



INFORMATION SHEET

REPRODUCTIVE HEALTH AND IBD

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It's important to find out as much about your disease, treatments and reproduction before you make decisions, to reduce anxiety as well as risks.

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Kyra, age 30, diagnosed with Crohn's Disease in 1998

INTRODUCTION

Crohn's Disease and Ulcerative Colitis (the two main forms of Inflammatory Bowel Disease – IBD) may sometimes affect reproductive health. This includes your sexual health as well as your fertility.

This information sheet is for men and women to find out more about fertility, appropriate contraception options, having periods (menstruation) and the menopause. We have related information sheets about **Pregnancy and IBD** and **Sexual Relationships and IBD** that you might also find useful.

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HOW MIGHT IBD AFFECT MY PERIODS (MENSTRUATION)?

Monthly periods usually begin around the age of 12. If you have IBD you might find that your periods start later particularly if your disease is active, you are underweight and not getting all the nutrients you need, or you are taking steroids. For some girls, their periods start when their disease is in remission.

Just before or during their periods women with IBD may experience increased bowel symptoms such as diarrhoea, and some women find that their IBD symptoms in general are worse. You may also find that you have worse period-related pains or cramps than women without IBD. Researchers think that symptoms might be worse because of hormonal changes during your menstrual cycle.

If you are taking pain medication, it is best to avoid ibuprofen and diclofenac, non-steroidal anti-inflammatory drugs (NSAIDs), which may make IBD symptoms worse, or possibly trigger a flare-up.

One research study has shown that taking hormonal contraception or 'the pill' may improve period-related IBD symptoms. Although we need more research into this you could speak to your IBD team or GP about contraceptive choices and how they might help. There is more information in the section **How might IBD affect my contraception choice?**

Talking to your IBD team could also help rule out other conditions that could cause symptoms during your periods, such as endometriosis.

OTHER ISSUES FOR WOMEN

Cervical Cancer

Cervical cancer is a type of cancer that develops in a woman's cervix (the entrance to the womb from the vagina).

Women taking immunosuppressive drugs, such as azathioprine and mercaptopurine, have a slightly increased risk of contracting the human papilloma virus (HPV) - the virus that causes cervical cancer. It takes many years for the virus to cause abnormal cells to grow in the cervix and for these abnormal cells to then develop into cervical cancer. Women taking drugs that weaken their immune system should ensure they have cervical screening when invited, but do not need to be tested more frequently.

From the age of 12 up until their 18th birthday, all girls can get the human papilloma virus (HPV) vaccine free on the NHS. The vaccine helps to protect against cervical cancer. NHS Choices provide more information on cervical screening and the HPV vaccine.

Menopause and hormone replacement therapy (HRT)

The menopause is when a woman stops having periods and is no longer able to get pregnant naturally. In the UK, the average age for a woman to reach the menopause is 51.

Hormone replacement therapy (HRT) is a treatment used to relieve symptoms of the menopause. It replaces hormones that are at a lower level as the menopause approachs. The effect of HRT on IBD is unclear, but one study has shown that women with IBD are 80% less likely to suffer from flares if they are taking HRT. This was a small study and we need more research before it is clear whether HRT really helps IBD symptoms at the time of the menopause.

HRT can also cause a small increase in your risk of certain serious problems, such as blood clots and breast cancer, as well as a possible increased risk of developing Ulcerative Colitis in the first place. Before you decide to start taking HRT you should talk to your GP about the risks and benefits.

HOW MIGHT IBD AFFECT MY CONTRACEPTION CHOICE?

Contraception is used to prevent unwanted pregnancies and some types can help stop the spread of sexually transmitted diseases. There are many methods of contraception available. Deciding which method is best for you depends on a number of factors, including your age, whether you smoke, your medical and family history, and any medicines you're taking. Find out more at www.nhs.uk.

Most people with IBD have normal fertility and need to use contraception if they do not wish to get pregnant. There are a few things to think about when choosing the best method of contraception for you.

