CROHN'S & COLITIS UK

FIGHTING INFLAMMATORY BOWEL DISEASE **TOGETHER**

INFORMATION SHEET

PREGNANCY AND IBD

INTRODUCTION

This information sheet is for women who want to know about the impact of Inflammatory Bowel Disease (IBD) on pregnancy. It may also be useful for partners of women with IBD.

It covers topics including fertility, medications, treatments and tests during pregnancy, looking after your health and the health of your unborn baby and the impact of IBD on pregnancy, birth and breastfeeding. There is also information at the end about how to get further support.

The good news is that, especially if your IBD is under control, most women with Ulcerative Colitis (UC) or Crohn's Disease (the two most common forms of IBD) can expect to have a normal pregnancy and a healthy baby. Also, for most women, having a baby does not make their IBD worse.

We have a companion sheet, **Reproductive Health and IBD**, which has more detail on contraception and fertility.

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HOW MIGHT IBD AFFECT MY FERTILITY?

Research suggests that in general men and women with IBD who have not had surgery are just as fertile as those who do not have IBD.

Although in general if you have IBD it's likely that you can become pregnant and have children, having active Crohn's Disease or having had an operation for Ulcerative Colitis may mean your fertility is reduced. Treatment is available to help people with fertility problems.

Most of the drugs prescribed for IBD do not affect fertility, but there are a few exceptions, including sulphasalazine and methotrexate that should be avoided if you are trying to conceive a child. There is more information in the section **How safe is my medication in pregnancy or if I am breastfeeding?**

For more details on fertility read our information sheet **Reproductive Health and IBD**.

HOW MIGHT IBD AFFECT MY PREGNANCY?

Most women with IBD will have normal pregnancies and healthy babies. However some research has linked IBD with an increased risk of early (preterm) birth, babies with a low birth weight and, more rarely, miscarriages. How active your disease is may play an important part in these risks (see **Getting your disease under control** below.)

Reading about these risks might make you feel anxious, there's more information about getting emotional support in the section **How can I get more support?** And the charity Tommy's also provides information about having a safe and healthy pregnancy (see **Other sources of help and support**.)

During pregnancy, you will receive antenatal care that will include scans and checks to make sure you and your baby are as well as possible. Your IBD team and antenatal team should work together to make sure you receive the best care. You could ask your consultant or IBD specialist nurse to contact your antenatal team to explain more about your condition and treatment.

> "My consultant was more receptive than I had expected about attempting pregnancy and managing my disease throughout my pregnancy. My IBD nurses were also invaluable support for questions and advice."
>
> **Kyra,** age 30
> Diagnosed with Crohn's Disease in 1998

GETTING YOUR DISEASE UNDER CONTROL

If are planning on getting pregnant, speak to your IBD team as soon as possible, so they can help you to bring your disease under control first.

Having inactive disease or being in remission, means periods of good health. Active disease means having flare-ups, or times when your symptoms are more troublesome.

Research has shown that most women with IBD who are in remission or have only mildly active disease at the time they become pregnant, are unlikely to have problems during their pregnancy and there may be less risks for their baby.

If your IBD is well controlled when you become pregnant, it is more likely to stay inactive during your pregnancy, and could mean an easier time for you and your baby.

So, if your IBD symptoms do begin to get worse, consult your IBD team as soon as possible.

SHOULD I KEEP TAKING MY MEDICATION WHILE I AM PREGNANT?

It is important to try to keep your IBD under control during your pregnancy, and your IBD team are likely to advise you to keep taking your medication. This is particularly important if you have had a recent flare-up and are trying to bring your IBD under control. The risk from most medication is lower than the risk of a flare-up.

There are some IBD drugs that pregnant women should definitely avoid. More details on how the most common IBD drugs might affect your pregnancy are given in the section **How safe is my medication in pregnancy or if I am breastfeeding?** You should not stop taking any of your medication unless your IBD team have advised you to.

Some people with Crohn's use nutritional therapy as part of their treatment. This is called exclusive enteral nutrition (a special liquid-only diet), which usually lasts for 2-8 weeks. It is safe to use enteral nutrition during pregnancy to treat a flare-up of disease or as a nutritional supplement. See our booklet **Food and IBD** for more information.

WHAT INVESTIGATIONS OR TESTS CAN I HAVE DURING PREGNANCY?

You may need to have an investigation or test to check on your IBD, especially if you have a flare-up. Make sure your doctor and IBD team know if you are, or may be, pregnant. They may delay some routine investigations until after you have had your baby.

Ultrasound tests and, after the first trimester, MRI tests are safe to have while pregnant.

