

Pregnancy, birth and beyond

A resource for patients, by patients

So now that you are pregnant, you may be wondering if your arthritis will feel better, worse or the same. Everyone is different but there are a few studies that tell us a little bit about what to expect.

- 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 ([Ostensen](#)) have shown that disease activity improves or went into remission in 80% of the pregnancies.

“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.”

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.

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 is getting larger.

Labour and delivery

You have made it – you’re almost there and baby is on the way! You are likely thinking about how you will 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, midwife 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. In some situations, your doctor may advise against the use of an epidural for people with arthritis in their spine
- 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 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 the birth.

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

After the birth

Often women will experience a flare of their inflammatory arthritis within three months of the birth of the baby. Studies ([Ursin](#), [Ostenson](#)) have shown that disease activity is increased after the birth and six months after the baby was born. While there is no way to predict your health, you should prepare yourself for a possible flare after the birth. Here are some considerations in planning for after the baby is born:

- Do you intend to breastfeed your baby? If so, what medications are compatible with breastfeeding?
 - Will you restart the same medications (if they were stopped during pregnancy) after the birth?
 - Do these medications pass through breast milk 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?
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Immunizing your baby

If you decide to keep taking medications during pregnancy and breastfeeding, it is important to ask your rheumatologist about the impact it may have on your baby's immunization schedule. Each province or state has their own [timetable](#) for immunizations and what is reimbursed so it's important to know what applies in the province you live or receive health care.

All vaccines should be routinely administered to babies of mothers with inflammatory arthritis except the rotavirus vaccine as noted in [Canadian guidelines](#). In North America, live vaccines like the rotavirus vaccine are usually not given to babies until they are twelve months of age, with rare exceptions. Speak with your rheumatologist to assess your situation and the impact on you and your baby.

Sexuality and family planning

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Are you considering a step into parenthood? You probably have a few questions about what this means for you if you live with inflammatory arthritis. For example, how will my arthritis be affected? What will parenting be like while living with inflammatory arthritis?

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

Your rheumatologist may review the medications with you to ensure they are safe to take during pregnancy. Some medications may be considered teratogenic which is the medical term for when a medication is known to affect the development of the fetus / baby. Men also need to review medications before trying to conceive. These first steps are important as it is recommended that inflammatory arthritis be in a state of low or no disease activity before attempting to become pregnant.

Sexuality and intimacy

There are so many **'medical'** items to address that sometimes we lose sight of how we are actually going to have a baby! Living with inflammatory arthritis can affect intimacy including how you see yourself and self-confidence. Fatigue can also get in the way of actually having sex. There are limited resources on sexuality and intimacy, and they are highlighted below:

- The [Chronic Sex website](#) has resources on sexuality and illness and disability. There are trustworthy resources on self-confidence, relationships and talking to your partner.
- The Arthritis Society has an [intimacy resource](#) that includes information on how arthritis affects intimacy, physical and emotional challenges, and comfortable positions.
- Help is available through a sexuality educator, counsellor, or therapist. The American Association of Sexuality Educators, Counsellors and Therapists has a [referral directory](#) if you want to learn more.

Fertility

You may be wondering if arthritis will affect your fertility or ability to have children. Research ([Jawaheer, Zhu, Nohr & Olsen](#)) has shown that the length of time to become pregnant is slightly longer for women with rheumatoid arthritis. For example, this study showed that if a woman has rheumatoid arthritis, up to 25% may take more than a year to conceive compared to 16% in women without RA.

There are some specific conditions associated with rheumatic disease that may impact fertility such as [antiphospholipid syndrome](#) that can cause high blood pressure and miscarriages. Speak to your rheumatologist to see whether you are at risk and to screen for this or other conditions.

