

## Pregnancy and arthritis

This booklet provides information  
and answers to your questions  
about pregnancy and arthritis.



# What should I know if I'm pregnant and have arthritis?



In this booklet we'll discuss the effect of pregnancy on your arthritis and how arthritis can affect pregnancy and your baby. We'll answer some common questions, from planning your pregnancy, to the birth, to breastfeeding. We'll also look at the effects of medications and the importance of discussing a treatment plan that will be best for you and your baby.

At the back of this booklet you'll find a brief glossary of medical words – we've underlined these when they're first used in the booklet.

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# At a glance

## Pregnancy and arthritis

Having arthritis doesn't usually mean you won't be able to have children. But arthritis could affect your pregnancy and your pregnancy may also affect your arthritis. Your treatment plan could also change. It's important to discuss your pregnancy plans with your doctor or specialist nurse before you start trying for a baby, or if you become pregnant unexpectedly.

**It's best to discuss your plans with your doctor or nurse before you become pregnant.**

### Do I need to talk to my doctor?

Because arthritic conditions are so variable it's important to get advice from your doctor or specialist nurse before you try for a baby. In particular, some of the drugs you're likely to be taking for your arthritis may need to be stopped before conception.

### What are the chances of my child having arthritis?

For most types of arthritis the chances of passing it on to your children are small, so it shouldn't affect your decision to have children.

### Drugs and pregnancy

If you have arthritis or a related condition you should think about the medications that you (or your partner) are taking as some of these can affect the pregnancy or even harm an unborn baby. Some medications will need to be stopped before you try for a baby and others will need to be stopped as soon as you discover you're pregnant. With careful planning, it's usually possible to change your treatments so that your disease remains under control and you have a safe pregnancy and a healthy baby.

You shouldn't stop taking prescribed drugs without talking to your doctor first. Your doctor will prescribe the safest combination of drugs at the lowest reasonable dose to reduce the risk of them affecting your pregnancy.

## What about breastfeeding?

Breastfeeding is best for your baby, so doctors and midwives will try very hard to keep you on drugs that won't affect your baby through your milk. Drugs you take while breastfeeding may pass into the breast milk, although in small amounts, so it's sensible to take as few as possible. Some things to remember:

- Many drugs **must not** be taken at all while breastfeeding – if these drugs are necessary then the baby should be bottle-fed. Examples include:
  - mycophenolate mofetil
  - gold injections
  - cyclophosphamide
  - methotrexate
  - leflunomide.
- Sulfasalazine, azathioprine and hydroxychloroquine have all been used successfully in breastfeeding women, and current guidelines recommend their use in this situation.
- Steroids are leaked in small amounts in breast milk, but research has not shown them to affect your baby so they can be used while breastfeeding.
- Most NSAIDs don't enter the breast milk in large quantities except high-

dose aspirin, and this should be avoided. Drugs such as ibuprofen, indometacin and diclofenac can be used but doses should be kept to a minimum, and you should check with your doctor first.

## What else might help?

The following might help:

- Take folic acid (0.4 mg) daily for three months before you get pregnant until 12 weeks into the pregnancy (this will reduce the risk of your baby developing spina bifida).
- You should take 5 mg of folic acid daily during pregnancy until the child is 12 weeks old, if you took methotrexate within three months of conceiving or if you're taking sulfasalazine during pregnancy.
- Take calcium and vitamin D supplements to prevent osteoporosis if you're taking steroids during pregnancy.
- Consider other pain-relief treatments such as physiotherapy and acupuncture.

## Introduction

If you have arthritis or a related condition and you're thinking about having a baby, you may have concerns about the effect of the pregnancy on your condition and the effect of your condition on the pregnancy and your baby. The general information in this booklet applies to most forms of arthritis, but there's a separate section for people who have lupus (systemic lupus erythematosus, or SLE), because this disease behaves differently in pregnancy from other types of arthritis (see section 'Lupus (SLE) and pregnancy').

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**i See Arthritis Research UK booklet  
*What is arthritis?***

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## Planning for a baby

It's best to discuss your pregnancy plans with your doctor or specialist nurse before conception, particularly because some of the drugs you're likely to be taking for your arthritis may need to be changed.

This way, you'll improve your chances of having a safe pregnancy and a healthy baby.

## When is the best time to have a baby?

It's better to try for a baby while you're in a good phase with your arthritis so you can reduce the drugs you need to take. Most women with lupus who want to become pregnant should do so during a quiet phase (remission).

If you're over 35 years old it may be harder to get pregnant. If you wait until you're over 40 you may be more likely to miscarry and there'll be a greater risk of having a baby with a condition such as Down's syndrome. These risks are not affected by whether you have arthritis.

Anyone trying for a baby should stop smoking to reduce the chance of having a small baby (due to restricted growth) and also reduce the risk of cot death. You should minimise the amount of alcohol you drink and not take any recreational drugs.

If you're overweight it'll be harder for you to become pregnant and could make you more likely to develop diabetes during

pregnancy. So try to lose some weight before you get pregnant, which will help your joints as well.

## Should I stop all my drugs before becoming pregnant?

You shouldn't stop taking prescribed drugs without talking to your doctor first. Many drugs can be continued safely in pregnancy. Your doctor will aim to prescribe the safest combination of drugs at the lowest reasonable dose that will keep your arthritis under control. This approach minimises the risk of the drugs causing problems with your pregnancy.

