



Pregnancy with Arthritis

A Resource for Patients by Patients

You're contemplating a step into parenthood and also live with inflammatory arthritis? Start with this resource written by patients for patients with arthritis. We've learned through our own personal trials and tribulations and want to pay it forward. This resource has also been reviewed by a leading rheumatologist and researcher in reproductive issues and rheumatic disease, [Dr. Evelyne Vinet](#). The resource is organized in the following topics - click on the titles below and take the first step in getting informed!

[Fertility and Family Planning](#)

How does living with inflammatory arthritis impact fertility? What things should I consider before we try to have a child? Find out more here...

[Talking to your Partner about Parenting](#)

What things should I discuss with my partner before we try to have a baby? Will their role as a parent be different because of my arthritis? Learn about the things you may wish to discuss with your partner here...

[Medication use during Pregnancy and Breastfeeding](#)

Many people may rely on prescription medications to manage and slow down the progression of our disease. Find out about the resources available to you about the effect of medications on the fetus / baby and breast milk here...

[Managing Arthritis during Pregnancy](#)

What effect does pregnancy have on arthritis? What should I expect after the birth of my baby? Find out more here...

[Labour and Delivery](#)

Will arthritis affect labour and delivery? Is there anything special I need to consider for labour and delivery? Find out more here...

[Pregnancy Resources](#)

This page contains a list of the trustworthy websites cited in the pregnancy section of this resource. To connect with other people living with chronic disease, request to join the [Mamas Facing Forward group](#) on Facebook. It is a group designed to help parents or those considering pregnancy while living with chronic illness.

Fertility and Family Planning

So, you're considering a step into parenthood – congratulations! You may have a few questions about what this means for you if you live with inflammatory arthritis. For example, how will my arthritis be affected? Will I be able to do every day parenting tasks if I have any functional limitations?

As a first step, it is important to speak with your rheumatologist and family doctor as early as possible regarding any plans on becoming a parent. Your family doctor may recommend a number of things to prepare for a possible pregnancy such as ensuring immunizations are up to date and recommending a prenatal vitamin with folic acid.

You will also need to speak with your rheumatologist to review the medications prescribed to ensure they are safe to take during pregnancy. This also applies to men who may need to stop taking certain teratogenic (materials that are known to affect the development of the fetus / baby) medications before trying to conceive. It is also recommended that your arthritis is stable before attempting to become pregnant.

Fertility

You may be wondering if your arthritis will affect your fertility or ability to have children. Some studies ([Jawaheer, Zhu, Nohr & Olsen](#)) have shown that the length of time to become pregnant is slightly longer for women with rheumatoid arthritis. This study showed women with Rheumatoid Arthritis were more likely to take longer than 12 months to become pregnant. There are some specific conditions associated with rheumatic disease that may affect the ability to carry a pregnancy to term such as [antiphospholipid syndrome](#). This is a condition where the immune system attacks blood proteins that can cause blood clots to form in the

It was worth it! Ten million times over, it was worth it. The decision to have a child is enough all on its own, but when you have a chronic condition that requires medication to function normally, it's an even tougher decision. At the advice of the best medical experts I could find, I stopped some medications (months in advance of trying to conceive) and stayed on others. This approach helped my arthritis stay under control during my pregnancy, which reduced the chance of preeclampsia or pre-term labor. I had a beautiful, healthy baby girl who is worth every fear and anxious thought.

- *Mom with arthritis on her pregnancy experiences*

veins and arteries. The condition can cause high blood pressure, miscarriages and still births. Speak to your doctor to see whether you are at risk and to screen for this or other conditions.

If your inflammatory arthritis is more severe and you have additional risk factors, you may wish to consider other options to pregnancy, such as adoption or surrogacy.

Some studies have shown ([Katz](#) and [Provost, Eaton & Clowse](#)) that women with rheumatoid arthritis have fewer children than the average woman. This may be because of physical limitations, reduced sex drive due to pain and the possible role of medications such as Non-Steroidal Anti-Inflammatory Drugs (NSAID's) on fertility (possible impacts on ovulation). Here are a few things to consider when deciding on the size of your family:

- Given any functional limits you may have, what modifications would you need to make in order to care for a newborn baby? A preschool aged child? A school aged child? (Don't forget to read the wealth of information in the Parenting Resource!)
- Do you have a supportive partner who is willing to take on more parenting responsibilities (e.g. getting up more in the night) to allow you to manage your arthritis?
- What other support is available for you and your partner to deal with the demands of parenting?
- What are you and your partner's expectations of parenthood? How might inflammatory arthritis impact day to day life including dealing with arthritis flares?