Preventing pregnancy

If you have active disease or are on certain types of treatment then it may be important to make sure you are using a really effective method of contraception to prevent pregnancy. This is because getting pregnant when your IBD is very active or when you are taking certain types of medication is linked to greater problems and risks in pregnancy. You can find out more in the section **How might IBD affect my fertility?**

Malabsorption

The combined oral contraceptive pill and the progestogen-only contraceptive pill may be less reliable if you have IBD and malabsorption, which is impaired absorption of nutrients and drugs from the gut into your body. This can be caused by severe small bowel disease or a shortened small bowel after surgery. Speak to your IBD team about other options. Contraceptive patches, injections, implants, or intrauterine methods (the coil) should still be effective in women with IBD who have these difficulties.

Vomiting and diarrhoea

If you have vomiting or severe diarrhoea for more than 24 hours, the oral contraceptive pill and the progestogen- only contraceptive pill may not work. You should follow the instructions about missing a pill that come with your medication.

Bone health

There is some evidence the contraceptive injection (also called the progestogen only injectable method) may affect bone mineral density and could cause osteoporosis. Having a serious loss of bone density means you might be at greater risk of fracturing (breaking) a bone. Research has suggested that having IBD may also make bone loss and fractures more likely. Speak to your IBD team and GP about whether this type of contraception is suitable for you or whether another method might be better. If you choose to use this contraceptive method then your risks should be re-evaluated every two years.

Blood clots

Women with IBD taking oral contraceptives can be at increased risk of developing blood clots. Again, speak to your GP or IBD team about the risk for you and about alternative contraceptive methods.

Having surgery, staying in hospital and not moving much are risk factors for blood clots. So if you are going to have surgery you should stop taking combined oral contraceptives at least four weeks before and use other methods of contraception.

Sterilisation

Sterilisation means having an operation to permanently prevent pregnancy. For a woman this means the fallopian tubes are blocked or sealed to prevent eggs from reaching the sperm and becoming fertilised. If you are a woman and have had surgery for your IBD this could have an impact on the safety and success of laparoscopic (keyhole) sterilisation surgery. You may wish to consider other contraceptive options.

HOW MIGHT HAVING IBD AFFECT MY SEXUAL RELATIONSHIPS?

Whether you are a man or a woman, whatever your sexual orientation, living with IBD can have an impact on your relationships and sexual activity.

Some of the symptoms of IBD may make sex more difficult. For example fatigue or extreme tiredness, abdominal pain, abscesses, fistulas or scarring of the skin around the anus or around the vagina, may make you feel less interested in sex or could make sex more uncomfortable.

Fears around having accidents (such as a bout of diarrhoea during sex), changes in how you feel about your body after surgery, side effects from steroid medication and depression related to IBD can cause sexual difficulties, such as changes in sexual satisfaction and difficulty with getting an erection in men.

The good news is that there is help and support available for these issues. You can find out more in our information sheet **Sexual Relationships and IBD**.

HOW MIGHT HAVING IBD AFFECT MY FERTILITY?

If you have Crohn's or Colitis but have never had surgery, you are just as fertile as those who do not have IBD.

Despite this, studies have shown that women with IBD are more likely to decide not to have children, perhaps because of worries about the impact of IBD on pregnancy, as well as concerns about passing on IBD to children. We have more information on this in our information sheet **Pregnancy and IBD**.

In general if you have IBD it's likely that you can become pregnant and have children. However there are some things that can impact on your fertility:

Getting your disease under control

If you have active Crohn's Disease your fertility may be reduced. Most women with IBD who are in remission, or have only mildly active disease at the time they become pregnant, are less likely to have problems in pregnancy, with fewer risks for the baby.

If possible, talk to your IBD team at an early stage and work with them to get your symptoms under control before you try to become pregnant.

Surgery (for women)

There is some evidence that the operations most commonly carried out to treat Ulcerative Colitis can affect fertility in women, especially ileal pouch–anal anastomosis surgery (also known as IPAA or pouch surgery). Some studies have found that this risk is lower in people who have had laparoscopic (or keyhole) surgery.

Any pelvic surgery, including some operations for Crohn's Disease, can lead to fertility issues if it affects the fallopian tubes. So, whichever condition you have, if

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At one point, I considered not having any children as I was worried that having Crohn's would affect my baby. I am so pleased we decided to though, as we are now parents to two healthy children.

Debbie, age 31

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

you are considering surgery for IBD and want to become pregnant, do discuss this with your surgical team. You may also find it helpful to talk to a fertility specialist.

For more information on types of surgery for IBD, see our **Surgery for Ulcerative Colitis** and **Surgery for Crohn's Disease** information sheets.

