Pregnancy and IBD- Patient Information Sheet

If you have Inflammatory Bowel Disease (IBD) and wish to start a family, you and your partner will naturally worry about the effects of your Ulcerative Colitis (UC) or Crohn's Disease on pregnancy. You may have concerns about the effects of any medication you are taking on the baby before birth and after birth on breast milk. You may worry too about the effects of pregnancy on your IBD. The good news is that the great majority of women with IBD have normal fertility and can expect a normal pregnancy and the delivery and development of a healthy baby. This information sheet answers some of the commonly asked questions.

Will I be able to conceive?

If you have Ulcerative Colitis, your chances of conceiving are unaffected by the disease. However, fertility may be affected if you undergo pouch surgery.
If you have Crohn's Disease, you could have a slightly lower chance of conceiving, particularly if you have Crohn's colitis. One reason for this may be that inflammation in your abdomen is blocking the fallopian tubes leading from the ovaries to the uterus, or making intercourse painful. If you can reduce the inflammation, using the medicines your doctor prescribes for you, you may improve your chances of getting pregnant.
Men taking the 5-ASA drug sulphasalazine (Salazopyrin) can develop a reduced sperm count and so become infertile. This is usually temporary and is reversible within two to three months of stopping the medication. Other 5-ASAs do not have an effect on male fertility, so it is advisable to change to one of these, such as mesalazine.

Is it better to conceive when my UC or Crohn's is under control?

Definitely. If you are well when your pregnancy begins, your chances of delivering a healthy baby are the same as a woman without IBD. A healthy mother has a far better chance of having a healthy baby.
If you conceive when your disease is inactive, there is also a good chance you will remain well throughout your pregnancy.
Therefore you and your doctor should do everything possible to ensure that your Ulcerative Colitis or Crohn's Disease is inactive when you conceive. However, if you do conceive when it is active, in general terms there is nothing to stop you taking your medicines to bring it under control.

What if I am taking drugs when I conceive?

It is not usually necessary to change the medicines you take for IBD before you try to conceive. The only exception to this is with methotrexate where there is a risk of birth defects. The most important way of improving your chances of having a healthy baby is to keep the disease under control before and during pregnancy. So if your current medication is working reasonably well, it is better not to change medication unless there is a good reason to do so.

Should I keep taking my medicines while I am pregnant?

It is important that you keep your UC or Crohn's under control while you are pregnant. The evidence is that the diseases do more harm to the growing baby than the medicines. The decision whether or not to take any medication during pregnancy is a difficult balance. If at all possible, you should try to discuss it with your hospital specialist prior to conception.

How safe is my medication in pregnancy?

Aminosalicylates (5-ASAs)

- **sulphasalazine (Salazopyrin),**
- **mesalazine (Asacol, Ipocol, Mesren, Pentasa, Salofalk),**
- **olsalazine (Dipentum)**
- **balsalazide (Colazide)**

These have been taken by women during pregnancy for many years and are thought to be safe. There is very little transfer of these drugs across the placenta to the baby. They can be used as maintenance therapy and during a flare-up. If you are taking sulphasalazine you are advised to take folic acid supplements. Mesalazine is safe in doses less than 3g a day, but higher doses are not usually advised as they can affect kidney function in the baby.
For men taking sulphasalazine it is advisable to change to another 5-ASA drug, such as mesalazine. Sulphasalazine reduces fertility in men, but this is usually temporary and is reversible within two to three months of stopping the medication. Also a study in Leicestershire has suggested that there may be an increased risk of a congenitally abnormal child if the father has been taking sulphasalazine. There are no known difficulties with fertility or pregnancy with other 5-ASA drugs.

Corticosteroids

- **prednisolone,**
- **budesonide (Entocort)**
- **hydrocortisone**

These drugs are considered safe in pregnancy. Rectal preparations (enemas and suppositories) may also be used until the third trimester, unless you are thought to be at an increased risk of a premature delivery.