I've had three children along with rheumatoid arthritis. I had amazing good health while pregnant, flares after. With good health care, family help, and being proactive these were fabulous moments in my life! I'm now a grandma! My saying is "if there's a will, there's a way".

- *Woman with arthritis on her pregnancy experiences*



Sex

Depending on what you've decided regarding medications and your current state of health, it may be painful to have sex when trying to conceive a child. Know that you aren't alone and talk with your partner to find ways to address the pain, such as modifying positions. Don't forget to check out some of the resources on the [Chronic Sex website](#).

A year after developing arthritis, we decided it was time to try and conceive. Of course, that meant having to stop taking (drug name) and waiting the 3 months before trying to get pregnant. By the time the 3 months was over, the arthritis symptoms had returned with a vengeance, which made the act of having sex painful. We were also faced with a timeline of how long my Rheumatologist felt I should be off the (drug name) to avoid developing joint erosions and deformities. In all, we only had 7 months to try and conceive. I have to say, they were the most stressful, emotionally draining and painful months of my life.

- Woman with arthritis on her pre-pregnancy experiences

Talking to your Partner about Parenting

You may be in a situation where your partner was well aware of your arthritis when you met or maybe it was something that came along once you had an established relationship. Either way, your partner is an important part of your life, management of your disease and any decisions regarding parenthood. Some things to consider are:

- What will my life look like as a parent?
- What additional things might I need to do or consider because of inflammatory arthritis?
- Will I need to take on certain responsibilities if my partner has functional limitations (e.g. waking up at night with the baby because of partner's fatigue, taking on more physical tasks like lifting and carrying children)?
- How will I support my partner and their disease throughout pregnancy and in their role as a parent?

To learn about what life may look like for a supportive partner, read this [homage](#) for a supportive partner written by Mariah Leach.

Don't forget to check out some important resources on sexuality and disability on the [Chronic Sex website](#). There are a variety of trustworthy [resources](#) on self-confidence, relationships and talking to your partner.



Medication use during Pregnancy and Breastfeeding

When considering a step into parenthood, you may be concerned about staying as healthy as possible during pregnancy. We worry not only about ourselves, we also worry about our fetus / baby. Living with a chronic disease means that we may rely on prescription medications to stay healthy and to manage and slow down the progression of the disease.

If you do take prescription medications, you will need to consider whether the medication(s) affects the fetus / baby and whether the medication transfers to breastmilk. It is important to consult with your doctor (ideally your rheumatologist and/or obstetrician) as early as possible to get advice on which medications may be appropriate before pregnancy, during pregnancy and when breastfeeding. This also applies to men who may need to stop certain teratogenic (materials that are known to affect the development of the fetus / baby) medications before trying to conceive.

All prescription medications are reviewed by government regulators, such as [Health Canada](#), the [Food and Drug administration \(FDA\)](#) (in the US) or the [European Medicines Agency \(EMA\)](#), before they can be widely sold and used in people. Medications are reviewed through various phases of clinical trials (studies that involve people to test medications) to see whether they work and are safe to use. You can learn more about clinical trials by visiting www.itstartswithme.ca.

Pregnant women and women of reproductive age are often excluded from clinical trials that test medications. Concerns have been raised that testing a medication may cause harm to the pregnant woman and their fetus / baby. As a result, information on medication use in pregnant and breastfeeding women is collected **after** a drug is approved. There are a number of organizations that do research on medication use during pregnancy and breastfeeding including:

- [Mother to Baby](#);
- [Lact Med](#);
- [Infant Risk](#);
- [Centre de référence sur les agents tératogènes \(CRAT\)](#);
- [Medication and Mother's Milk \(subscription-based service\)](#), and
- [Reprotox \(book\)](#).

You can also read the [results of a European League Against Rheumatism \(EULAR\) taskforce on the use of anti-rheumatic medications before pregnancy, during pregnancy and during lactation](#). These websites contain trustworthy and evidence-based information about the use of a variety of medications during pregnancy and breastfeeding.



