



Crohn's and
Colitis Canada
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FAMILY MATTERS

FERTILITY, PREGNANCY
AND CROHN'S DISEASE &
ULCERATIVE COLITIS



crohnsandcolitis.ca

STARTING A FAMILY

You or your loved one has Crohn's disease or ulcerative colitis – and you want to start a family. What are the considerations involved in making this decision? If you are a woman, you may wonder if you can get pregnant; if you are a man, you may wonder if you can father a child. What are the health consequences of starting a family? Should you take your meds if you are pregnant? Will your children have the disease?

These questions and many others may arise as you sort out the life and health issues related to fertility, pregnancy and Crohn's disease or ulcerative colitis. Crohn's and Colitis Canada understands that this is one of the biggest decisions of your life and we want to provide you with some facts that will assist you during this time. You should also seek out the advice of your health care team – your gastroenterologist, family physician, nurse specialist, pharmacist and dietitian – and now your obstetrician or gynecologist. They are the best source of insight into the unique characteristics of your particular journey. Your health does not follow a cookie-cutter approach and the factors you and your partner need to consider when having a family will be specific to your situation.

CAN YOU GET PREGNANT?

If you are a woman that has been diagnosed with Crohn's or colitis, one of the first questions that may cross your mind is whether or not you can even get pregnant. You may have heard that it is more difficult to conceive if you have Crohn's disease or ulcerative colitis. Is this true?

Yes and no. Research shows that women suffering from a flare-up have a decreased rate of fertility than women who do not have Crohn's disease or ulcerative colitis. In other words, if you are in the midst of an acute episode of your disease, you are less likely to conceive during that period of time than women in the general population. However the good news is that women whose disease is in remission have just about the same fertility rates as women in the general population. The key is this: **if your disease is not active and you are healthy and well-nourished, you are just as likely to get pregnant as anyone else!**

An exception is women who have had surgery known as an "Ileal Pouch with Anal Anastomosis" (IPAA). This group of women tends to have reduced fertility rates, perhaps because of internal scarring around the fallopian tubes (please see our booklet "The Cutting Edge: Surgery for Crohn's Disease & Ulcerative Colitis" for more details on the procedure). For that reason, be sure to discuss family planning with your surgeon if you are considering an IPAA. You should also wait one year after having any surgery before getting pregnant, to allow time for your body to heal.

If you have had surgery to remove part of your colon, studies show that there is NO detrimental effect on fertility rates. However women who have an ileostomy as a result of a bowel resection could have a slightly decreased fertility rate.

SHOULD YOU GET PREGNANT?



In spite of the good news about fertility rates amongst women diagnosed with Crohn's disease or ulcerative colitis, current studies show that the actual rate of conception is lower than the general population. This indicates that women with Crohn's disease or ulcerative colitis are physically able to get pregnant, but some are choosing not to. Why? Surveys suggest two possibilities: some women with Crohn's disease or ulcerative colitis are concerned about the adverse health consequences to themselves during and after pregnancy; others are concerned for their children as a result of their disease and are therefore choosing not to have any.

Are these concerns grounded in fact? Let's start off by stating that the best time for you to get pregnant is when your disease is in remission. If your disease is active at the time you conceive, there is a good chance that it will remain active throughout your pregnancy. In this case, there is an increased risk of having a miscarriage, delivering your baby prematurely, having a stillbirth or giving birth to a newborn with low birth weight (LBW). On the other hand, about 30 percent of women actually find that their disease improves during

pregnancy for reasons currently unknown to researchers and physicians.

If you conceive when your disease is in remission, most studies show that you are as likely to have a normal pregnancy as a woman who does not have Crohn's disease or ulcerative colitis. Some studies indicate that there is still a slightly increased risk of premature births or LBW for women with Crohn's disease or ulcerative colitis (even when in remission), but no increases in stillbirths, miscarriages or newborn death. Regardless of which study you consider, remember that you should plan your pregnancy at a time when your body is healthy and your disease is under control. This makes a huge difference to you and your baby.

