Your pregnancy journey

what is important to know before, during and after the birth of your baby

Information for women with rheumatoid arthritis, psoriatic arthritis or axial spondyloarthritis

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Chronic inflammatory diseases such as rheumatoid arthritis (RA), psoriatic arthritis (PsA) or axial spondyloarthritis - including ankylosing spondylitis (axSpA) - can bring challenges to your daily life. When you suffer from an inflammatory arthritis, it is important to plan your pregnancy so you can be changed to medication which is more appropriate in pregnancy. If a pregnancy is planned, your doctor can help to make you as well as possible before you conceive.

Around half of pregnancies are unplanned; so even you are not considering having a baby this information might still be important for you. This booklet will offer some information on things to know and consider before, during and after your pregnancy.

### Before pregnancy

- **Having RA, axSpA or PsA does not mean you cannot get pregnant, but it may take longer than usual to conceive.** This can be due to different reasons including disease activity or drugs you may be taking. Studies have shown that if the disease is well controlled, 3 out of 4 women with RA become pregnant within 1 year of trying. Good control of your disease may help you become pregnant sooner. Discuss your pregnancy plan with your healthcare team (e.g. your general practitioner, nurse, rheumatologist, obstetrician, midwife and pharmacist) early on. Although important, only around 1 in 5 patients ask for guidance from their rheumatologist before becoming pregnant. By discussing your plans with more than one specialist, they can help you develop a personalised treatment plan and answer any questions you may have.

- **You may be worried about passing on your disease.** The way your disease is inherited is complex. The risk of passing on the disease varies between up to 1 in 30 for RA and PsA, and between 1 in 6 to 1 in 10 for axSpA.

- **Some women in your situation worry that their risk of miscarriage or birth defects is increased.** As long as certain drugs are avoided, the risk of major birth defects is not higher than the general population (about 2% of births). Although miscarriages may be slightly more frequent than the usual rate of 10-15%, this may be due to how well symptoms are controlled and certain medications. You should discuss this and any other concerns with your healthcare team.

- **Controlling your symptoms before pregnancy is essential to ensure you and the baby have the best health possible.** This can also help to reduce the chance of pre-eclampsia, an early delivery, the baby having a lower birth weight, or of having a miscarriage.

- **Deciding when to get pregnant can be difficult.** It may help to wait until your symptoms are controlled. Following a healthier lifestyle beforehand could also help make your pregnancy easier. However, delaying pregnancy may make it more difficult to conceive as older women may take longer to become pregnant.

**Your treatment should be managed by all members of your healthcare team, such as your general practitioner, nurse, rheumatologist, obstetrician, midwife and pharmacist.** It is very important that all members communicate and understand your needs in order to ensure the best outcomes for you and your baby. You are at the centre of your treatment plan, so pass on details of your treating specialists to each member of the team.
Before you attend your appointments, it is a good idea to make a note of any questions you want to ask your healthcare team. It may help to take someone with you to help you remember what has been said.

Possible questions you may include:

- Are there any risks to me or my baby if I get pregnant?
- Will I be able to carry my baby to full term?
- Will I need to stop taking my medications?
- Will I get backache during my pregnancy?
- Can I give birth naturally?

There may be a need to continue to control your disease before, during and after pregnancy. However, not all drugs are compatible with pregnancy so your rheumatologist will be able to explain if your treatment needs to be adapted.

On the other hand, there are treatments available that are compatible with pregnancy which you can take before, during and after pregnancy. Speak to your healthcare team about the most suitable options for you.

Once you decide to become pregnant, you should continue or start taking vitamin and mineral supplements suggested by your healthcare team.6,16

Consult your healthcare team if you are taking medications other than for treatment of your RA, PsA or axSpA. Your healthcare team should check for drug interactions and advice regarding its use during pregnancy.

Your healthcare team is there to guide and support you, so talk to them about any questions or concerns you have. It is important to fully understand all of your options before making any decisions.
Before pregnancy Checklist

- Discuss your wish to get pregnant with your healthcare team
- Connect your healthcare team members to each other by passing on their contact details and the treatment plan you have agreed
- Understand your treatment options and the need to adapt medication if required
- Start your new treatment plan and stop using contraception when appropriate (as agreed with your healthcare team)
- Maintain a healthy lifestyle (eat a good diet, exercise when possible, get enough sleep, stop smoking) to enhance your ability to manage your day-to-day life
- Start taking any additional vitamins or supplements as suggested by your healthcare team

Your healthcare team is your general practitioner, rheumatologist, obstetrician, nurse, midwife and any other healthcare professional you may meet. Your pharmacist will also be able to advise you about your treatments, how to take them or any other questions regarding the drugs you are prescribed.
During pregnancy

There are **three stages to pregnancy** (the first, second and third trimesters, each of which is three months long, and 40 weeks in total).

