time normally characterized by rapid change, both physical and emotional, in the new mother. These changes also may cause a temporary worsening of symptoms.

Are My Chances Of Having Osteoporosis Higher If I Have IBD?

Yes, they are. Crohn's patients are particularly at risk for osteoporosis secondary to decreased calcium intake or absorption, steroid use, and smoking. After menopause, this risk becomes even higher, as a majority of IBD patients in the United States are Caucasian. (Caucasians are at a higher risk for osteoporosis.)

Does Having IBD Have An Effect On Menopause?

No. If the disease is inactive and periods are regular, menopause occurs naturally. Surgical menopause has been noted to have a positive effect on symptoms that otherwise occur with menses.

We hope that the information offered in this brochure has been helpful to you. For more information about some of the other topics discussed here, please be sure to request the appropriate brochures in this series. All are available free of charge.

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