Some drugs may have to be stopped before you get pregnant, for example you shouldn't become pregnant while you're on methotrexate, cyclophosphamide or leflunomide as they can harm the unborn baby. Also, some recent studies suggest that non-steroidal anti-inflammatory drugs (NSAIDs) could make it more difficult to conceive and, if taken around the time of conception, may increase the risk of miscarriage, so you might want to discuss this risk with your doctor. Paracetamol, taken in normal doses, hasn't been linked with either of these problems.

Stopping your drugs could make your arthritis worse, but your doctor will be able to advise you on drugs that you'll be able to take. You may also be able to use other pain-relief treatments, such as physiotherapy and acupuncture.

## **Does it matter if the father is taking drugs for arthritis?**

Some arthritis drugs can cause problems in men trying to father a child. For instance, cyclophosphamide can reduce fertility in men. Doctors advise men to stop this drug three months before trying to father a child. Many doctors used to advise men to stop taking sulfasalazine and methotrexate before trying to father a child. Current guidelines, however, advise that men do not need to stop sulfasalazine or methotrexate unless they have been trying to father a child for more than one year, and have been unsuccessful. This advice is discussed in more detail in the section 'Drugs, pregnancy and breastfeeding'.

Sperm count can be improved by eating a healthy diet, not smoking, and reducing alcohol and caffeine intake. Remember that caffeine isn't just found in coffee but also in tea, energy drinks and many other soft drinks, such as cola.

## **What supplements should I take?**

Women who want to have a baby should take a folic acid tablet (standard dose is 0.4 mg) every day from three months before the time of conception until 12 weeks into the pregnancy. Women who stopped taking methotrexate more than three months before getting pregnant can take the standard dose.

Women who had not stopped taking methotrexate less than the suggested three months before becoming pregnant, should take a higher dose of folic acid (5 mg a day) throughout pregnancy and up to when their child turns 12 weeks old. This is because the methotrexate that was previously taken will have reduced folic acid levels.

Women who decide to continue taking the drug sulfasalazine during pregnancy are also advised to take 5 mg of folic acid a day during pregnancy up until when their child turns 12 weeks old.

**It's a good idea to try to become pregnant while your arthritis is in a good phase.**

Folic acid will reduce the risk of your baby having a defect in the spinal canal (spina bifida). You can get folic acid from supermarkets, health food shops or chemists. Daily doses of 5 mg of folic acid will need to be prescribed by a doctor.

You should avoid supplements other than folic acid and iron unless you have a specific deficiency, such as a lack of vitamin D. Some Asian women may be particularly at risk of vitamin D deficiency due to low exposure to sunlight with some traditional dress and a diet that's low in this vitamin. This can lead to osteomalacia.

If you're taking steroids during pregnancy you may also be advised to take calcium and vitamin D tablets to help protect your bones from thinning (osteoporosis).

### **i See Arthritis Research UK booklets**

*Complementary and alternative medicine for arthritis;  
Osteomalacia; Osteoporosis.*

### **What are the chances of my child having arthritis?**

You may be worried that your baby could develop arthritis in later life. Most forms of arthritis do run in families to some extent, and the chances vary depending on the type of arthritis you have. But for most types the chances of passing it on to your children aren't very high and shouldn't usually affect your decision to have children. There are also many other factors involved in the development of arthritis, not just the genes inherited from parents – these include, for example, chance itself, joint injury, certain jobs, smoking, being overweight and environmental triggers, such as certain infections. You should discuss the risks associated with your particular type of arthritis with your doctor, but the risks associated with common forms of arthritis are detailed on the next page.



## Osteoarthritis

Most forms of osteoarthritis aren't usually passed on from parent to child. Other factors – such as age, joint injury, being overweight and certain occupations involving heavy labour – play a more important part.

One common form of osteoarthritis that does run strongly in families is nodal osteoarthritis. This form of arthritis mainly affects women and causes firm knobbly swellings on the fingers and often swelling at the base of the thumb, just above the wrist. Nodal osteoarthritis usually doesn't start until women are in their 40s or 50s, around the time of the menopause, so you may not develop it while you're of child-bearing age. The chance of nodal osteoarthritis being passed on from mother to daughter is about one in two (50%).

**i** See Arthritis Research UK booklet  
*Osteoarthritis.*

## Rheumatoid arthritis

Although several members of the same family can be affected by rheumatoid arthritis, the tendency to pass it on from parent to child isn't very strong. Research is continuing in this area, but the risk of a child inheriting rheumatoid arthritis from a parent is between 1 in 100 to 1 in 30 (about 1–3%) so they're far more likely not to get it than to get it.

**i** See Arthritis Research UK booklet  
*Rheumatoid arthritis.*

## Ankylosing spondylitis

The chance of a child inheriting ankylosing spondylitis is estimated at about one in six if the parent has the gene HLA-B27, and about one in 10 if not. However, the way that the condition runs in families isn't straightforward so it's best to discuss this with your rheumatologist. When ankylosing spondylitis occurs in a family where other members have it, it tends to be less severe than when there's no apparent family link.

**i** See Arthritis Research UK booklet  
*Ankylosing spondylitis.*

## Psoriatic arthritis

The risk of passing on psoriatic arthritis to your child is probably similar to the risk for rheumatoid arthritis at about one in 30, although the risk of the child developing psoriasis is higher.

**i** See Arthritis Research UK booklet  
*Psoriatic arthritis.*

## Lupus (SLE)

If you have lupus the chances of your child developing it in later life are about one in 100. Because of the way the genes involved work, there's actually a greater risk of other relatives developing the disease – for example, one in 33 (3%) for the sister of someone with lupus (the risk is lower for brothers).