You can also have gastroscopy (an examination of the oesophagus, stomach and duodenum using a slim tube inserted through the mouth), sigmoidoscopy and colonoscopy, if these examinations cannot be delayed. They are best done during the second trimester (months 4-6) rather than earlier or later. It's also ok to be sedated during these tests. Your IBD team may talk to your obstetrician before going ahead with these investigations.

Investigations that involve x-rays or other radiation should normally be avoided by pregnant women unless absolutely essential. This includes barium examinations, CT scans, radio-isotope and PET scans.

For more details about these tests see our information sheet **Tests and Investigations in IBD**.

WHAT ABOUT SURGERY WHILE I AM PREGNANT?

Surgery for IBD can be carried out safely during pregnancy. If you needed surgery urgently, it should not be delayed, but it is only likely to be advised if it would be riskier not to have the surgery.

HOW CAN I LOOK AFTER MYSELF AND MY BABY WHILE I AM PREGNANT?

It will help to work with your IBD team to keep your disease under control, and with your antenatal team to monitor you and your baby's health. There are also many things you can do to look after yourself and your baby – see the brief information below. The NHS website provides more detailed information on keeping well while you are pregnant (see **Other sources of information and support** at the end of this leaflet).

Eat a balanced and varied diet
Make sure you are getting enough calories, vitamins and minerals to nourish you and your growing baby. Our booklet **Food and IBD** covers healthy eating for anyone with UC or Crohn's Disease.

Supplement your diet if needed
You may need to supplement your diet, especially if you are underweight or have active disease. Talk to a dietitian or your IBD team for more information. Some oft the supplements you may need to take include:

- **Folic acid** (also known as vitamin B9) can help reduce the risk of birth defects such as spina bifida. Most women trying to get pregnant should take 400 micrograms (400mcg) daily, and once pregnant, continue this until at least the twelfth week of pregnancy. If you are on sulphasalazine, have Crohn's in the small intestine, or have had surgery to remove part of your small intestine, you may need a higher dose of folic acid. Your doctor will prescribe the right dose for you.

- **Vitamin D**. All adults, including pregnant and breastfeeding women, need 10 micrograms (10mcg) of vitamin D a day, and should consider taking a supplement containing this amount.

- **Iron**. Iron deficiency is quite common in IBD and you may need extra iron when you are pregnant. Your doctor will be able to recommend a suitable supplement.

- **Do not take vitamin A supplements,** or any supplements containing retinol, as too much can harm your baby.

Avoid or give up alcohol
Drinking alcohol excessively while you are pregnant can seriously harm your baby's development. NICE (the National Institute for Health and Care Excellence) also advises giving up alcohol for at least the first 3 months of a pregnancy as it may increase the risk of miscarriage.

Give up smoking
Smoking when you are pregnant harms the unborn baby. If you stop smoking you will reduce the risk of complications in pregnancy and birth. For more information on the impact of smoking on your own health, see our information sheet **Smoking and IBD.**

The NHS website provides more information about how to stop smoking and where to get support.

"I found gentle walking helped during my pregnancy. I also did a pregnancy yoga class, which I really enjoyed as I found it relaxing."

Cari, age 34
Mother to one child, diagnosed with Crohn's Disease in 2007

Exercise - and fatigue
Keeping active and fit during pregnancy can help you to adapt to the changes happening to your body and help you cope during labour. Keep up your normal daily physical activity (sport, running, yoga, dancing, or even walking to the shops and back) for as long as you are able. Exercise is not dangerous for your baby, there is some evidence that active women are less likely to experience problems in later pregnancy and labour.

IBD can cause fatigue, as can being pregnant. There is some evidence that low to moderate intensity physical activity may reduce fatigue associated with IBD. See our information sheet **Fatigue** for more information and other tips for managing tiredness.

WILL PREGNANCY MAKE MY ULCERATIVE COLITIS OR CROHN'S DISEASE WORSE?

If you have mildly active or inactive IBD when you become pregnant it is unlikely to worsen during pregnancy. If you become pregnant while your disease is active, it is more likely to remain active during your pregnancy.

We need more research before we know the long term effects of pregnancy on IBD are known. Some research suggests that pregnancy can have a positive effect on IBD – some women have fewer relapses and are less likely to need surgery after they have had children, whereas others studies show no change.

If you do have a flare-up in the early days after giving birth it can be hard to prioritise your own health, but it is vital to look after yourself as well. Tell your doctor or IBD team about any new symptoms or if your symptoms worsen. For more information about looking after yourself, read the section **How can I get more support?**

"I had vaginal births with both my children and I had no complications."

