



Sexuality, Fertility & Pregnancy

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This booklet sets out to answer the questions most commonly asked about the impact of inflammatory bowel disease (IBD) on sexuality, fertility and pregnancy. Most new cases of IBD are diagnosed during the teens and early 20's. As a result issues such as intimacy, sex, fertility and pregnancy are of some concern especially given the chronic nature of Crohn's disease and ulcerative colitis. If this booklet can both fill in some of the gaps in your knowledge, and help to allay your natural anxieties, then it has served its purpose.

Crohn's disease and ulcerative colitis are chronic digestive diseases of the gastrointestinal tract, known together as inflammatory bowel disease (IBD). Crohn's disease causes inflammation most commonly in the lower part of the small intestine (ileum), the large intestine (colon), but may affect any part of the digestive tract. Ulcerative colitis causes inflammation of the inner lining of the colon and rectum of varying severity. People with these diseases experience diarrhoea, abdominal pain, rectal bleeding, and fever. Loss of appetite and weight are common. The inflammatory process may involve the joints, skin, eyes, mouth, and liver. Cancer of the colon is a rare complication in people with extensive, long-term, ulcerative colitis. The onset of these diseases may be rapid or insidious, and surgery may be required.

For more information see CCSG Information Leaflet No. 1, *Crohn's Disease* and CCSG Information Leaflet No. 2, *Ulcerative Colitis*.

Does having IBD affect the sex drive?

People with IBD (and those with other chronic illness) may find that they have less interest in sex when their disease is active. Although IBD has no direct effect on the sex organs, Crohn's disease may have an

indirect effect in women due to the possible formation of a fistula (an opening) between the vagina and another organ such as the rectum.

Sexual desire and performance are not affected. Drugs used most commonly used to treat IBD.

Can having surgery alter sexual function or fertility?

Patients who have had surgery are often advised to avoid strenuous activity (including sex) to allow time for healing. However, normal activities can usually be resumed following full recovery. As a result of improved health after diseased bowel is removed, surgery usually brings increased libido and improved sexual relationships.

For men who have their rectum removed and a pelvic pouch formed, there is a very slight risk of impotency and problems with ejaculation. This possibility should be discussed with your doctor before having this procedure. Surgery in the pelvic area of women can lead to scarring and adhesions which may affect the fallopian tubes making it difficult to conceive. Generally bowel surgery will not affect the ability of women to give birth normally.

Some types of surgery may affect sexual activity indirectly. The formation of an ileostomy in which the patient has to wear a "bag" over a stoma to collect waste can be initially embarrassing but it has no physical effect on sexual function.

Women who have a total colectomy (removal of the colon) often develop a heavy vaginal discharge. Some women find intercourse painful after a total colectomy, but this is temporary.

Does IBD affect puberty?

Both growth and sexual maturity can be delayed by having IBD. Children with Crohn's

disease are affected more (up to 40%) than those with ulcerative colitis (up to 20%). The most significant cause is inadequate nutrition due to active disease but the prepubertal levels of sex hormones may also be important.

Are men and women with IBD less fertile than people without IBD?

The fertility of people with ulcerative colitis is the same as that of anyone else. It is also normal in people with inactive Crohn's disease. However, women with active Crohn's disease are slightly less likely to become pregnant, and men with active Crohn's disease may have a reduced sperm count.

Malnutrition (which is common in IBD) can have an effect on male and female fertility. In men it can result in a reduced sperm count while in women it may lead to the stopping of menstrual periods. Both these effects are reversible upon regaining healthy nutritional status.

The symptoms of IBD, however painful and uncomfortable, do not permanently affect fertility.

Will IBD medications affect my fertility?

Most drugs used to treat IBD have no effect on fertility. There is an exception and that is the drug sulfasalazine (Salazopyrin®). This anti-inflammatory drug may cause men taking it to have a reduced sperm count, but this returns to normal when the drug is stopped.

IBD medications are not affected by any form of contraception and "the pill" may be taken safely.

Can women with Crohn's disease or ulcerative colitis conceive as easily as other women?

Generally, yes. Those women who have had difficulty conceiving have usually had Crohn's disease (often with disease in the colon), and not ulcerative colitis. This reduced fertility is usually temporary, and probably is not caused by any mechanical blocking of the Fallopian tubes. It is probably caused by the symptoms of active Crohn's disease, ie. fever, fistulas, and anaemia. If a woman with Crohn's disease has difficulty conceiving, she may need more vigorous treatment of her disease. In this case, it may

be a good idea to postpone pregnancy until the symptoms are under control, and the woman feels stronger.

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. Women with either Crohn's disease or ulcerative colitis should do well during the pregnancy if the disease was inactive at the time of conception. However, if a pregnancy occurs during a period of active disease, both diseases are likely to remain active or to worsen. This worsening generally occurs during the first trimester (three months) in ulcerative colitis and during the third trimester in Crohn's disease.

If either disease can be brought into remission with drug therapy during the pregnancy, the woman's health should be good for the remainder of the pregnancy

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 foetus becomes even greater. Thus, it is better to treat flares quickly and effectively with drugs and avoid surgery.