Considerations

As you consult your doctor and other resources, you will discover that the information about medication use during pregnancy and breastfeeding is not as complete since it is often studied in a smaller number of patients or perhaps not at all. In some situations, the medications may have been tested in animals but not in humans. It is ideal to do this research before pregnancy or breastfeeding to limit decision-making when you might be stressed or in pain.

Here are a few questions to ask your doctor when making a decision:

- What are the risks of NOT taking your medication (e.g. pain, inflammation) before pregnancy? During pregnancy? While breastfeeding?
- What are the benefits of taking your medication or keeping disease under control during your pregnancy?
- What are the risks to the fetus / baby of taking the medication including long-term outcomes on their health?
- What other medications can you take that have a safety record?
- If a medication is known to not be safe during pregnancy, how long must it be stopped before trying to have a baby (you may wish to get information on the medication half-life which is how long it takes for half the medication to be eliminated from your body)?
- What other medications are available to manage arthritis during pregnancy and after birth?
- What precautions might need to be taken after the baby is born if you do take medications during pregnancy (e.g. delay in 'live immunizations)?
- Do you have any life-threatening complications of arthritis (e.g. heart or lung involvement, breathing difficulties, etc.)?
- What are the benefits of breastfeeding your baby?

Unfortunately, with some of the newer medications there was no black and white answer for me as to how long to stay on them for and when pregnant. In the end, I had to make decisions that I could live with. It was difficult to not have solid research behind some of these decisions that needed to be made.

- Woman with arthritis on her pregnancy experiences

Regardless of the research you've done before pregnancy and breastfeeding, be prepared to adjust your decision about medication use. We can never predict what might happen and sometimes things happen and new circumstances arise which may mean you don't stick to your original plan.

Understanding the Research Data

The government regulators (e.g. FDA, EMA, Health Canada) that approve medications for use in people typically provide information or medication guides on how to properly use the medication. This information or medication guides may also provide information about the use of the medication during pregnancy or breastfeeding. For example, the FDA will be implementing a new way of showing information on medication use during pregnancy and breastfeeding. They will be moving from a [five letter risk labelling system](#) (A, B, C, D, and X) to a more helpful way of [showing the information on medication](#). When reading through the medication information, here are a few important questions to ask your pharmacist or doctor:

Consult with your medical team and be honest about how you're doing. There's no shame asking for help or looking to others for support during the time of pregnancy or trying to conceive.

- *Woman with arthritis on her pregnancy experiences*

- How many pregnant or breastfeeding moms were part of the study or studies?
- If there weren't a lot of patients in the clinical trial or study, what assurances can your doctor offer about the data?
- Did they track the short and long-term outcomes in the child? If so, for how long? What were the outcomes?
- Do any of the medications affect or potentially affect fertility?
- If birth defects are found in approximately 3 out of 100 children born (or potentially more), what is the risk of a birth defect if I take the medication?
- Were there birth defects or negative outcomes in the child? What were they and when did they happen?

Talk to your rheumatologist or obstetrician before making any decisions about medication use during pregnancy and breastfeeding. It is best to learn as much information as possible before your appointment to allow for a meaningful discussion with your doctor. Read through the CAPA [Discussion Guide](#) in order to prepare for your next appointment.

It is possible that your doctor may have a different opinion on which medication(s) are appropriate to use during pregnancy and breastfeeding. This is why it's important to communicate your personal goal(s) to them as clearly as possible (e.g. I really want to breastfeed my baby. Dealing with the pain is really important to me but I still need to function).

In some situations, you may wish to do further reading or research and discuss what you learned with your doctor.

Participating in Pregnancy Registries

Some of the organizations that provide information on medication use during pregnancy and breastfeeding run create or maintain what are called Pregnancy Registries. These registries track the outcomes in moms and babies who are exposed to medication during pregnancy or breastfeeding.

If you decide to take a medication during pregnancy or when breastfeeding, consider participating in one of these registries. Every person

who participates in a registry can help us all learn more about how medications affect us and our babies. You can access a list of pregnancy registries on the [FDA website](#) and [Mother to Baby website](#) - contact them to get involved!

Don't ever say never to pregnancy - it could be the best thing you ever do. My arthritis symptoms disappeared and for many months I was drug-free and pain-free.