**i** See Arthritis Research UK booklet  
*Lupus (SLE).*



## Conception and fertility problems

Your fertility isn't likely to be affected by arthritis, but it may take longer for you to become pregnant if your arthritis is active. An increased rate of miscarriage is seen in some patients with lupus and antiphospholipid syndrome (APS). In other patients, the disease being active and taking certain drugs (such as cyclophosphamide) are the main risk factors that make it more difficult to get pregnant. This means it's very important to plan to get pregnant at times when your condition is under control and stop certain harmful drugs in advance.

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**See Arthritis Research UK booklet  
*Antiphospholipid syndrome.***

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## During the pregnancy

All pregnant women (whether they have arthritis or not) are recommended to have an ultrasound scan at 11-12 weeks to check the dates of the pregnancy. This scan can also be used to look for any abnormalities in the pregnancy but a further scan is carried out at 18-20 weeks to check that everything is fine.

The doctors choose this time because the baby is bigger and it's easier to check for any problems then. If any problem is found at your 20-week scan, the doctors and midwives will talk to you about it and discuss the implications and options available to you. Additional, more detailed scans may sometimes be needed in people with arthritis, for example if you've taken tablets or drugs

during the pregnancy that may cause particular problems or if you carry anti-Ro antibodies in your blood (see section 'Will the Lupus affect my baby?').

Sometimes you may need two or three scans before the doctors can see everything clearly, but that doesn't necessarily mean that there'll be a problem. Sometimes the parts that need to be seen may be hidden, by the baby's hand for example. So don't worry if everything can't be seen clearly at first and you're asked to return for a further scan.

### **Will I be able to do my exercises?**

It's important to keep exercising for as long as possible during your pregnancy. As your pregnancy advances and you gain weight you may find it easier to exercise in a swimming pool, where the water will help to support your weight.

### **Will the pregnancy affect my arthritis?**

Most women get aches and pains, particularly backache, during pregnancy. The effect of pregnancy on arthritis varies depending on the type:

- Most women with rheumatoid arthritis will be free of flare-ups during pregnancy, although they'll probably return after the baby is born.
- If you have osteoarthritis, particularly of the knee or hip, the increase in your weight as the baby grows may cause you problems.

- Other disorders, such as ankylosing spondylitis, may improve or become worse – there's no consistent pattern.

### **Will my arthritis affect the pregnancy?**

Apart from lupus, most types of arthritis don't harm the baby or increase the risk of problems during pregnancy. You should be aware about the possible effects of the drugs you take while you're pregnant, as they can sometimes affect the pregnancy. See the 'Drugs, pregnancy and breastfeeding' section for a list of the common drugs taken and what we know about their effects during pregnancy.

### **Will my arthritis affect the delivery?**

Your arthritis shouldn't usually affect the delivery. However, if you have arthritis in your back or hips then moving these joints during labour may cause pain. Different positions can be used in childbirth which should allow you to give birth naturally, even if you've had hip replacements. If you have a lot of problems with your back, it's a good idea to talk to an anaesthetist about whether you should have an epidural for pain relief. It's not always possible (especially with ankylosing spondylitis) to perform an epidural, but the anaesthetist will tell you about the options that are available.

## How do blood tests help doctors to manage my pregnancy?

When you're pregnant you may have symptoms like tiredness and joint pain, and it can be difficult to tell whether these are due to the pregnancy or your arthritis. Blood and urine tests can help doctors to tell the two things apart, so these tests will be done regularly throughout your pregnancy, especially if you're feeling unwell.

Some special blood tests are carried out either before you start trying to get pregnant or early in pregnancy to help your doctors decide whether you need any special treatment or monitoring. These tests are for:

**Anti-Ro antibodies** – These are present in about 30% of patients with lupus and also occur in Sjogren's syndrome. If you have these there's a small chance (about one in 50) that they could affect your baby. The effect could be that the baby is born with a rash that will clear up (usually within a few weeks to months) or that your baby's heartbeat may become slow (congenital heart block). This heart problem develops around 18 weeks into pregnancy and there are different types that may continue after the birth. Remember that even if you have anti-Ro antibodies there's only a small chance that your baby's heart will be affected, but your doctor will carefully monitor your baby's heartbeat during the pregnancy. Some babies affected in this way may need to have a heart pace-

**Many women find that flare-ups reduce during pregnancy.**

making device inserted after birth, but most will do very well.

Babies who are affected by anti-Ro antibodies from their mother are said to have the neonatal lupus syndrome. This doesn't mean that they'll get lupus when they're adults, but if you've had one baby with this syndrome then your chances of having the same problem in future pregnancies are higher. You should discuss future pregnancy plans carefully with your lupus specialist.

**Antiphospholipid antibodies** – These antibodies are present in 20–30% of patients with lupus. They're also found in patients with APS. There are two main tests for these antibodies, called the anticardiolipin test and the lupus anticoagulant test. Usually both tests are done. If either or both is positive then you have antiphospholipid antibodies in your blood.

In many people antiphospholipid antibodies don't cause any problems, but in some people they can increase the chance of miscarriage or slowing the baby's growth in the womb. If you're a pregnant woman with antiphospholipid antibodies you'll usually

see a consultant with expertise in high-risk pregnancies. You'll be given a low-dose aspirin tablet to take every day, but you may also need daily injections (which you can give yourself) of a blood-thinning drug (anticoagulant) called heparin. This drug doesn't cross the placenta so it won't affect your baby.

## Lupus (SLE) and pregnancy

### Will the pregnancy affect my lupus?

It's difficult to give advice for everyone as lupus can vary from mild to severe. Although all lupus pregnancies are still considered 'high risk', improvements in healthcare have meant that many patients with lupus have had no complications, particularly if their pregnancy has coincided with a quiet phase of their disease (remission). If, however, you have severe lupus you may be advised against having a baby as pregnancy can put an enormous strain on your heart, lungs and kidneys. For most women, however, it's

safe to proceed under careful supervision. It's always best to discuss this with your doctor or rheumatology nurse specialist before conception.

Women with lupus who want to become pregnant should do so during a quiet phase (remission) after talking to their doctor or rheumatology nurse specialist. You may stay in remission or have flare-ups while you're pregnant, although flare-ups involving the skin and joints are less likely towards the end of pregnancy.

You should take care about the drugs you take during pregnancy; however, the risk of a problem to the baby may be greater if you don't take the drugs necessary to keep your lupus under control or if you stop them suddenly, so it's vital to discuss and plan pregnancy in advance with your doctor. While your doctor will try to avoid using drugs if possible, it's fine to use steroids, hydroxychloroquine and azathioprine throughout pregnancy.

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**See Arthritis Research UK drug leaflet *Drugs and arthritis*.**

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### Will my lupus affect the pregnancy?

Some women with lupus do have a higher risk of complications during pregnancy, though most will have a successful pregnancy. Your pregnancy will be closely monitored, and your obstetric consultant will need to see you frequently in the antenatal clinic. There's a higher risk of miscarriage if you have lupus, and the

**It's important to keep exercising for as long as possible.**

miscarriage may be later than usual in the pregnancy – up to 24 weeks if you also have APS.

Planning your pregnancy will mean that your lupus specialists and the obstetric team can work closely together. Because babies born to women with lupus can be smaller than average, you may be advised not to have your baby at your local hospital but at a more specialist site where they can work better as a team and which has the best facilities to look after very small babies.

You and your baby may be checked more often than most women during pregnancy. If your lupus is mild you probably won't need any extra scans, but you may need additional scans if your disease is more severe, especially if your kidneys are affected, or if you test positive for certain antibodies in your blood.

These antibodies are called lupus anticoagulant, anticardiolipin and anti-Ro, and these tests will usually be done either before you become pregnant or early in the pregnancy (see section 'How do blood tests help the doctors to manage my pregnancy?').

The medical team will also use other ways of monitoring your baby, which may include regularly monitoring its heartbeat and checks on the blood flow to the womb and the umbilical cord (using ultrasound scans). Your blood pressure and urine will also be checked regularly.

### What types of problem can happen with lupus later in pregnancy?

If you have kidney disease from your lupus or your blood pressure is high before you become pregnant your blood pressure may increase during pregnancy. If that happens after 20 weeks of pregnancy with protein in your urine it's called pre-eclampsia, so you'll need regular checks for blood pressure and for protein in your urine. High blood pressure can cause severe headaches and vision problems, so you should talk to your doctor if you develop these symptoms during pregnancy.

Your baby may not grow as fast as normal (growth restriction), and your waters may break much earlier than usual or you may go into labour early (pre-term delivery).

There's some evidence that a low-dose aspirin tablet taken every day can lower the risk of some of these problems.

Your doctor will discuss this with you when you first go to the antenatal clinic.



## Will my lupus affect the labour?

You should have a normal labour. But if you go into labour too early, the doctors may try to stop you giving birth, with drugs, to allow more time for the baby's lungs to mature. Doctors may sometimes feel that it's safer (for you or for the baby) if your baby is delivered by caesarean section. This option would be discussed with you during the pregnancy, well before the time of labour.

## Will my lupus affect the baby?

There's a risk of babies born to mothers with lupus being smaller than usual. If that happens, your baby may need to spend

a few days in the newborn (neonatal) nursery. If your baby is born very early, they'll spend longer in the nursery and may need help with breathing initially.

## After the birth

Coping with the demands of a small baby is exhausting for any new mother, and if you have arthritis the stresses can be much greater. Women with rheumatoid arthritis may find that their arthritis flares up again in the weeks after the birth (often after going into remission during the pregnancy). To help prevent flares in arthritis during and after pregnancy it's important that you don't stop safe treatment during pregnancy or breastfeeding. Before the birth it may be worthwhile to arrange for extra help from family and friends for once the baby is born. If necessary, extra help can be arranged – discuss this with your doctor or with Social Services.

Following the birth, a physiotherapist or occupational therapist may need to be involved in the aftercare; holding, dressing, washing and feeding a baby can all be difficult because of stiffness. There are practical steps you can take to reduce impact on your wrists, hands and back. For example, a high changing station would mean you don't place undue strain while you're bent over changing your baby's nappy. Or, a changing station which you could use sitting down might help.

There are alternatives to carrying your baby in your arms, for example there are



You may need to visit the antenatal clinic more often if you have lupus.

products that allow you to safely strap your baby to your chest to reduce the load on your hands and wrist. Ask your doctor how to go about getting help.

If you already have another small child or children, you may need to arrange for extra help in caring for them. Extra support from a partner, other family members or friends is crucial in sharing the care of a small baby, and help from Social Services can also help you to manage in the first few months after birth.

**i See Arthritis Research UK booklets**  
*Occupational therapy and arthritis;  
Physiotherapy and arthritis.*

## What about my medication?

If any drugs for arthritis were stopped before or during your pregnancy most doctors recommend going straight back on them, except where you've been put on alternative drugs which are safe in pregnancy and when breastfeeding or when the drugs would stop you breastfeeding (see section 'Drugs, pregnancy and breastfeeding'). It's important that women continue safe treatments during breastfeeding and not wait until after their arthritis flares up again before returning to their medication. Ask your doctor or rheumatology nurse specialist for advice on this.

If you have a flare-up shortly after the birth, perhaps before the disease-modifying anti-rheumatic drugs

(DMARDs) have started working again, then your doctor may give you a short course of steroids. If only one or two joints are troublesome these can be injected with steroids. Physiotherapy can also be helpful during this time.

## Will I be able to breastfeed?

Breastfeeding is best for your baby. Even if you only breastfeed for a few weeks it will still benefit your baby, so the doctors and midwives will try very hard to keep you on drugs that won't affect your baby through your milk. Drugs you take while breastfeeding may pass into the breast milk, although only in small amounts, so it's sensible to take as few as possible.

The following section 'Drugs, pregnancy and breastfeeding' will give more details on which drugs you're able to take while breastfeeding.

**i See Arthritis Research UK drug leaflet *Drugs and arthritis.***

**Some drugs for arthritis can be taken during pregnancy without harming the mother or the baby. However, in an ideal world every pregnancy would be drug-free to reduce the risks of side-effects.**

## Drugs, pregnancy and breastfeeding

In an ideal world the process of having children, from conception to breastfeeding, for all women would be drug-free because we can never be 100% sure that the drug will be harmless to the developing child. In pregnant women with arthritis however, certain drugs are important to have a successful outcome to prevent disease flares which may cause harm to the baby.

The following section provides a summary of what we know about the effects of these drugs during pregnancy and while breastfeeding. This summary is based on guidelines produced by the British Society for Rheumatology (BSR). In some cases there's only limited information available, but we do know that, for most drugs, many pregnant or breastfeeding women will take them without any problems. We strongly recommend that you discuss each drug you take with your doctor – either when you're planning a family or as soon as possible if you unexpectedly become pregnant.

### Paracetamol

Paracetamol is a good form of pain relief and is often used by women who are pregnant or breastfeeding without causing any problems. BSR guidelines advise intermittent use by pregnant women if possible to reduce an increased risk of childhood asthma found in some but not all research studies. Most women can take the usual dose, even during pregnancy, but if your liver or kidneys aren't working properly you may be told to take a lower dose.

### Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs include aspirin, naproxen, meloxicam, etodolac, ibuprofen and indometacin. They may reduce the amount of fluid in the womb surrounding the baby, but they don't affect the baby. Some studies suggest that taking NSAIDs may make it more difficult to get pregnant and that they may increase the risk of miscarriage if taken around the time of conception. BSR guidelines advise cautious use of these drugs in early pregnancy.

It's best to use the lowest dose of NSAIDs you can, and your doctor will advise you to stop them completely after 32 weeks of pregnancy. When babies are born a blood vessel in their heart closes, which redirects the baby's blood to allow it to get oxygen from its lungs, rather than the placenta. But large doses of NSAIDs taken towards the end of pregnancy may cause this blood vessel in the baby's heart to close early, while the baby is still in the womb rather than at birth. This problem usually resolves

itself completely if the NSAIDs are stopped. NSAIDs might also be stopped during delivery as they can prolong the labour and cause excessive bleeding.

If you have lupus or APS you may need to take low-dose aspirin (usually 75 to 150 mg per day) throughout pregnancy, especially if you've had previous miscarriages. Low-dose aspirin doesn't affect early pregnancy, the development of the blood vessel in the baby's heart later in pregnancy or delivery as described for NSAIDs above.

Most NSAIDs don't enter the breast milk in large quantities, but high-dose aspirin (300 mg or more per day) should be avoided while breastfeeding. You should talk to your doctor about what is best for you and your baby.

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**i** See Arthritis Research UK  
drug leaflet *Non-steroidal  
anti-inflammatory drugs.*

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### Corticosteroids (steroids)

These drugs are often used in pregnancy. There's no evidence that steroids harm your baby and doctors often give them during pregnancy to help the baby's lungs to mature (usually when labour begins before 34 weeks). If you're planning a family or find you're pregnant while you're taking steroids, don't stop taking them but discuss things with your doctor. If you're taking steroids regularly, you may be slightly more likely to develop high blood sugar (diabetes of pregnancy), so you may need to have a test called a

glucose tolerance test at 26–28 weeks. This problem usually clears up when the steroids are stopped. You won't need a test if you're taking the steroids temporarily to help the baby's lungs mature.



If you've been on high doses of steroids for a long time you may be given an extra boost of steroids to help your body cope with the stress of labour, which is routine in this situation. Women taking steroids throughout pregnancy are advised to take supplements of calcium and vitamin D to help prevent osteoporosis.

Steroids are transferred in small amounts in breast milk, but it's very unlikely to affect your baby at doses less than 40 mg daily of oral prednisolone.

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**i** See Arthritis Research UK drug leaflet *Steroid tablets*.

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## Disease-modifying anti-rheumatic drugs (DMARDs)

### Azathioprine

This drug doesn't affect fertility in men or women. BSR guidelines advise that it can be taken in pregnancy at doses no higher than 2 mg/kg. Tiny amounts of it do appear in breast milk but it has not been shown to cause any harm so it can be taken by breastfeeding mothers. If you're planning a family or become pregnant while taking azathioprine, you should talk to your doctor as soon as possible.

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**i** See Arthritis Research UK drug leaflet *Azathioprine*.