There is a possibility that your disease could flare up while you are pregnant, but the possibilities of that are no greater than when you are not pregnant.

In fact, some women find that their disease improves when they are carrying a baby, possibly because their immune system is somewhat depressed during this time or because the production of hormones reduces the formation of scar tissue.

WHAT ABOUT FATHERING A CHILD?

Males who are experiencing an acute episode of Crohn's disease or ulcerative colitis tend to have decreased sperm counts during this time. However, once their symptoms have gone into remission, their sperm counts become normal – provided they are well nourished. A very small percentage of men can also experience impotence or a condition known as "retrograde ejaculation" (sperm is ejaculated back into the bladder rather than out the penis) following rectal excisions or an IPAA.

When family planning begins, men should (in consultation with their physician) stop taking sulfasalazine and consider switching to an alternative medication such as 5-ASA at least three months before trying to father a child because this drug is known to decrease sperm counts.

WILL YOUR CHILDREN DEVELOP CROHN'S OR COLITIS?



At this time, the links between genetics, the environment, microbes and these diseases are still being explored. (In fact, Crohn's and Colitis Canada is sponsoring the Genetics, Environmental and Microbial (GEM) project, to uncover some of those relationships and how they result in Crohn's or colitis) Some studies show there is a slightly increased risk for children to develop Crohn's disease or ulcerative colitis if one or both parents have the disease. However, keep in mind that there is a greater possibility that children **will not** develop the disease than there is the chance that they will. Family history may be a consideration, but it should not be the final word in your decision to start a family.

WHAT ABOUT MY IBD MEDICATION?

1. Fertility

While most Crohn's and colitis medications are fine for men and women to take when trying to start a family, methotrexate (an immunosuppressant drug) is definitely NOT recommended during this time. Methotrexate not only reduces sperm counts in men, it has been known to cause miscarriages and fetal deformities. Both men and women should (in partnership with their doctor) seek alternatives to methotrexate before trying to conceive.

As we noted earlier, sperm counts are reduced while men are taking sulfasalazine, but will resume normal levels approximately three months after stopping the drug. If you want to start a family, seek your physician's advice on when to stop taking medications, as well as alternatives.

2. During Pregnancy

Good control of your disease is essential to a healthy pregnancy and a healthy baby; your medication contributes to that healthy state. Your gastroenterologist prescribes drugs for you because of the benefits associated with it, but of course there are also varying degrees of side effects associated with any medication. As always, you should talk with your gastroenterologist and weigh the risks versus the benefits of taking any drug, particularly if you are pregnant. Please see our booklet, "Prescription for Health: Medication and Crohn's Disease & Ulcerative Colitis" for more information on side effects.

Having said that, if you decide to stop your medication because you are pregnant and your disease subsequently flares up, the risks to your baby can be much greater than those associated with the drugs. Malabsorption, malnutrition, inflammation, diarrhea, and dehydration can all play havoc on the developing fetus.



For that reason, current medical thinking advises women to stay on their medication regimes prior to and during their pregnancy, and if their disease flares during the pregnancy, to take the necessary medications (with certain exceptions as we have noted). It is not advisable to automatically discontinue your medications simply because you are pregnant.

The following list reflects current research on medications and pregnancy. We want to again emphasize that all drugs have some side effects, but these must be weighed against their benefits. A healthy mother whose Crohn's disease or ulcerative colitis is under control is more helpful to her developing fetus than a mother who is suffering from an acute flare-up.

Aminosalicylates

General consensus is that the aminosalicylates (e.g., sulfasalazines and the 5-ASA compounds) pose an acceptable risk for pregnant women and their fetuses. In fact, results from studies vary from NO risk at all, to a very small risk of increased premature deliveries, low birth weights (LBW) for newborns, congenital abnormalities and cleft palates. Bottom line – the very small risks associated with aminosalicylates pose less of a hazard to your

baby than not taking the medication if you need it. In fact, doctors can and will prescribe these drugs after your baby is born, even if you want to breastfeed.