Some studies have shown ([Katz, Provost, Eaton & Clowse and Ostensen](#)) that women with rheumatoid arthritis tend to have fewer children than the average woman. This may be due to disease activity, personal choices, pain, and medications especially Non-Steroidal Anti-Inflammatory Drugs (NSAID's) that can affect ovulation. Here are a few things to consider when deciding on the size of your family:

- What changes might you need to make to care for a newborn baby? A preschool aged child? A school aged child? (Check out the Parenting resource for more information)
- Is your partner willing to take on more parenting responsibilities (e.g., getting up more in the night) to allow you to manage your arthritis?
- What other social support is available to you and your partner to deal with the demands of parenting? [Research](#) has shown that social support, e.g., family or friends to help with caregiving, can help parents living with Rheumatoid Arthritis.
- What are you and your partner's expectations of parenthood? How might inflammatory arthritis impact day to day life such as managing arthritis flares?

Talking to your partner

You may be in a situation where your partner was 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 a flare or other 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?

“My biggest advice is to rally your supports. This is true for all new parents but living with a chronic condition, such as arthritis, throws more complexities into the scenario...not knowing what your pain and coping will be like after baby arrives is anxiety-provoking. Having someone to voice your concerns to is helpful and having people in your life that are aware of what you're dealing with is crucial so they can offer support.”

Medication use during pregnancy and breastfeeding

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Living with a chronic disease means that we may rely on prescription medications to stay healthy and to manage and slow the progression of the disease. When pregnancy or breastfeeding enters the picture, we worry about our health but also the health of the baby.

It is important to consider how medications – including over the counter and prescription medications – could affect the developing fetus / baby or whether the medication transfers to breast milk. Working with and consulting your doctor (ideally your rheumatologist and/or obstetrician) as early as possible and throughout pregnancy is important 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 review what medications they take. Some medications, like Methotrexate, Leflunomide, Cyclophosphamide, and Cellcept, are not recommended before or during pregnancy as they are known to be teratogenic. This means they contain materials that are known to negatively affect the development of the fetus / baby.

How medications are approved

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 prescribed to 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.

Clinical trials recruit people living with health conditions that represent different ages, backgrounds, etc. However, pregnant women and women of reproductive age are often excluded from clinical trials that test medications. This is often done because of ethical concerns about 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.

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 has implemented a new way of showing information on medication use during pregnancy and breastfeeding. To learn more, you can find the medication on the [FDA website](#) and refer to the “Pregnancy” section of the medication guide.

There are several organizations that do research on medication use during pregnancy and breastfeeding. The following websites include information on medication used during pregnancy and breastfeeding:

- [Mother to Baby](#)
- [Lact Med](#)
- [Infant Risk](#)
- [Centre de référence sur les agents tératogènes \(CRAT\)](#)
- [E-lactancia](#)

Other resources are also available but are not available in plain language summaries. However, you are welcome to visit the American College of Rheumatology [Reproductive Health Guidelines](#), [European League Against Rheumatism recommendations for Women’s Health](#) and the [results of a 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 medications during pregnancy and breastfeeding.

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. Refer to the CAPA resource “[Making the most out of your next appointment](#)” for more information.

Questions to consider

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

- What are the risks to the fetus / baby of taking the medication including long-term outcomes on their health?
- 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?
- Do any of the medications affect or potentially affect fertility?
- 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 of the dose of medication to be eliminated from your body)?
- What other medications are available to manage arthritis during pregnancy and after birth?
- How many pregnant or breastfeeding moms were part of the study or studies? If there were not a lot of patients in the clinical trial or study, what assurances can your doctor offer about the data?
- If birth defects are found in approximately 1 out of 100 children born, what is the risk of a birth defect if I take the medication?

“Having a good relationship with a trusted rheumatologist was so helpful. Feeling comfortable calling to request more medication support or guidance from my rheumatologist made a difficult pregnancy much easier.”

Making decisions on how to feed your baby is a personal one that is best made by you. There is a lot of pressure on new Moms that “breast is best,” but it is not necessarily the best choice, especially for one living with a chronic illness. Breastfeeding adds extra physical strain on a new mom. The [Fed is Best foundation](#) offers resources to support moms feeding their children, no matter how your child is fed. You can listen to [this podcast](#) with Mariah Leach and Cheryl Crow as they speak about breastfeeding with autoimmune arthritis.

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!