Navigating the pregnancy journey:

From pre-conception to post-partum considerations

A guide for people with ulcerative colitis (UC)

FERRING
PHARMACEUTICALS

START ColitisCare
Patient Empowerment Program

How this booklet can help you

While becoming a parent can be a fulfilling experience, it is not always easy. It can be especially challenging when suffering from a chronic condition like ulcerative colitis (UC).

It is not uncommon to experience the onset of an inflammatory bowel disease, such as UC, before or during childbearing years, making it an important factor in the family-planning decision-making process.

Like many others with UC, you may have concerns about becoming pregnant and starting a family. Results from some studies show that voluntary childlessness is more common among people with IBD than in the general population.

This may be due to concerns about how the pregnancy will impact UC or whether it will be passed on to the child. Some may have doubts about their ability to care for a child.

While people with IBD may have an increased risk of pregnancy complications, most pregnant people with UC can have healthy pregnancies and deliver healthy babies.

There is a large body of evidence suggesting that the frequencies of pregnancy loss, stillbirth, and congenital abnormalities in women with UC are no different from those of the general population.

The purpose of this guide is to provide you with information and tips to consider during every step of the journey, from planning your pregnancy to breastfeeding. The more you know, the better equipped you will be to make the best decision for you.

Keep in mind that this booklet is not meant to replace any advice from your doctor or other members of your healthcare team.

The planning stage

Involve your healthcare team

When you begin to consider starting a family, inform your healthcare providers, including your gastroenterologist.

Because there is a 30% to 35% chance of women with UC experiencing flares during their pregnancies, involving your healthcare team from the outset can establish clear expectations about your care plan throughout your journey.

Your team can also help address any concerns that you may have about becoming pregnant. While 1 in 4 individuals with UC report fear of infertility due to their condition, only 15% consult their doctor for medical advice. Common fears include fear of congenital abnormalities, fear of the toxicity of drugs to the baby, or fear of genetic transmission. Having an open discussion with your doctor can help them address your feelings and develop an individualized pregnancy plan.

Remember that your healthcare team is there to support you throughout this journey.

Get the conversation started

The following is a list of questions you may want to ask your doctor when considering whether to start a family:

- Will my children inherit IBD, specifically UC?
- Is my fertility impaired by UC?
- Will my UC treatment affect my ability to conceive?
- Will my UC treatment harm my baby?
- Will my UC flare up during pregnancy?
- What happens if I experience a flare? (i.e., what therapies can I use?)

Considerations for conception

Get control of your condition

It is well established that pregnancy outcomes are better in women **who are in remission** at the time of conception. Flares are more likely to occur in mothers with UC who had active disease when they conceived, as opposed to mothers who were in remission when they conceived.

Having active disease at the time of conception:

- may affect the ability to become pregnant (i.e., fertility)
- can increase the likelihood of flaring during pregnancy
- is associated with a higher risk of preterm delivery
- is associated with lower birth weight infants and small for gestational age infants
- is associated with a higher risk of pregnancy loss

Getting control of UC is key

Part of your disease management strategy includes continuing to take your medications while trying to conceive. You may be concerned that your UC treatment could affect your ability to conceive; however, research shows that medications, such as 5-aminosalicylic acid (5-ASA) and biologics, do not affect fertility in females.

If you are taking medications such as methotrexate, a JAK inhibitor or an S1P modulator, talk to your gastroenterologist, as these should be avoided during pregnancy.

Continue taking your medications and don't stop until you talk to your doctor

If you are concerned about any potential association between fertility and your treatments, ask your healthcare team about whether your current medication is safe to take. If not, your doctor may decide to switch your medication. Ideally, this should be done at least **3 months before the pregnancy**, so that there is enough time for the new medication to work and for you to be in remission at the time of conception.

Certain UC medications can affect fertility in males

Some medications can affect sperm motility and cause a reduction in sperm production. If you and your partner are trying to conceive, talk to your healthcare professional about whether your partner's current treatment may influence their fertility.

Lifestyle tips to prepare for pregnancy

The following tips can help you achieve remission and also help prepare your body for a positive experience.

Eat well

- Good nutrition is very important both before and during pregnancy
- Consider eating a variety of food from the major food groups to ensure you get enough important nutrients, including folic acid, calcium, iron, protein, iodine, vitamin C, vitamin B12, and vitamin D
- If you have been on a specific diet for complications related to UC, speak to a dietitian to ensure you follow a healthy diet for pregnancy

Take supplements

- It is generally advised to take prenatal vitamins before becoming pregnant and until 4–6 weeks after childbirth
- Speak with your healthcare team regarding supplements that are right for you

Stop smoking and consuming alcohol

- Smoking, alcohol consumption, and the use of recreational drugs can have harmful effects on the baby's development
- Smoking can also increase symptoms of UC
- If you use any of these, please seek help from your healthcare team to try to stop

Take care of your mental health

- Living with UC can cause stress and take a toll on your mental health
- Try to relax by engaging in activities you enjoy, such as reading, meditation, or taking a walk
- Talk to family, friends, and your healthcare team if you need extra support

Be active

- Exercising before and during pregnancy is just as safe in women with IBD as it is in those without the disease
- Ask your healthcare team about the exercise intensity that is right for you

Speak with your obstetrician and gastroenterologist if you have special concerns or complications that you think could interfere with your ability to exercise

Problems conceiving

It may be comforting to know that women with UC generally appear to have fertility that is similar to the general population, especially when in remission.