How pregnancy affects your body may vary by trimester. Some effects are similar to those caused by your RA, PsA or axSpA and are normal. These include swelling, backache or tiredness.⁶

You will need the same check-ups as any other pregnant woman. However, you may need extra depending on your symptoms. It is therefore important to monitor your symptoms during pregnancy and be aware of any changes.

If you or anyone in your healthcare team feels your symptoms are worsening, do not hesitate to **book an appointment to seek further advice**.

Self-help

Some complementary therapies may help you feel more comfortable, such as yoga, massages and stress management. Aqua-gym classes can also help as they are low impact on your joints. However, not all exercises are suitable for all pregnant women.

Consult your healthcare team beforehand to see what will be suitable and how they can be tailored for you.
Pregnancy triggers short term changes in your immune system. As a result, some women with RA, PsA or axSpA experience their symptoms improving or disappearing during pregnancy especially in the second and third trimester. In some women symptoms do not change or may even worsen and therefore 1 in 2 women living with RA, PsA or axSpA still need treatment during pregnancy. In addition, some women’s symptoms may worsen if treatment is stopped.

It is important to plan for the possibility of flares during pregnancy and after birth by enquiring about suitable medication and making lifestyle adjustments if necessary. Several treatment options are available that are compatible with pregnancy and breastfeeding.

Not all vaccinations can be given during pregnancy or when taking certain treatments. Consult your healthcare team about the vaccinations you may need.

Your healthcare team is there to support you throughout your pregnancy journey. Make sure you continue to discuss your treatment plan, delivery plan and symptoms with them.
During pregnancy
Checklist

- It’s important to keep a healthy lifestyle during your pregnancy. Try to find the right balance between work, exercise and rest according to your individual needs.
- Consider a birth preparation course or support from home ergonomics experts for setting up care spaces efficiently.
- Do not alter your treatment without talking to your healthcare team.
- Try to exercise and stay active, unless your healthcare team suggests otherwise.
- Plan visits to your healthcare team during your pregnancy, especially if there are any changes in your symptoms.
- Visit your healthcare team regularly for any required tests, such as blood tests, and for any relevant vaccinations.
- Discuss the options and decisions to be taken regarding labour and delivery with your healthcare team. Remind them of your disease so treatment can be planned accordingly.
- Think about if you plan to breastfeed or not. If you do, discuss this with your healthcare team.
- If appropriate, speak to your employer about any support you may need.
Birth and after

There is usually no reason why women living with RA, PsA or axSpA should not have a normal delivery. Sometimes if you have arthritis in your back or hips labour can be more difficult. In these situations, different labour positions can be used and epidural anaesthesia can be considered. Caesarean sections may also be considered. It is advisable to discuss all these options with your healthcare team during pregnancy to plan the optimum delivery for you.6,8-10

Looking after a newborn baby can be very demanding, especially if you are living with RA, PsA or axSpA. You may feel tired managing both your symptoms and the demands of your newborn, and there is also the possibility that you will experience flares in your symptoms.6,22 There is no consistent symptom pattern for women with RA, PsA or axSpA. Even if your symptoms get better during pregnancy, they may return after delivery.17,19 Having your disease under control can help you manage this challenging but special time.

There are people there to support you along your journey. Remember to ask family, friends and support networks for help whilst you get used to life with your newborn. This will give you more time to rest if you need to.

Make sure you ask for guidance from your healthcare team and for extra support from social services, physiotherapists or occupational therapists who can give you advice to make holding, dressing, washing and feeding your baby easier. Your healthcare team may also be able to provide information about specifically designed products which could assist you in taking care of your baby.

Please talk to your healthcare team before the birth to discuss a delivery plan.
Breastfeeding

Many women with RA, PsA and axSpA breastfeed successfully. Whether you decide to breastfeed or not depends on several factors, including your personal choice, your treatment and your level of disease control.

Breastfeeding is beneficial for both you and your baby, however not all drugs can be used when breastfeeding. Stopping treatment in order to breastfeed may worsen symptoms and impact your ability to care for your baby.

It is very important that you talk to your healthcare team (e.g. your general practitioner, nurse, rheumatologist, obstetrician, midwife and health visitor) before making any decisions about your treatment. They will ensure that your treatment is compatible with breastfeeding.⁶

By discussing treatment options ahead of time, you can adapt your treatment if necessary and you would not have to choose between breastfeeding and treatment.
Post pregnancy

Checklist

Speak to your healthcare team about any support you may need after birth, such as having a family member or friend stay at the hospital overnight while you recover.