Surgery (for men)

A small minority of men who have had an IPAA (pouch) operation, or have had their colon and rectum removed, may have sexual dysfunction (problems with erections or ejaculation). This type of problem is often temporary or can be successfully treated with medication. Again, you may want to discuss this possibility with your surgical team before having surgery.

Your sexual relationships

As mentioned above, IBD may affect sexual relations, which can have an impact on how often you have sex and the opportunity to become pregnant. Support and help are available – see our information sheet **Sexual Relationships and IBD**.

HOW DO IBD DRUG TREATMENTS AFFECT FERTILITY?

The majority of medications for IBD do not appear to affect fertility and are also considered safe in pregnancy, but there are some exceptions, as shown below.

If you are trying to start a family, or if you are already pregnant, discuss this and your drug treatment with your doctor or IBD team.

It is important to try to keep your IBD under control when you are trying to become pregnant and during your pregnancy. Your IBD team are likely to advise you to keep taking your medication, so do not stop any of your medication unless your IBD team has advised this.

If the drugs you are on are not thought to be completely safe there are usually suitable alternatives.

SPECIFIC DRUG TREATMENTS THAT MAY AFFECT FERTILITY OR CONCEPTION

Some general information is provided on the next page, but it is important to get specific advice about your situation from your IBD team before starting or stopping any drugs or treatment.

For more information about using these and other medications in pregnancy, see our information sheet **Pregnancy and IBD** or see our individual drug treatment leaflets.

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I did have concerns that having Crohn's would make it harder to conceive, but I did become pregnant and now have a five month old son.

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

| MEDICATION | IMPACT ON FERTILITY |
|--|---|
| Sulphasalazine, an aminosalicylate (5-ASA) | Can cause male infertility by reducing sperm count, but this usually resolves within two to three months once you stop the drug. If you are trying for a baby, your IBD team may advise changing to a different brand, as other 5-ASAs do not affect fertility. Sulphasalazine has not been shown to affect fertility in women. |
| Methotrexate, an immunosuppressant | Should not be taken by either men or women when trying to get pregnant, or by pregnant women, as it can increase the risk of birth defects. Men and women should use contraception while being treated with methotrexate and avoid pregnancy for at least 3-6 months after stopping treatment. |
| Mycophenolate Mofetil, an immunosuppressant | May also cause miscarriages or birth defects if used during pregnancy. If you're being treated with this drug, you'll 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. |
| Azathioprine or mercaptopurine, immunosuppressants | Most doctors recommend women to continue with these drugs while pregnant as there may be a greater risk to the baby if the woman stops her treatment and as a consequence becomes unwell. |
| Infliximab (Remicade, Inflectra, Remsima) Adalimumab (Humira) and golimumab, anti-TNF biologic drugs | Researchers are still looking into the long term effects of these drugs during conception and pregnancy, but there is evidence that they are low risk during conception and for at least the first two trimesters (up to 6 months). A few studies have shown that infliximab may affect sperm motility (movement), but it is not clear whether this actually reduces male fertility. |
| | The manufacturers still recommend caution and the use of contraception to avoid pregnancy. But many doctors now consider that it may be better to continue with treatment if it's keeping your IBD in check, for at least the first six months. or sometimes longer. Your IBD team should talk through the possible risks and benefits with you if you are planning a pregnancy. |
| | There is less evidence for those wanting to father a child while on these drugs, but it is thought that it is safe for a man to conceive a child. |
| Ustekinumab, an anti- Interleukin biologic drug | The effects of this drug on fertility and pregnancy are not yet known. If you are a woman who could become pregnant, you should use effective contraception while taking ustekinumab, and keep using contraception for at least 15 weeks after your last dose. Discuss pregnancy plans with your IBD team first, and if your pregnancy is unplanned, notify your IBD team as soon as possible. |
| Vedolizumab, an anti- integrin biologic drug | The effects of vedolizumab during pregnancy are not yet known. Women should use effective contraception during treatment and keep using it for at least 5 months after your treatment with vedolizumab has finished. Again talk through your specific circumstances with your IBD team. There has not been any research about whether vedolizumab has an effect on male fertility. Ask your IBD team for advice if you have concerns. |

CAN I IMPROVE MY FERTILITY?

For women, it helps if you can bring your IBD under control for at least 3 months before trying to conceive. As your fertility may be affected by factors other than your IBD, you may also find it helpful to follow some of the following suggestions and tips.

- Don't smoke. Smoking may reduce fertility and is linked to complications in pregnancy.
- Reduce or cut out alcohol altogether to avoid harm to the unborn baby.
 Excessive drinking can impact on semen quality and the chances of getting pregnant.
- Take folic acid. Most women trying to become pregnant should take 400 micrograms daily, and once pregnant, continue this until the 12th week of pregnancy. Extra folic acid (also known as vitamin B9) can help reduce the risk of neural tube birth defects such as spina bifida. 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.
- Check your B12. Lack of vitamin B12 can also affect fertility and increase the risk of your baby developing birth defects. It is particularly important to have enough B12 if you are taking extra folic acid, so ask your doctor to check your vitamin B12 levels too.
- Lose weight. Being overweight (BMI over 30) or underweight (BMI under 18.5) is linked to reduced fertility. As well as eating a healthy diet, regular moderate exercise of about 30 minutes a day can help by maximising your fitness and keeping your weight in check.
- **Supplement.** If eating well is difficult because of your IBD, you could talk to your doctor about taking supplements to ensure you get all the nutrients you need. Zinc and vitamin B6 are particularly important for fertility in both men and women. See our booklet **Food and IBD** for more information on healthy eating for people with Crohn's or Colitis.
- Have regular sexual intercourse! Having sex every two to three days can optimise your chance of getting pregnant. Experts now recommend that there is no need to plan sex to coincide with ovulation (when the egg is released from your ovaries), as this does not increase the chances of success and might cause you and your partner added stress.

WHAT IF I STILL CAN'T GET PREGNANT?

It may be nothing to do with your IBD. Around $\bf 1$ in 7 heterosexual couples in the UK seek advice at some time in their lives about difficulties in becoming pregnant.

If you are having difficulties becoming pregnant, speak to your GP. If you and your partner have been trying to get pregnant for more than 1 year, you should both be offered fertility tests. You might be offered tests sooner if you're a woman aged over 36 or if there is a known medical reason affecting your fertility.

It may be helpful if your IBD team can liaise with your GP and gynaecologist about possible impact of IBD on your fertility. Make an appointment to discuss any concerns with your IBD nurse or with whichever doctor you feel most at ease.

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To help my fertility, I took folic acid. I also tried to eat a healthy and well-balanced diet, and avoided alcohol.

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

HAVING FERTILITY TREATMENT

If you have fertility problems, the treatment you're offered will depend on what's causing the problem and what's available in your local area. Treatment includes medicines, surgical procedures and assisted conception – including intrauterine insemination (IUI) and in vitro fertilisation (IVF). NHS Choices has more information about these treatments.

When receiving fertility treatments, it is important to stay well and keep your IBD under control to increase the chance of success. Most people can continue with their IBD treatment whilst having fertility treatment, but again discuss with your IBD team and the doctors and nurses carrying out your fertility treatment what is best for you.

HOW CAN I GET MORE SUPPORT?

If you have Crohn's or Colitis you may find at times that your illness has a considerable impact on your life and emotional well-being.

Issues to do with your reproductive health may also be sensitive for both you and your partner if you have one. Our booklet **Living With IBD** and our information sheet **Counselling for IBD** have more information about looking after yourself and finding support.

Fertility problems, investigations and treatment can be stressful. It can help to discuss with someone your feelings about the future, whether or not your treatment enables you to have a baby. You should be given the opportunity to have counselling before, during or after any fertility treatments or tests you have.

There are also more general sources of support available through Crohn's and Colitis UK, see below.

OTHER USEFUL ORGANISATIONS

NHS Choices

www.nhs.uk

Helpful information on contraception and fertility.

Fertility Network UK

www.fertilitynetworkuk.org

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 Food 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 **info@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

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at **publications@crohnsandcolitis.org.uk**. You can also write to us at Crohn's and Colitis UK, 1st Floor Helios Court, Bishops Square, Hatfield Business Park, Hatfield, AL10 9NE or contact us through the **Information Line:** 0300 222 5700.

ABOUT CROHN'S & COLITIS UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Crohn's or Colitis. We have over 35,000 members and 50 Local Networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit **www.crohnsandcolitis.org.uk**