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### Ciclosporin

Ciclosporin is used widely in people who've had transplants as well as for arthritis, and many women who have used the drug have had successful pregnancies. BSR guidelines advise that it can be taken in pregnancy. Very small amounts of the drug get into breast milk but it has not been shown to harm babies, and BSR guidelines advise cautious use in breastfeeding. If you're planning a family or become pregnant while taking ciclosporin, you should talk to your doctor as soon as possible.

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**i** See Arthritis Research UK drug leaflet *Ciclosporin*.

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### Cyclophosphamide

Cyclophosphamide can reduce fertility in both men and women, so you may be advised to 'bank' sperm or have ovarian tissue stored before you start treatment with the drug. If possible, cyclophosphamide should be stopped at least three months before trying for a baby, and it should be avoided during pregnancy as it's likely to be harmful. Bottle-feeding is recommended if you need to take this drug after the baby is born.

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**i** See Arthritis Research UK drug leaflet *Cyclophosphamide*.

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We strongly recommend that you discuss each drug you take with your doctor – either when you're planning a family or as soon as possible if you unexpectedly become pregnant.

### Hydroxychloroquine

This drug is often taken to prevent malaria as well as to treat arthritis and lupus. It doesn't increase the risk of birth problems at doses used to treat arthritis and lupus. In fact, research has shown that women with lupus who stop this drug before pregnancy have worse pregnancy outcomes than those who carry it on. BSR guidelines advise that it can be taken during pregnancy and breastfeeding.

**i** See Arthritis Research UK drug leaflet *Hydroxychloroquine*.

### Leflunomide

There is concern that leflunomide may cause birth defects and so it should be avoided before and during pregnancy. Reliable contraception should be used when taking this drug.

Leflunomide stays in the body for a long time. If you're taking leflunomide and want to start a family, talk to your doctor. BSR guidelines advise that women on leflunomide who want to get pregnant should stop it, have a special wash-out treatment to remove it from the body more quickly and switch to other drugs that can be used in pregnancy before trying for a baby. If you become pregnant while taking leflunomide, stop the drug and speak to your doctor as soon as possible about having the wash-out treatment.

As long as you do both of these things it is very unlikely that leflunomide will have caused harm to your baby. The guidelines also advise that leflunomide can be taken

by men without the need for the wash-out treatment before trying to father a child.

Leflunomide shouldn't be used while breastfeeding.

**i** See Arthritis Research UK drug leaflet *Leflunomide*.

### Mycophenolate mofetil

You shouldn't take mycophenolate when you're pregnant, and you shouldn't become pregnant for at least six weeks after you stop taking the drug. Mycophenolate must not be taken while you're breastfeeding. If you're planning a family or if you become pregnant while taking mycophenolate, you should discuss this with your doctor as soon as possible.

**i** See Arthritis Research UK drug leaflet *Mycophenolate mofetil*.

## **Methotrexate**

Methotrexate must not be taken while you're pregnant or breastfeeding, and it should be stopped three months before you try to become pregnant. Previously, there was concern that methotrexate may affect sperm and thus any fertilised egg but this has not been shown to be a problem in research studies. BSR guidelines state that men do not need to stop methotrexate before trying for a baby. If you're planning a family or become pregnant while on methotrexate, you should speak to your doctor as soon as possible.

**i** See Arthritis Research UK drug leaflet *Methotrexate*.

## **Sulfasalazine**

Women can continue taking sulfasalazine when trying for a baby and during pregnancy with 5 mg folic acid tablets per day (these will need to be prescribed by a doctor). It's often recommended women continue taking sulfasalazine through pregnancy to prevent a flare-up of their disease. Although sulfasalazine may cause a fall in sperm count, leading to a temporary decrease in male fertility, that is reversed if treatment is stopped and this has not been shown to be a problem in research studies. BSR guidelines advise that men do not need to stop sulfasalazine before trying for a baby unless they have already been trying unsuccessfully for one year.

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**i** See Arthritis Research UK drug leaflet *Sulfasalazine*.

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## **Biological therapies**

The biological therapies include adalimumab, anakinra, etanercept, infliximab and rituximab. They're all relatively new drugs so there's less experience of their effects either during pregnancy or while breastfeeding than with other, older drugs. Increasing numbers of women, however, have successfully used adalimumab, etanercept and infliximab during pregnancy and while breastfeeding.

These drugs last for different lengths of time in the body and there is a concern that they may increase the risk of infection in new-born babies. BSR guidelines advise that these biological therapies are stopped at different times in pregnancy. Or, if they're given throughout pregnancy to control disease flares then new-born babies should not be given live vaccines until they are at least seven months old.

There's much less experience using anakinra, abatacept, rituximab and the newer biological therapies such as tocilizumab, golimumab and certolizumab pegol. Women of childbearing age are generally recommended to use contraception while taking these drugs. We recommend that you discuss it with your doctor if you're planning a family, become pregnant or wish to breastfeed while taking any of these drugs.

If you're taking methotrexate along with a biological drug, you should also follow the advice for methotrexate.

**i** See Arthritis Research UK drug leaflets *Adalimumab; Certolizumab pegol; Etanercept; Infliximab; Rituximab; Tocilizumab.*

**Indigestion can be a problem with NSAIDs and also in pregnancy. Antacid medications usually help, but if it's very troublesome you should tell your doctor.**

## Research and new developments

Our understanding of biological therapies and newer immunosuppressive drugs is growing. For instance, in the UK the British Society for Rheumatology (BSR) is gathering information on more than 16,000 patients treated with adalimumab, etanercept and infliximab in a biologics registry (called the BSRBR) to examine the safety of these drugs.

Information from this registry on patients who continue taking these drugs while pregnant or breastfeeding will allow doctors to better determine their safety in these circumstances. There is, however, still an urgent need for studies clarifying the risk of anti-rheumatic drugs during breastfeeding and in men trying to father a child.





# Charlotte's story

**Charlotte, 27, was diagnosed with juvenile idiopathic arthritis at the age of 18 months.**

**She suffered severe symptoms from her JIA when she was growing up.**

**She now has two healthy children – a daughter aged four and a son aged 11 months.**

**Charlotte decided to come off medication for her arthritis during her pregnancy.**

'The first time I became pregnant they were about to start me on adalimumab. But they delayed it until after my daughter was born,' said Charlotte.

'I went into remission during my first pregnancy. My arthritis then flared when my daughter was six weeks old as my hormones settled.'

'When I became pregnant again I came off adalimumab. They said I could continue on it, but I decided to come off it.'

'During my second pregnancy my arthritis was horrendous. I ended up having steroid injections in both knees.'

'I took ibuprofen during the early stages of my second pregnancy, but then came off it as instructed by my care team.'

'I found my second pregnancy hard going.'

'During my pregnancies I had extra appointments including pregnancy physiotherapy and anaesthetic appointments to make special arrangements for labour. I also rested a lot.'

'I had consultant-led care, rather than midwife-led care. That gave me more reassurance and they can make more informed choices about your care.'

'I had five scans as they wanted to monitor the growth of the babies more closely. Because of my arthritis there were greater risks of complications during my pregnancies, so I was monitored more than an average pregnancy.'

Charlotte has this advice for women who have arthritis and would like to have a baby.

'After the baby is born you need to be prepared for flare ups,' Charlotte said.

'That happened to me after both my children were born.'

'You need to make sure you have your medication lined up and you need to have plenty of help and support lined up. You also need to know that you can access your medical team if needed.'

'During pregnancy your hormones can offset your arthritis. After your baby is born your hormones return to normal and your arthritis can flare.'

'This can be tough because you're physically very tired anyway and this can make it really difficult when you have a young baby.'

'With my second baby I couldn't hold him so much because I was experiencing flares in my elbows and when he was six months old I had my wrist fusion operation. I used pillows instead of holding him so much.'

'You do find ways of adapting when things are tough.'

## Glossary

**Acupuncture** – a method of obtaining pain relief that originated in China. Very fine needles are inserted, virtually painlessly, at a number of sites (called meridians) but not necessarily at the painful area. Pain relief is obtained by interfering with pain signals to the brain and by causing the release of natural painkillers (called endorphins).

**Ankylosing spondylitis** – an inflammatory arthritis affecting mainly the joints in the back, which can lead to stiffening of the spine. It can be associated with inflammation in tendons and ligaments.

**Antibodies** – blood proteins that form in response to germs, viruses or any other substances that the body sees as foreign or dangerous. The role of antibodies is to attack these foreign substances and make them harmless.

**Anticardiolipin test** – a blood test used to diagnose antiphospholipid syndrome (APS). This test measures the amount of antiphospholipid antibodies in the blood.

**Antiphospholipid antibody** – an antibody that attacks phospholipids (a type of fat) which often make up the surface of cells. Because the antibody attacks the body's own cells, rather than bacteria, it is called an autoantibody.

**Antiphospholipid syndrome (APS)** – a disorder in which the blood has a tendency to clot too quickly (sticky blood syndrome). The clotting can affect any vein or artery in the body, resulting

in a wide range of symptoms. It's caused by an antibody that attacks phospholipids found particularly in the outer coating of white blood cells. APS can occur in lupus or on its own.

**Caesarean section (or C-section)** – a method of delivering a child where a surgical incision is made in the mother's abdomen.

**Conception** – fertilisation of the female's egg by the male's sperm and successful implantation of this fertilised egg in the womb.

**Diabetes** – a medical condition that affects the body's ability to use glucose (sugar) for energy. The body needs insulin, normally produced in the pancreas, in order to use glucose. In diabetes the body may produce no insulin or not enough insulin, or may become resistant to insulin. When the body is unable to use glucose obtained from foods the level of sugar in the blood increases. If untreated, raised blood sugar can cause a wide variety of symptoms.

**Disease-modifying anti-rheumatic drugs (DMARDs)** – drugs used in rheumatoid arthritis and some other rheumatic diseases to suppress the disease and reduce inflammation. Unlike painkillers and non-steroidal anti-inflammatory drugs (NSAIDs), DMARDs treat the disease itself rather than just reducing the pain and stiffness caused by the disease. Examples of DMARDs are methotrexate, azathioprine and sulfasalazine.

**Epidural** – an injection given into the space around the spinal cord in the small of your back to anaesthetize the lower half of the body. The full name is epidural blockade.

**Heparin** – a daily injection to slow blood clotting.

**HLA-B27** (human leukocyte antigen B27) – a gene which is often present in people who have conditions such as reactive arthritis, psoriatic arthritis or ankylosing spondylitis.

**Lupus** (systemic lupus erythematosus or SLE) – an autoimmune disease in which the immune system attacks the body's own tissues. It can affect the skin, the hair and joints and may also affect internal organs. It's often linked to a condition called antiphospholipid syndrome (APS).

**Lupus anticoagulant test** – a blood test used to help diagnose antiphospholipid syndrome (APS). This test measures the effect of antiphospholipid antibodies on the time it takes for blood to clot.

**Non-steroidal anti-inflammatory drugs (NSAIDs)** – a large family of drugs prescribed for different kinds of arthritis that reduce inflammation and control pain, swelling and stiffness. Common examples include ibuprofen, naproxen and diclofenac.

**Obstetric consultant** – a doctor who specialises in helping women who have medical problems during pregnancy.

**Occupational therapist** – a therapist who helps you to get on with your daily activities (e.g. dressing, eating, bathing)

by giving practical advice on aids, appliances and altering your technique.

**Osteoarthritis** – the most common form of arthritis (mainly affecting the joints in the fingers, knees, hips), causing cartilage thinning and bony overgrowths (osteophytes) and resulting in pain, swelling and stiffness.

**Osteomalacia (soft bones)** – this often happens because of a lack of vitamin D. It causes severe symptoms of bone pain and muscle weakness. In Victorian times the condition often affected children and was called rickets, but today osteomalacia usually affects adults, especially the elderly and/or people of South Asian origin.

**Osteoporosis** – a condition where bones become less dense and more fragile, which means they break or fracture more easily.

**Physiotherapist** – a trained specialist who helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

**Placenta** – an organ within the womb that provides nourishment to the developing baby. The placenta is discharged after the baby is born and is sometimes known as the afterbirth.

**Pre-eclampsia** – a common condition in the second half of pregnancy causing high blood pressure, protein in the urine and fluid retention. Pre-eclampsia occurs most commonly in first pregnancies as well as antiphospholipid syndrome (APS).

**Pre-term delivery** – when the baby is born before 37 completed weeks of pregnancy.

**Psoriasis** – a common skin condition characterised by patches of thickened, red and inflamed skin, often with silvery scales. New skin cells are produced more quickly than normal leading to a build-up of excess skin cells. The condition is sometimes associated with psoriatic arthritis.

**Rheumatoid arthritis** – a common inflammatory disease affecting the joints, particularly the lining of the joint. It most commonly starts in the smaller joints in a symmetrical pattern – that is, for example, in both hands or both wrists at once.

**Spina bifida** – a defect in the spinal canal that can cause damage to the nerves to the legs.

**Ultrasound scan** – a type of scan that uses high-frequency sound waves to examine and build up pictures of the inside of the body.



You can download all of our booklets and leaflets from our website or order them by contacting:

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Copeman House  
St Mary's Gate  
Chesterfield  
Derbyshire S41 7TD  
Phone: 0300 790 0400  
[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

**Related organisations**

The following organisations may be able to provide additional advice and information:

**Arthritis Care**

Helpline: 0808 800 4050  
[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

**Brook**

[www.brook.org.uk](http://www.brook.org.uk)

**The British Society for Rheumatology**

(BSR) 020 7842 0900  
[www.rheumatology.org.uk](http://www.rheumatology.org.uk)

**College of Sexual and Relationship**

Therapists (COSRT) 020 8543 2707  
[www.cosrt.org.uk](http://www.cosrt.org.uk)

**Disability, Pregnancy & Parenthood International**

<http://disabledparent.org.uk/>

**Disabled Living Foundation**

Helpline: 0300 999 0004  
[www.dlf.org.uk](http://www.dlf.org.uk)

**fpa (formerly the Family Planning Association)**

Helpline Northern Ireland:  
0845 122 8687  
[www.fpa.org.uk](http://www.fpa.org.uk)

**NRAS (National Rheumatoid Arthritis Society)**

Freephone helpline: 0800 298 7650  
[www.nras.org.uk](http://www.nras.org.uk)

**RADAR (Royal Association for Disability & Rehabilitation)**

General enquiries: 020 7250 8181  
[www.radar.org.uk](http://www.radar.org.uk)

**Relate** 0300 100 1234

[www.relate.org.uk](http://www.relate.org.uk)

**Ricability**

[www.ricability.org.uk](http://www.ricability.org.uk)

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## We're here to help

Arthritis Research UK is the charity leading the fight against arthritis.

We fund scientific and medical research into all types of arthritis and musculoskeletal conditions.

We're working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We'll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish more than 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please also let us know if you'd like to receive an email alert about our online quarterly magazine, *Arthritis Today*, which keeps you up to date with current research and education news, highlighting key projects that we're funding and giving insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers' hints and tips for managing arthritis.

### Tell us what you think of our booklet

Please send your views to:

**bookletfeedback@  
arthritisresearchuk.org**

or write to us at: Arthritis Research UK  
Copeman House, St Mary's Gate,  
Chesterfield, Derbyshire S41 7TD

A team of people contributed to this booklet. The original text was written by Derek Tuffnell, who has expertise in the subject. It was assessed at draft stage by reader in rheumatology Dr Ian Giles, senior lecturer/consultant physician Prof. Munther Khamashta, senior lecturer/nurse practitioner Janice Mooney, nurse specialist Jenny Mynett and nurse specialist Tracy French. An **Arthritis Research UK** editor revised the text to make it easy to read. An **Arthritis Research UK** medical advisor, Prof. Anisur Rahman, is responsible for the content overall. Thank you to Charlotte for sharing her story.

## Get involved

You can help to take the pain away  
from millions of people in the UK by:

- Volunteering
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- Taking part in a fundraising event
- Making a donation
- Asking your company to support us
- Buying gifts from our catalogue.

To get more **actively involved**, please  
call us **0300 790 0400** or e-mail us at  
**enquiries@arthritisresearchuk.org**

Or go to:

[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)





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