However, some aspects of the disease may affect the ability to become pregnant, such as active disease and certain IBD-related surgeries. In particular, lower rates of fertility have been reported in people who have had a procedure called ileal-pouch anal anastomosis (IPAA), also known as J-pouch surgery. This involves removing the diseased colon and rectum, creating an internal pouch from the ileum to store stool, and allowing for natural bowel movements.

There are also non-IBD factors that may affect fertility, so if you do experience difficulties conceiving, don't get discouraged. Infertility affects 1 in 6 couples in Canada. It is not your or your partner's fault.

If you have had or require an IPAA, talk to your healthcare team. They can talk to you about the potential effects on fertility and advise you on what to do. They can explain assisted reproductive technology (ART) and how these procedures can be used to help women with UC successfully conceive.

A closer look at ART

Assisted reproductive technology (ART) describes several different medical procedures used to help with conception when a couple is unable to conceive after trying for at least a year.

The most common type of ART is *in vitro* fertilization (IVF).

During IVF, mature eggs are collected from the ovaries and fertilized by sperm in a lab. One or more of the fertilized eggs, called embryos, are then placed in the uterus.

IVF can be done using a couple's eggs and sperm, or it may involve eggs, sperm, or embryos from a known or unknown donor. In some cases, a couple may not be able to or want to carry the pregnancy and thus may involve a surrogate, a woman who carries the pregnancy for the intended parents.

The following steps are used in the IVF process:

1. **Ovarian stimulation hormone therapy**
   - Hormones, including follicle-stimulating hormone (FSH) and/or luteinizing hormone (LH), are usually administered via subcutaneous injection to stimulate the ovaries to produce multiple mature eggs
   - This increases the chances of successful fertilization
2. **Egg retrieval (aspiration)**
   - A thin needle is used to retrieve the eggs from the ovaries
3. **Sperm preparation**
   - The healthiest sperm are isolated from a semen sample
4. **Egg fertilization**
   - The egg(s) and sperm are then combined in a laboratory setting, outside of the body
5. **Embryo development**
   - The fertilized egg(s) are then monitored for several days for embryo development
6. **Embryo transfer**
   - The embryo is transferred into the uterus

In some cases, these steps are divided into separate parts, and the process may take longer.

Your chances of having a healthy baby using ART depend on many factors, such as your age and the cause of infertility. Keep in mind that these procedures can be time-consuming, expensive, and invasive. **Your healthcare team can help you understand how ART works, what the risks are, and whether it's appropriate or the right time for you.**

ART has been shown to be safe and effective in patients with ulcerative colitis, and the rate of live births is comparable to that of the general population

Pregnancy and beyond

Take care of your body to take care of your baby

Discovering you are pregnant is an exciting and emotional experience.

It can also be overwhelming, especially if you are worried about how UC can affect your pregnancy or your baby. Although pregnancy may, in some people, have a beneficial effect on symptoms associated with UC, this doesn't mean pregnancy will stop flares completely.

Women who are in remission at the time of conception still have a 26–35% chance of flare during pregnancy, especially during the first and second trimesters and the postpartum period.

Just as being in remission before and during conception is better for you and the baby, so is staying in remission during the pregnancy.

It's normal to wonder whether you should stay on your UC medications during pregnancy to help prevent flares.

Do not stop any treatments you may be taking *before* consulting with your healthcare team.

Research shows that most UC medications, such as 5-ASAs, are considered to be safe for use during pregnancy, and that it may be more harmful to have active disease during pregnancy.

You and your healthcare team can evaluate and balance the risk associated with active disease against any possible risk associated with medications for UC. The decision about whether or not to remain on treatment can be made together.

Some medications may be harmful to your baby

If you are unsure about whether your UC treatment can cause negative effects on the fetus during pregnancy, consult with your doctor about your treatment. They can advise about whether you should continue, stop or switch medications.

When it's time to deliver

In general, most women with UC experience a safe delivery.

The decision regarding which delivery method you choose should be discussed with your obstetrician, gastroenterologist, and general surgeon, if applicable.

There are two main reasons why your healthcare team might recommend having a C-section over a vaginal delivery:

- If you have severe active disease
- If you have had or are likely to require J-pouch surgery

Most women with UC do well during pregnancy and after delivery

However, there is a slightly increased chance that flares could occur in the first 3 to 6 months after delivery. This risk can be minimized through proper maintenance of your medications, as well as by following up regularly with your healthcare team.

Considerations for breastfeeding

The method of feeding your baby is a personal choice. You may be concerned about taking medications for your UC while breastfeeding because you are unsure how it may affect your baby. This is normal.

Involve your healthcare team when deciding how to feed your baby. Some medications may be taken while breastfeeding, such as 5-ASAs, while others should be avoided.

Speak with your healthcare team about whether you need to adjust or change your UC medications while breastfeeding

Take note

Use this space to write down any questions you may have for your healthcare team and information you receive from them. You can also take note of your medications and vitamins that you will be taking throughout your pregnancy journey.

Scan:

for more resources to help you manage UC

Sinai Health

crohnsandcolitis.ca

to learn more about UC, including information about the pregnancy journey

Scan to access the *Dietary Tips for people living with ulcerative colitis* booklet that provides general dietary management strategies to reduce flares

Consult a dietitian and your obstetrician for personalized dietary guidance during pregnancy

Mount Sinai Handbook

Written in collaboration with Dr. Vivian Huang, MSc, MD, FRCPC

Associate Professor and Clinician Investigator in the Division of Gastroenterology at Mount Sinai Hospital and the University of Toronto

START ColitisCare
Patient Empowerment Program

FERRING
PHARMACEUTICALS

CA-PA-2500019