Do these diseases ever begin during pregnancy?

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

Is it safe to take sulfasalazine 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 foetus. Sulfasalazine and prednisone are the two drugs used most commonly to control the symptoms of Crohn's disease and ulcerative colitis. Studies have found no evidence that the foetus is harmed by either of these drugs taken by the mother during pregnancy. Since the major threat to the pregnancy comes from having active disease 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 and/or sulfasalazine may be introduced or increased. Sulfasalazine may also be used to maintain a remission for the remainder of the pregnancy and after.

The newer 5-ASA drugs such as mesalazine (Pentasa®, Asacol®) and olsalazine (Dipentum®) are probably also safe during pregnancy.

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 may also cause heartburn very much like the heartburn sometimes experienced in the later months of pregnancy.

Should a woman taking sulfasalazine or prednisone breastfeed 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. 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 breastfeed her baby while still taking a moderate or high dose of prednisone, the baby should be monitored carefully by a paediatrician.

What about immunosuppressive drugs such as Imuran® (azathioprine), 6-mercaptopurine (6-MP) and cyclosporin? Are they safe to take during pregnancy?

Animal studies using these drugs have found evidence of genetic damage to offspring but this has not been observed in

humans. Studies on women with IBD who have been taking azathioprine and become pregnant show no congenital abnormalities in their babies, even in women who continued the drug throughout pregnancy. Results have been similar with 6-MP, when taken before and during pregnancy.

Cyclosporin is less well understood. Evidence suggests that up to 50% of babies may be premature or underweight. Opinion is divided on its use in women who are considering pregnancy. There may be some benefit to its use in avoiding surgery during pregnancy, while others consider the risks to the foetus too great. It should not be taken while breastfeeding.

Use of these drugs before and during pregnancy should be discussed with your doctor. If pregnancy results while taking these drugs therapeutic abortion is not required or indicated solely because of the use of these drugs.

Are there any other drugs that are unsafe to take before, during or after pregnancy?

Metronidazole (Flagyl®, an antibiotic) is used in the treatment of some types of IBD but in animal studies has been shown to cross the placenta and in high doses is teratogenic and tumorigenic. There have been no studies on its use in pregnant women with IBD and therefore it should be used with caution.

The antidiarrhoeal drugs Lomotil® and loperamide (Imodium®) should not be used in pregnant or breastfeeding women.

Which diagnostic procedures are safe to perform during pregnancy?

There is no reason why a sigmoidoscopy, rectal biopsy, or gastroscopy cannot be performed on the pregnant patient, if these tests are necessary in the management of the disease. A limited colonoscopy with a flexible colonoscope may also be performed, if clearly needed, but should be avoided otherwise because of the limited information about its safety. Diagnostic x-rays should be postponed until after delivery, but CAT scan (which uses lower levels of radiation) may be considered as an alternative if necessary.

Is surgery for Crohn's disease or ulcerative colitis ever performed during pregnancy?

Whenever possible, surgery should be postponed until after delivery. However, if the disease is severe and not responding to drug therapy, 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 foetus 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 underlying disease.

Women with ileostomies occasionally suffer prolapse or obstruction of the ileostomy during pregnancy. It is best to postpone pregnancy for one year after the ileostomy is constructed to allow the body time to adapt to it. In Crohn's disease complicated by abscesses or fistulas around the rectum, episiotomy (standard surgery to widen the birth canal) may have to be avoided. In these cases, delivery is by Caesarean section.

If active Crohn's disease or ulcerative colitis complicates one pregnancy, 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 Crohn's disease or ulcerative colitis will develop one of these diseases?

It is possible, but certainly not inevitable that the child of a mother with Crohn's disease or ulcerative colitis might develop either. Studies have shown that about 10% of people with ulcerative colitis, and 25-35% of people with Crohn's disease, have a near relative with IBD. The percentage is higher when you count more distant relatives. But even when the diseases cluster in families, there does not seem to be any clear-cut pattern to their distribution. Because of this,

the diseases are called "familial" and not "genetic" For this reason, no one can predict whether a child will "inherit" the disease from his or her parent, and physicians do not generally discourage a couple from having a child, simply because one parent has IBD. If a child has one parent with IBD the risk of that child developing IBD is approximately 5%, but the risk is greater if it is the mother who has IBD. If both parents have IBD the chances of a child developing IBD can be up to 50%.

Do pregnant women with Crohn's disease or ulcerative colitis 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. Her obstetrician and/or gastroenterologist may recommend the addition of specific foods, vitamins and minerals.

If the disease is active, however, it may be necessary to eliminate foods from the diet which cause discomfort. Pregnant patients can be adequately nourished with enteral diets or total parenteral nutrition if necessary. CCSG Information Leaflet No. 3 - *Nutrition & Diet*, contains helpful advice on what foods may cause discomfort.

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 may at any other time. But this does not mean that stress plays any role in causing the disease. Similarly, the post partum period is a time normally characterised by rapid change, both physical and emotional, in the new mother. These changes may also cause a temporary worsening of symptoms.