Antibiotic

Current opinion seems to vary as to whether or not antibiotics are safe during pregnancy. Generally, physicians do not prescribe metronidazole for pregnant women, except for short courses (such as 7 days).

As for other antibiotics such as ciprofloxacin and tetracycline, there are mixed findings on their effects on the fetus. Some studies indicate concern over possible fetal deformities while others simply recommend that antibiotics be avoided during pregnancy. Once again, the clinical necessity of taking an antibiotic must be weighed against the potential risk to the fetus.

Anti-Diarrheals

Loperamide and diphenoxylates are two anti-spasmodic drugs used to relieve diarrhea. Unfortunately there is not much information available on their effects on fetuses, nor is there information about their effects if the mother is breastfeeding her baby. Discuss with your doctor or pharmacist if you require an anti-spasmodic when pregnant (or afterwards, if you intend to breastfeed).

Biologics

Biologics such as infliximab and adalimumab appear to be safe both during pregnancy as well as breastfeeding. There have been no significant increases in fetal malformations, miscarriages or other problems found with taking this class of drugs while carrying a baby. However, there has been less experience with these drugs in pregnant women with Crohn's disease or ulcerative colitis compared to some of the other drugs.

Corticosteroids

Taking corticosteroids has been shown to be quite safe for the fetus, except in the early stages of pregnancy when it would be preferable (if possible) not to be taking the drug. There is a very small risk of fetal deformity (cleft palate), premature delivery or LBW, but these are deemed acceptable against the need for a woman to take the lowest possible doses of the medication to control her disease. Babies of breastfeeding moms who are taking a corticosteroid should be monitored by a paediatrician.

Immunosuppressants

Research has shown that there are better outcomes for babies whose mothers stay on their immunosuppressants, than for babies whose mothers went off the medication and subsequently suffered a relapse of their Crohn's disease or ulcerative colitis. Depending on the study, data shows that there is either NO increase in abnormalities for babies or a very small but insignificant increase when mothers continued with their immunosuppressants.

The exception to this is methotrexate. Men who want to father a child and women who want to get pregnant must consult with their physicians and stop taking this drug. It should also not be taken during pregnancy or when breastfeeding.

CONGRATULATIONS – YOU’RE PREGNANT!



If you have already gone through the fertility and conception stages and find that you are pregnant, the next nine months are an exciting time as you feel your baby grow and move within you. Enjoy the anticipation of your child’s birth and the joy you and your partner will share as you bring your baby into the world.

Many women with Crohn’s disease or ulcerative colitis have a normal pregnancy and delivery. Occasionally there are chances of premature delivery or LBW, particularly if the mother experiences a relapse of her disease during pregnancy. However, there are far more women who have a wonderful, full-term pregnancy than those who have trouble.

Here are a few more thoughts we want to share, to help you maximize the health of your growing child as well as your own.

Diet

Make sure you eat a healthy diet during this time. Your baby is depending on you for its nutrition, so be sure you are eating properly. Also, you should talk with your doctor about taking folic acid supplements, as women with Crohn's disease or ulcerative colitis are often deficient in this nutrient and it is important for proper neural development in the fetus.

Please see our booklet "Food for Thought: Diet and Nutrition for Adults Living with Crohn's Disease & Ulcerative Colitis" for more information on your diet, nutrition and vitamin supplements.

Your Symptoms and the Fetus

If you do suffer from symptoms of Crohn's or colitis while you are pregnant, you can take comfort in knowing that the cramping, gas, nausea and diarrhea that you experience are not adversely affecting the fetus. In other words, your disease is not directly harming your baby unless these symptoms are interfering with your ability to eat a proper diet and absorb the necessary nutrients.

Smoking

Regardless of whether or not you have Crohn's disease or ulcerative colitis, smoking before, during or after you are pregnant is a bad idea. Smoking has been associated with LBW and possibly the development or worsening of Crohn's disease.