Immunosuppressants

- **azathioprine (Imuran)**
- **6-mercaptopurine (6-MP) (Purinethol)**

These are the two main immunosuppressive drugs used as a part of mainstream treatment of IBD. The aim of these drugs is to make the body's immune system less responsive. This has the effect of reducing inflammation in IBD (as inflammation is part of the immune system's processes). However, a less-responsive immune system can make a person more susceptible to infections. There is still relatively little known about the effects of these drugs on women with IBD during pregnancy, due to the limited number of studies. However, a nationwide Danish study of women taking these drugs during pregnancy, published in 2007, suggests that any adverse birth outcomes were caused by the underlying disease rather than by azathioprine or 6-MP. There are growing numbers of women who have had successful births while taking an immunosuppressive. Most doctors will therefore advise the continued use of azathioprine and 6-MP during pregnancy, as there may be more risk if the mother becomes unwell. However, some doctors advise women to stop taking them on the basis that not enough is yet known about their effects. Although your doctor may give you advice, the decision will be up to you.
The final area of debate about azathioprine and 6-MP relates to men. While fertility does not appear to be affected, one study showed that conceiving a child with a man who is taking these immunosuppressives may carry an increased risk of miscarriage or congenital abnormalities, particularly if the drug has been taken in the three months before conception. However, the reliability of this study has been questioned.

- **ciclosporin**

This is a very strong immunosuppressant drug which has a significant rate of serious side effects. It has not been associated with any harm to an unborn baby. The risks of this treatment are to the mother and include liver, kidney and neurological problems. This treatment would not be suggested unless you developed a very severe (acute) colitis which did not respond to steroids. It is usually taken to avoid surgery to remove the bowel, in which case its use may sometimes be justified.

- **tacrolimus**

This immunosuppressant is similar in action to ciclosporin. There has only been a single case report of a pregnant woman with UC taking tacrolimus. This woman kept in remission throughout her pregnancy and delivered a healthy baby.

- **methotrexate**

- **mycophenolate mofetil**

You should **not** take methotrexate or mycophenolate mofetil during pregnancy or when trying to conceive as there is a risk of birth defects. Men and women taking these drugs are advised to use two forms of reliable contraception during treatment**.** Couples should avoid pregnancy if methotrexate or mycophenolate mofetil has been taken by either partner within the last three to twelve months or as advised by their doctor. If you do conceive during this time it is likely you would be advised by your doctor to terminate the pregnancy because of the risk of severe damage to the baby. If you would not consider a termination, high dose

folic acid treatment for the remainder of the pregnancy may slightly reduce the risk.

Antibiotics

- **metronidazole**
- **ciprofloxacin**

These are probably best avoided during pregnancy, as there are better alternatives to control your disease. But do not worry if you find yourself pregnant while taking them, as there is no evidence that they will harm the baby.

Biologics - Anti-TNFα antibodies

- **infliximab (Remicade)**
- **adalimumab (Humira)**

These relatively new drugs affect the immune process and are used in severe cases of Crohn's Disease, when other drugs have not worked. Treatment should be avoided during pregnancy or if you are planning to get pregnant. Both men and women should use contraception for at least 6 months after receiving infliximab or adalimumab. While studies show that over a hundred women taking infliximab during pregnancy and others becoming pregnant accidentally while on the drug had the same outcome as for the general population of pregnant women, there is insufficient evidence about the safety of infliximab during pregnancy. Infliximab crosses the placenta during the third trimester of pregnancy but there is insufficient evidence regarding any effect on the newborn. There have been several successful pregnancies in women with Crohn's exposed to adalimumab before conception or during pregnancy, but again the evidence is limited.

Antidiarrhoeals

- **diphenoxylate (Lomotil)**
- **loperamide (Imodium, Arret)**

These drugs are not recommended for use during pregnancy as it is not known whether they cross the placenta.

- **cholestyramine (Questran)**

This bile salt drug which can treat diarrhoea associated with surgery for Crohn's, is safe to take during pregnancy.

Antispasmodics

- **hyoscine butylbromide (Buscopan)**

This over-the-counter medicine is best avoided during pregnancy.

What about nutritional therapy?

Some people with Crohn's take special liquid feeds called elemental or polymeric diets as treatment. These diets may be safely used during pregnancy to treat active disease or as a nutritional supplement.

See our booklet on Food and IBD for more information on nutritional treatment.

What investigations for my UC or Crohn's can I have during pregnancy?

If your disease flares up during pregnancy you may need further investigations. It is important to make your doctor aware of your pregnancy before any procedure, as it may be possible to delay it until afterwards. Generally flexible sigmoidoscopy, rectal biopsy, ultrasound, MRI, endoscopy and colonoscopy can be carried out during pregnancy.

Investigations which involve x-rays and radiation should normally be avoided by pregnant women unless absolutely essential. This includes CT scans.

What about surgery while I am pregnant?

Surgery is very rarely indicated during pregnancy, but very occasionally there are situations when an operation is the only option. In these cases, the risk to the baby is less than if the operation is not performed.

How can I increase the likelihood of having a healthy baby?

You can increase the likelihood of having a healthy baby in a number of the following ways:

♦ Maintaining remission

For women with IBD, the most important message is that if your disease is under control then the baby is more likely to be healthy. Therefore it is important to take your medicines as directed to ensure that you are as fit as possible before you try to conceive. It is also important to consult your doctor at an early stage if you fail to gain weight as expected or begin an active episode of IBD.

♦ Diet

For any woman during pregnancy a balanced and varied diet with sufficient calories, vitamins and minerals is important for the growth of their baby. The Food Standards Agency has advice on diet during pregnancy (see Other Organisations). Having IBD, the increased nutritional demands of pregnancy may mean you will have to supplement your diet, particularly if you are underweight or have active disease. It is best to seek the advice of a dietitian.

If you are taking steroids, calcium and vitamin D supplements are important to prevent bone loss: The British Society of Gastroenterology recommends1500 mg of calcium and 800 units of Vitamin D daily.

If you have Crohn's Disease and have had surgery to remove the terminal ileum (the end of the small intestine), you may need regular injections of Vitamin B12 to prevent anaemia.

Iron deficiency is quite common in IBD and iron supplements are often necessary to meet the increased demands of pregnancy. Iron supplements can cause constipation. Some people with IBD find a liquid iron supplement, 'Spatone' available from health food shops, avoids this problem. However, it is important to check with a dietitian or your specialist before taking any supplements.

Like any other woman planning for pregnancy, you should take a folic acid supplement before conception and for the first twelve weeks of your pregnancy to reduce the risk of the baby having problems such as spina bifida. The usual

recommendation is 400 micrograms a day. This may be particularly important for people with Crohn's of the small intestine in which it may be more difficult to absorb folic acid. An increased requirement is important if you take sulphasalazine, which reduces the absorption of folic acid. If you are on sulphasalazine or if you have had surgery to remove part of the small intestine, it is suggested that you increase your folic acid supplement to 2 mg (2000 micrograms) a day.
Fish oil supplements are quite often used by people with IBD. Research shows that for women with IBD who may be at increased risk of preterm birth and miscarriage, these supplements are not harmful and may be of some benefit.

♦ Exercise

Regular exercise can help to keep you healthy. You could try gentle exercises such as walking, yoga and swimming.

♦ Smoking

It is important for any woman not to smoke during pregnancy, as smoking harms the baby and leads to low birth weight with a higher risk of deformity and miscarriage. It also increases risks of blood clots during pregnancy and other complications. The risk is even greater for women with IBD as smoking increases the activity of Crohn's and increases the need for surgery and medication.
The effects of smoking with UC are inconclusive; it certainly causes the same direct damage to the baby as in any non-IBD pregnancy but it may also reduce the severity of UC disease activity. On balance it is widely accepted that the damage caused by smoking is far more than any possible reduction in disease activity.

♦ Alcohol

Drinking alcohol during pregnancy can seriously harm your baby's development. It is best to avoid alcohol, particularly during the first three months because of the risk of miscarriage.

Will my pregnancy be normal?

If your disease is in remission at the beginning of your pregnancy, your chances of delivering a healthy baby are the same as a woman without IBD.
If your disease is active at the beginning or you suffer flare-ups during pregnancy, there is a risk of affecting the baby. It is twice as likely that your baby will be premature and will have a low birth weight. This is still a small risk and the baby is likely to be healthy. There is no evidence of an increased risk of the baby being still-born.
Severe Crohn's Disease or a very severe flare-up of Ulcerative Colitis in pregnancy, although very rare, is very dangerous for the baby, with only 4 out of 10 babies surviving. It is, therefore, important to consult your doctor as soon as you are aware of any symptoms.
In most cases, the risk of affecting the baby is related to the disease activity itself, rather than to the medicines you are taking. So, if you find yourself pregnant and your IBD is active, it is best to visit your doctor as soon as possible to discuss how to try to get the disease under control.

Will pregnancy make my Ulcerative Colitis or Crohn's Disease worse?

Pregnancy has little effect on either UC or Crohn's. About one third of women will have a relapse while they are pregnant. This is similar to non-pregnant women with IBD over that period of time. If you do have a relapse it is more likely to be in the first three months.
A recent European study of women with Crohn's and UC found that the rate of relapse decreased in the years following pregnancy. This suggests that pregnancy may sometimes have a positive effect on the disease process.
If IBD becomes active during a pregnancy there is no evidence to suggest that it will do so again in future pregnancies. Similarly, if a pregnancy occurs without an episode of IBD, this is no assurance that the disease will remain inactive in subsequent pregnancies.

What sort of delivery should I have?

In most cases, normal vaginal delivery is perfectly all right. A caesarian section may be suggested or recommended by your medical team, particularly if you have severe disease or peri-anal Crohn's. However, a recent survey of some 500 women with IBD in Wales found that a significant minority experienced ongoing faecal incontinence after vaginal delivery. But further studies are needed to confirm any risk with this type of delivery. It is also worth considering that vaginal delivery avoids surgery and its possible risks.

What about my ileostomy?

Many women with ileostomies have a normal pregnancy and delivery. Sometimes a caesarean section may be necessary. Occasionally a stoma can move during pregnancy and cause discomfort, especially if you get a lot of morning sickness. It will usually return to normal after the delivery. You may also find there is an increase in output during the third trimester of pregnancy, but this will resolve after the birth.
If you have scar tissue around your anus your doctor may advise an episiotomy (a cut at the opening of the vagina) to prevent tearing or caesarean section. Again, these are issues which should be discussed with the teams involved in your care.

What about my pouch?

If you have an ileo-anal pouch you may find you pass stools more frequently while you are pregnant. This will return to normal after the delivery.
There is debate about the need for a caesarean section in women who have a pouch. However women with pouches have had vaginal deliveries. Talk to your gastroenterologist or obstetrician about any worries you and your partner may have.

I want to breast-feed. Will my medicines do any harm to the baby?

Breast-feeding is important for the development of a healthy immune system and may even reduce the risk of a child developing IBD in later life. There is no

evidence that many of the drugs used to treat IBD are harmful to a breastfed baby, although hardly any drugs are actually licensed for use in breast-feeding mothers due to caution on the part of the drug companies. They are cautious about conducting trials in breast-feeding mothers and therefore will advise against the use of most medications while breast-feeding. This is due to caution rather than a clear indication that the drug should be stopped.
Based on past experience, **corticosteroids** and the **5-ASAs** are considered by doctors to be safe in breast-feeding. Research has shown that they are transferred into the breast milk, but in very low concentrations. However, if you are on large doses of steroids, breastfeeding is not recommended. If you are on 20mg or more a day, you can reduce the effects of steroids on your baby by waiting to breastfeed until 4 hours after taking a dose.
Although some doctors would not advise breastfeeding in mothers on **azathioprine** or **6-MP**, very little of the active drug is secreted into breast milk and there is no evidence of harm in children of mothers who have breastfed on the drug. Thus the benefits of breast feeding may outweigh any small potential risk, although if you have any concerns you should discuss these with your doctor.
Other drugs are excreted in breast milk and breast-feeding is not advisable in mothers on **methotrexate, mycophenolate mofetil, ciclosporin, tacrolimus, antibiotics** and the anti-diarrhoeals, **loperamide** and **diphenoxylate**.
There is very little evidence on whether **infliximab** and **adalimumab** pass into breast milk. In one case report inflximab was not found in the breast milk of a woman receiving an infliximab infusion. As the long-term effects of these drugs on a child's developing immune system are still not known, it is recommended that you do not breast-feed during treatment with these medicines or for six months after your last dose. Any concerns you have about your medication should again be discussed with your doctor at the earliest opportunity.

What are the chances of my child having IBD?

Parents with IBD are slightly more likely to have a child who develops IBD. If one parent has the disease, the chances of a child developing IBD at some point in their life is around 5%. This risk seems to be slightly higher with Crohn's than UC. If both parents have IBD the risk can increase to 35%. However, even with genetic predisposition, other additional factors are needed to trigger IBD.
Another risk factor has been suggested in a recent study, which links parental smoking during pregnancy to the development of IBD in children.

Further help

If you have any further queries please call the **Crohn's and Colitis UK Information Line** on **0845 130 2233** or email: Info@crohnsandcolitis.org.uk
Trained information staff will help with any IBD related queries.

Crohn's and Colitis Support:
0845 130 3344 Mondays to Fridays,
1- 3.30pm and evenings 6.30- 9pm.
This is a supportive listening service run by trained volunteers who have IBD or a relative with IBD.

Other organisations

IA (The Ileostomy and Internal Pouch Support Group)
Peverill House, 1-5 Mill Road
Ballyclare, Co Antrim BT39 9DR
 0800 018 4724 or 028 9334 4043
Website: www.iasupport.org

Colostomy Association
2 London Court, East Street,
Reading RG1 4QL
 Helpline - Freephone 0800 328 4257
(24 hours every day) Website: www.colostomyassociation.org.uk

Food Standards Agency
UK Headquarters Aviation House, 125 Kingsway London WC2B 6NH 020 7276 8000