Woman with arthritis on her pregnancy experiences

Managing arthritis during pregnancy

So now that you're pregnant, you may be wondering if your arthritis will feel better or worse. Everyone is different but there are a few studies that tell us a little bit about what to expect. It seems like it depends on the type of inflammatory arthritis:

- If you have Rheumatoid Arthritis, various studies ([De Man et al](#) & [Barrett et al](#)) have concluded that disease activity decreases during pregnancy though perhaps not as much as originally thought.
- In contrast to the experience of women with Rheumatoid Arthritis, some studies ([Ostensen](#)) have shown that the overall disease for women with Ankylosing Spondylitis stays the same or worsens during pregnancy.
- If you have Psoriatic Arthritis, some studies ([Ostenson](#)) have shown that disease activity improves or went into remission in 80% of the pregnancies.

Although we can remain hopeful of an improvement in your arthritis's activity during pregnancy, it is important to plan for the possibility that the disease may not improve. You may wish to consider what medications might be an option, what adjustments you may wish to make to your lifestyle and what additional support you may need from your partner, family and friends.

During my first pregnancy, my arthritis went to remission. I thought it was almost guaranteed to do the same during my second pregnancy but it was the complete opposite. I wish I had been better prepared mentally for the fact that my arthritis may not go away as it did with my first.

- *Woman with arthritis on her pregnancy experiences*

If you have joint damage to your spine, you may also feel additional pressure and pain in the spine throughout pregnancy. This may become a problem during the later stages of pregnancy where the baby / fetus may be putting additional pressure on the spine.

It is also important to discuss the risk of pregnancy complications with your physician. There are certain pregnancy complications that are seen in women with lupus or rheumatoid arthritis, such as anti-Ro and/or anti-La antibodies which cross the placenta and can rarely cause complications in the fetus/baby. Speak to your doctor to see whether you are at risk and ask about whether screening is right for you.

Labour and Delivery

You've made it – you're almost there and baby is on the way! You're likely thinking about how you'll manage through labour and delivery. There are some joints that may cause problems during labour and delivery, such as the spine, sacroiliac joints (found in the lower right and left parts of the pelvis) and the hips. If you have arthritis in any of these joints, they may cause additional pain or limitations during labour and delivery.

Here are a few things to consider to prepare for labour and delivery:

- Work with your obstetrician, mid-wife and/or doula (a person who is trained to assist another woman during childbirth) in advance of the birth to identify ways to address pain in problem areas;
- Discuss what medications are available to manage pain during labour and delivery;
- Read up about different ways to manage pain during labour and delivery, such as labouring on a ball, using a bath and meditation. You may wish to limit any pressure on the spine or sacroiliac joints (found in the lower right and left parts of the pelvis) during labour and so you may want to avoid lying down or sitting during labour.

In some situations, your doctor or obstetrician may recommend a caesarian section (C-section) for the birth. Read through the resources provided below for further information about the surgery and to guide you in the early days after delivery.

- [Kids Health](#)
- [BabyCenter](#)
- [Mayo Clinic](#)



After the Birth

Often women will experience a flare of their inflammatory arthritis within three months of the birth of the baby. Some [studies](#) have shown that the postpartum flares will occur in 90% of Ankylosing Spondylitis pregnancies, 70% of Psoriatic Arthritis pregnancy and 50% of Juvenile Rheumatoid Arthritis pregnancies. While there is no way to predict this, you should prepare yourself mentally and physically in case this happens.

Here are few things to consider to plan for this possibility:

- Do you intend to breastfeed your baby?
- Will you re-start your medications (if they were stopped during pregnancy) after the birth?
- Do these medications pass through breastmilk to the baby? If they do, what are the effects on the baby?
- How long do you intend to breastfeed your baby?
- What additional support will you need from your partner, family, friends and health care team immediately after and in the months following birth?



Pregnancy Resources

- [Mother to Baby](#)
- [Lact Med](#)
- [Infant Risk](#)
- [Results of a EULAR taskforce on the use of anti-rheumatic medications](#)
- [Medication and Mother's Milk](#)
- [Reprotox \(book\)](#)
- [Centre de référence sur les agents tératogènes \(CRAT\)](#)
- [From This Point Forward](#)
- [Chronic Sex website](#)
- [Rheumatoid Arthritis.net](#) (section on pregnancy and parenting)
- [Mamas Facing Forward Facebook group](#)
- [Arthritis Ireland: Parenting with Arthritis](#)

DISCLAIMER – This Resource is subject to the CAPA Legal and Privacy Policy which can be viewed on the [CAPA website](#).