Debbie, age 31
Mother to two children, diagnosed with Crohn's Disease in 2002

WHAT WILL HAPPEN WHEN I GIVE BIRTH?

You can give birth at home, in a unit run by midwives (a midwifery unit or birth centre) or in hospital. Your options about where to have your baby will depend on your needs, risks and, to some extent, on where you live. For women with some medical conditions, including IBD, it may be better to give birth in hospital, where specialists are available, in case you need treatment during labour. Work with your midwife, obstetrician and IBD team to plan what will be best for you and your baby.

Your ante-natal team should discuss all the options for giving birth with you, so do talk to your IBD specialist and your obstetrician about your preferences and about any worries you have. Your midwife will be able to give you further support and can help you make a birth plan - a record of what you would like to happen during your labour and after the birth.

Some women with IBD may have a caesarean section, or C-section, which is an operation to deliver your baby through a cut made in your tummy and womb.

Your doctors may advise a C- section if you have active perianal Crohn's Disease or an ileo-anal pouch. A C-section may reduce the risk of damage to the muscles of your anus and perineum, which might affect your continence. Having a C-Section will also depend on your preferences, and the health of you and your baby.

WHAT ABOUT MY STOMA?

Pregnancy and delivery in women with a stoma is considered safe.

If you do have an ileostomy or colostomy, it might be helpful to tell your stoma nurse about your pregnancy at an early stage. Your nurse will be able to talk you through any changes to expect. For example, your stoma may change shape or become larger as your tummy expands. It will usually return to normal after the delivery.

Occasionally as your womb enlarges it can temporarily block the stoma. A change of diet may help – your stoma nurse will be able to advise on this. You may also find there is an increase in output from your stoma during the later stages of pregnancy. This is likely to return to normal after the birth.

Most women with a stoma will be able to have a vaginal birth, although sometimes a caesarean section is necessary.

I WANT TO BREASTFEED. ARE MY MEDICATIONS LIKELY TO HARM MY BABY?

Exclusive breastfeeding (breast milk only) is recommended by the NHS and World Health Organisation for around the first 6 months of your baby's life. Breastfeeding alongside introducing solids is best for babies from 6 months. Some research has suggested that breastfeeding may protect against early onset IBD in the children of mothers with have IBD.

Whether you can breastfeed while on medication for IBD will depend on which drug you are taking, whether it passes through into breast milk, and what is known about the possible effects on your baby.

Most of the drugs used to treat IBD are probably safe to use when you are breastfeeding – although many of the drug companies advise caution. This may be because little is known about the drug's long term effects and because it is difficult to carry out trials with breastfeeding mothers.

It may still be possible to breastfeed, so talk to your doctor and your IBD team about any likely problems from your medication.

For information about different drugs, see the section **How safe is my medication in pregnancy or if I am breastfeeding?** Our specific drug treatment leaflets have more information about all these drugs.

Breastfeeding is not always easy, especially if you are also living with IBD. You can obtain support from your midwife, health visitor or find out about other local support via the National Breastfeeding Helpline. There are also some online forums dedicated to this issue.

WHAT ARE THE CHANCES OF MY CHILD HAVING IBD?

Parents with IBD are slightly more likely to have a child who develops IBD. How likely seems to vary with the condition and is also higher in some groups of people than others.

If one parent has Crohn's, the risk of their child developing IBD is generally thought to be between 5% and 10% – that is, for every 100 people with Crohn's having a child, 5 to 10 of the children will develop IBD.

Estimates vary but research suggests that in general, if one parent has UC, the risk of their child developing IBD is about 2%. That is, 2 out of 100 children born to couples where one parent has UC might be expected to develop IBD at some point in their lives.

If both parents have IBD, the risk can rise to above 30% (3 out of 10 people). We still cannot predict exactly how IBD is passed on. Even with genetic predisposition, other additional factors are needed to trigger the development of IBD.

HOW CAN I GET MORE SUPPORT?

> "I was worried about my own health as well as my babies' but I luckily had a really good support network around me throughout both pregnancies and they reassured me when I needed it."
>
> **Debbie,** age 31
> Mother to two children, diagnosed with Crohn's Disease in 2002

Being pregnant and then having a new born can be exhausting. At times it may be difficult to do everything you would like for your baby because you are also living with IBD. Try to take care of yourself, as this will make it easier to take care of your baby as well!

The skills that you have developed to cope with your illness can be good preparation for pregnancy and motherhood. Mums with IBD very often have already developed ways to deal with tiredness and have learned how to be flexible.

Some women feel more vulnerable and anxious while pregnant and after birth. Hormonal changes may play a part in this. The "baby blues" affects many new mothers who may feel low and tearful, usually in the first week after giving birth.

Pregnancy and birth can trigger more serious depression in some women (postnatal depression). Your midwife, GP and health visitor should ask you about your mental health, which will give you the opportunity to talk about any concerns and to receive help if necessary.

The best way to treat depression is to seek help from a healthcare professional, but there are steps you can take yourself to reduce your chances of developing depression and help you recover once you've been diagnosed, The NHS website provides more information and getting support from friends,family and other mums in the same situation can be helpful.

If you have a partner they may also need support and many of these services are also open to them. They may also find our information sheet **Supporting someone with IBD: A guide for friends and family** useful.

Find out more about our information line, webchat, forum and local support in the section **Help and support from Crohn's and Colitis UK.**

HOW SAFE IS MY MEDICATION IN PREGNANCY OR IF I AM BREASTFEEDING?

Speak to your IBD team as soon as possible about your treatment during pregnancy and breastfeeding. We have provided some general information below, **but it is important to get specific advice about your situation from your IBD team, before starting or stopping any drugs or treatment**.

MEDICATION	USE WHEN PREGNANT	USE WHEN BREASTFEEDING
Aminosalicylates (5-ASAs) • **Sulphasalazine (Salazopyrin)** • **Mesalazine (Asacol, Ipocol, Mesren, Octasa, Pentasa, Salofalk),** • **Olsalazine (Dipentum)** • **Balsalazide (Colazide)**	Generally considered to be safe during pregnancy. Sulphasalazine can reduce your ability to absorb folic acid, an important vitamin for the unborn baby. You will be advised to take higher levels of folic acid supplements.	Some babies may have an allergic reaction to the drug in their mother's breast milk that may cause diarrhoea. They should be carefully monitored, but this normally stops if their mother stops the drug or they switch to bottle feeding.
Corticosteroids (steroids) • **Prednisolone** • **Budesonide (Entocort)**	Steroids can cross the placenta but they quickly convert to less active chemicals and can be used in pregnancy if needed.	Generally considered safe - a small amount of the drug may pass to the baby, but studies have found no harmful effects.
Immunosuppressants • **Azathioprine (Imuran)** • **Mercaptopurine (6-MP) (Purinethol)**	Most doctors recommend continuing azathioprine or mercaptopurine while pregnant as there may be a greater risk to the baby if you stop treatment and become unwell.	Small amounts pass into breast milk, but recent research has not found any evidence of harm in the children of mothers who have breastfed while on these drugs.
Methotrexate	You should not take methotrexate if you are: • the male partner of a woman trying to get pregnant, or • you are a woman trying to get pregnant, or, • if you are a pregnant woman. Methotrexate can increase the risk of birth defects. Use contraception while being treated with methotrexate and avoid pregnancy for at least 3-6 months after stopping treatment.	Avoid breastfeeding while taking methotrexate. It passes into breast milk and may affect the baby's immune system and growth.
Mycophenolate Mofetil	This immunosuppressant may also cause miscarriages or birth defects if used during pregnancy. If you're being treated with this drug and you want to get pregnant, you will usually be advised to stop taking it at least 6 weeks before conception. Men should use reliable contraception during treatment and for at least 90 days after they stop taking the drug.	Not recommended
Ciclosporin	Can be used if the benefits outweigh the risks.	Not recommended

HOW SAFE IS MY MEDICATION IN PREGNANCY OR IF I AM BREASTFEEDING?

Table continued from previous page:

MEDICATION	USE WHEN PREGNANT	USE WHEN BREASTFEEDING
Tacrolimus	There is currently little evidence about its safety for pregnant women with IBD. If you are taking tacrolimus, and you are pregnant, or thinking about becoming pregnant, talk to your IBD team about your treatment.	Not recommended
Biologics • **Infliximab (Remicade or biosimilars Inflectra, Flixabi, Remsima)** • **Adalimumab (Humira)**	Researchers are still looking into the long term effects of using these drugs during pregnancy, but there is evidence that they are low risk during conception and for at least the first two trimesters (up to 6 months). Stopping these medications during the second trimester reduces the unborn baby's exposure to the medication, but your doctor may consider it advisable to continue the drug in the third trimester to keep your IBD in remission. Manufacturers advise using adequate contraception while being treated with these drugs, and for 6 months after you stop treatment with infliximab, and for at least 5 months after stopping adalimumab. You can discuss contraception options with your doctor. Infliximab and adalimumab should only be used during pregnancy if clearly needed – you will be able to discuss this with your doctor. If you receive these treatments while you are pregnant, your baby may have a higher risk of getting an infection. Before your baby receives any vaccine, it is important to tell your baby's doctors if you received either of these treatments while pregnant. Your baby should not be given live vaccinations such as BCG until the age of 6 months if you received infliximab, and 5 months if you received adalimumab. In a pregnancy study, there was no higher risk of birth defects when the mother had received adalimumab compared with mothers who did not receive the drug.	It is currently unknown whether **infliximab** passes into breast milk. Manufacturers state you should not breastfeed when being treated with infliximab, or for at least 6 months after your last treatment. Studies have shown very small amounts of **adalimumab** present in breast milk, but that the drug is destroyed in the digestive system. Manufacturers advise that it can be used during breastfeeding.

HOW SAFE IS MY MEDICATION IN PREGNANCY OR IF I AM BREASTFEEDING?

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MEDICATION	USE WHEN PREGNANT	USE WHEN BREASTFEEDING
Vedolizumab	Not currently recommended, unless you and your IBD team have decided that the benefits of taking it strongly outweigh any risks to you and your baby. Use effective contraception while you're having treatment, and keep using it for at least 5 months after your treatment has finished.	It is not yet known whether vedolizumab passes into breast milk, or what effect this could have on your baby. Speak to your IBD team for more advice.
Antibiotics • **Metronidazole** • **Ciprofloxacin** These antibiotics are sometimes used to treat infections linked to Crohn's Disease or pouchitis following IPAA surgery.	Metronidazole is considered low risk during pregnancy. Doctors advise against using ciprofloxacin during pregnancy, particularly during the first trimester.	It is better not to breastfeed whilst you are taking these antibiotics.
Antidiarrhoeals • **Colestyramine (Questran)** This is a bile salt binding drug often used to treat diarrhoea associated with surgery for Crohn's.	Considered safe to take during pregnancy.	May be used if needed but seek medical advice first.
• **Diphenoxylate (Lomotil)** • **Loperamide (Imodium, Arret)**	It's best to check with your IBD team before taking these when you are pregnant.	May be used if needed but seek medical advice first.
Antispasmodics • **Hyoscine butylbromide (Buscopan)**	Avoid this over-the-counter medicine during pregnancy.	Avoid if breastfeeding.
Allopurinol	It is normally ok to take in pregnancy if there is no safer alternative.	Speak to your IBD team about whether you can take this medication when breastfeeding.

HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

We offer more than 50 publications on many aspects of Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease. You may be interested in our comprehensive booklets on each disease, and other topics such as **Reproductive Health and IBD**. We also publish information sheets on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships, school and employment.

All publications are available to download from crohnsandcolitis.org.uk/quick-list

Health professionals can order booklets in bulk by using our online ordering system, available from the webpage above.

If you would like a printed copy of a booklet or information sheet, please contact our Helpline.

Our Helpline is a confidential service providing information and support to anyone affected by Inflammatory Bowel Disease.

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

Call us on **0300 222 5700** or email **helpline@crohnsandcolitis.org.uk**
See our website for Live Chat: crohnsandcolitis.org.uk/livechat

Crohn's and Colitis UK Forum
This closed-group community on Facebook is for everyone affected by IBD. You can share your experiences and receive support from others at www.facebook.com/groups/CCUKforum.

Crohn's and Colitis UK Local Networks
Our Local Networks of volunteers across the UK organise events and provide opportunities to get to know other people in an informal setting, as well as to get involved with educational, awareness-raising and fundraising activities. Families and relatives may also find it useful to meet other people with IBD. All events are open to members of Crohn's and Colitis UK. Visit www. crohnsandcolitis.org.uk/membership to become a member.

OTHER SOURCES OF INFORMATION AND SUPPORT

NHS Pregnancy and Baby Guide
www.nhs.uk/conditions/pregnancy-and-baby

National Breastfeeding Helpline
www.nationalbreastfeedinghelpline.org.uk (including live chat support)
Helpline: 0300 100 0212

National Childbirth Trust
www.nct.org.uk
Helpline: 0300 330 0700
Email: **enquiries@nct.org.uk**

IA (Ileostomy and Internal Pouch Support Group)
www.iasupport.org
Helpline: 0800 018 4274
Email: **info@iasupport.org**

Colostomy UK
www.colostomyuk.org
Helpline: 0800 328 42357
Email: **info@colostomyuk.org**

Tommy's
www.tommys.org
Helpline: 0800 147 800
Email: **mailbox@tommys.org**

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ABOUT CROHN'S & COLITIS UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This publication is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit **crohnsandcolitis.org.uk.**