Diagnostic Procedures

Most diagnostic procedures are perfectly safe when you are pregnant. That includes endoscopic procedures for your bowel, biopsies, ultrasounds and MRI's. However you should NOT have a CT scan or X-ray while you are pregnant, unless there is a medical emergency that necessitates them; this is true for all women, regardless of whether they have Crohn's disease or ulcerative colitis or not.

DELIVERY!

The moment has arrived and your baby is on the way! Let's talk briefly about options in the delivery process.

VAGINAL DELIVERIES, EPISIOTOMIES AND CAESAREAN SECTIONS

Women with Crohn's disease or ulcerative colitis have the same rates of vaginal deliveries as women without Crohn's disease or ulcerative colitis. It is recommended that you tell your obstetrician about your disease so that they know your full medical history. Your obstetrician may decide to do an episiotomy at the time of delivery to avoid an uncontrolled tear in your perineum. This is particularly important for women with Crohn's disease or ulcerative colitis, as the presence of active inflammation in the area can inhibit post-partum healing of an uncontrolled tear around the anal sphincter or rectum.

If you have a lot of perineal inflammation or fistulas prior to giving birth, your obstetrician may recommend a Caesarean section to avoid the possibility of further trauma to your perineum.

SOME ADDITIONAL POST-PARTUM THOUGHTS



Breastfeeding

Doctors recommend that women breastfeed their babies whenever possible because it is healthier for both mom and baby. However, if your disease is active, you may not be able to produce enough breast milk. If you decide to try, you should let your doctors know because sulfasalazine, 5-ASAs, steroids, anti-diarrheals, immunosuppressants and antibiotics do pass into your breast milk.

Do not let this be a cause for panic. The risks to your baby vary according to the drug and the dosage, so they should be discussed with your doctor. It is certainly not the rule that all drugs must be stopped just because you are breastfeeding. And remember, the primary consideration is that you remain as healthy as possible with whatever medications are necessary, to ensure that you are able to take care of your baby.

Future Pregnancies

What happens during one pregnancy is not an indicator of what you will experience in another. If you have a rough ride with your disease during your first pregnancy, it is by no means an indicator that a

subsequent pregnancy will be the same. Make decisions about additional children based on other life and health issues, not based on the relapse or remission of your symptoms during your last pregnancy.

Contraception

Women with Crohn's disease or ulcerative colitis can use any form of contraception their doctor recommends. There is research suggesting that some types of birth control pills (the pill) can aggravate symptoms of Crohn's disease or ulcerative colitis, while other studies flatly reject this idea. There appears to be some question about the absorption and effectiveness of birth control pills for women who have had an ostomy. If you have suffered a relapse of your symptoms, your gastroenterologist may test the effects of your contraceptive medicine by temporarily taking you off the pill and seeing if it makes any difference. If contraception is your intent, be sure you take other precautions to ensure you can control when you become pregnant.

Pregnancy can be one of the greatest joys you will ever experience. A decision to bring a child into this world is one that takes careful thought and love. For those with Crohn's disease and ulcerative colitis, it poses more challenging health considerations than for those who do not live with a chronic disease, not only for the mother but also for the baby.



ABOUT CROHN'S AND COLITIS CANADA

Crohn's and Colitis Canada is the only national, volunteer-based charity focused on finding the cures for Crohn's disease and ulcerative colitis and improving the lives of children and adults affected by these diseases. We are one of the top two health charity funders of Crohn's and colitis research in the world and the largest non-governmental funder in Canada. We are transforming the lives of people affected by Crohn's and colitis (the two main forms of inflammatory bowel disease) through research, patient programs, advocacy, and awareness.

Our Crohn's & Colitis – Make it stop. For life. campaign will raise \$100 million by 2020 to advance our mission.

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For more information on Crohn's disease or ulcerative colitis visit our website **crohnsandcolitis.ca** or call 1-800-387-1479

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