Discuss your treatment options with your healthcare team.

Enlist as wide a support network as possible.

Ask your healthcare team about any tips and equipment that can make childcare easier (such as different movements, methods or objects), and can help you care for your baby e.g. cradles, chairs, beds, car seats and baby clothing with simple fasteners such as Velcro.

Contact your health visitor in advance to inform them about your situation.
Frequently asked questions

Before

**Can I pass my rheumatic disease onto my baby?**
The way your disease is inherited is complex. The risk of passing on the disease varies between up to 1 in 30 for RA and PsA, and between 1 in 6 to 1 in 10 for axSpA.6

**Am I at high risk of miscarriage?**
There is a slightly higher risk of miscarriages in women with RA, PsA or axSpA. This may be linked to having uncontrolled disease during pregnancy and certain drugs.3,6,14 You may want to discuss this risk with your healthcare team who should monitor you closely before and during your pregnancy.

**Is my baby likely to have abnormalities?**
The risk of birth defects is no greater for you than for other women. Some drugs increase the risk of birth defects if taken during pregnancy (e.g. methotrexate) and should be stopped in advance.5,6 It is advised to take folic acid supplements before and during pregnancy, especially if you have been treated with drugs such as methotrexate.16

**Does it matter if the father is taking medication for his rheumatic disease?**
Some drugs may reduce fertility in men. It is generally advised to stop taking such medications before trying for a baby. Your healthcare team can offer advice about which drugs may need to be stopped and if an alternative treatment can be offered.6

**What else can I do before, during or after pregnancy?**
Following a healthy lifestyle (e.g. balanced diet, no alcohol, appropriate exercise) is very important and may help reduce potential problems during pregnancy.16,25

During

**Will my disease affect my baby’s growth?**
There is a slightly increased risk of having a lower birth weight baby, particularly if symptoms are not well controlled during pregnancy. However, you and your baby will be closely monitored throughout pregnancy.5

**Will taking medication affect my baby?**
Some medications will need to be stopped before you become pregnant or during pregnancy and when breastfeeding. However, by planning properly, your treatment can be adapted to allow you to continue with medication that is compatible with pregnancy.6

**Is my baby likely to be born prematurely?**
There is a slightly increased risk of having a premature baby particularly if your disease is not well controlled during pregnancy. You will be monitored closely throughout your pregnancy.4,9,10,15,25

**Can I have a normal delivery?**
There is usually no reason why you should not have a normal delivery. Sometimes different labour positions can be used if there is arthritis in the hips or back. Epidural anaesthesia or caesarean section can also be considered.6
Importance of controlling your disease before, during and after pregnancy

Your healthcare team (e.g. your general practitioner, nurse, rheumatologist, obstetrician, midwife, pharmacist and health visitor) will support you to have a pregnancy journey that is as similar as possible to that of any other woman. Ensuring your disease is well controlled is central to achieving this. Control of disease activity before, during and after pregnancy is very important for you and your baby. Speak with your healthcare team early about your pregnancy wish so that a proper and well aligned treatment plan is tailored for you throughout your pregnancy journey.

Before

Controlling your symptoms can improve your chances of conceiving. Although it may take longer, most women with RA, PsA or axSpA become pregnant within a year. Better symptom control before pregnancy may also improve control during pregnancy and reduces the risk of poorer outcomes for you and your baby.

During

Effective disease control during pregnancy may help to reduce the risk of poorer outcomes for you and your baby, such as premature delivery or lower birth weight. Proper planning and effective treatment can also help make a natural delivery more likely.

After

The period following the birth can be difficult as you begin to deal with the demands of looking after the baby, but it can be made more difficult if your disease is not well controlled. Furthermore, many patients experience a flare in their symptoms after delivery, which could affect your ability to breastfeed should you want to. Effective treatment and symptom control after delivery will help you care for yourself and your baby as best as possible.

Will my symptoms change after birth?

Your symptoms may increase following delivery even if they improved during pregnancy. You should continue with or restart your treatment, upon advice from your rheumatologist, to help control your disease activity and regularly discuss your symptoms with your healthcare team. If you wish to breastfeed, there are treatments that are compatible with breastfeeding. Discuss these options with your healthcare team.

What kind of equipment should I consider to prepare for taking care of my baby?

Adjustable bed, height adjustable tables, chairs and carrier seats, positioning-breastfeeding cushions, and adjustable baby-carriers can all help you care for your baby. Consider seeing an occupational or physical therapist who can offer further advice.
References: