

Pregnancy & Parenting with Arthritis: Bridging the Information Gap

Laurie Proulx, Dawn P. Richards, Nathalie Robertson and Linda Wilhelm

About CAPA

Canadian Arthritis Patient Alliance (CAPA) is a grass-root, patient-driven, independent, national organization with members across Canada and supporters both Canadian and International. CAPA believes the first expert on arthritis is the individual who has the disease, as theirs is a unique perspective. We assist members to become advocates not only for themselves but all people with arthritis.

Background

For any individual, the decision to start a family is an important one but for individuals with arthritis, the decision is even more difficult. Many decisions need to be taken, including the risks of taking or not taking medication while trying to conceive and during pregnancy, and the ability to carry out their role as a parent. Few resources exist to help individuals navigate these important, life-changing decisions^{1,2}. It is for this reason and through our collective experience as people living with arthritis that the Canadian Arthritis Patient Alliance (CAPA) launched a project on pregnancy and parenting with arthritis. The first phase of the project involved a survey to identify patient information needs as it relates to pregnancy and parenting. The second phase focused on the creation of a resource for people living with arthritis.

Objectives

The objectives are to:

- Outline the process for developing the educational resource, and
- Discuss the content of the pregnancy and parenting resource.

Methods

Priority was placed on developing content for the topics identified as “very important” and “important” from the pregnancy and parenting survey undertaken in the first phase of the project. The issues identified as highest priority include:

- medication safety during pregnancy and breastfeeding;
- dealing with fatigue and flares, and
- the physical care of children.

One Board member acted as project manager to develop the resource content and obtain input from people living with arthritis, researchers and rheumatologists. Methods to obtain input include software tools, e-mails and in-person meetings.

Results

The educational resource is divided in two sections – one focused on pregnancy and the other on parenting. The visual below outlines the topics found in the resource and advice provided by people living with arthritis about pregnancy and parenting.

A Resource for Patients by Patients

Pregnancy with Arthritis

- ✓ Fertility and Family Planning
- ✓ Talking to your Partner about Parenting
- ✓ Medication use during Pregnancy and Breastfeeding
- ✓ Managing Arthritis during Pregnancy
- ✓ Labour and Delivery
- ✓ Pregnancy Resources

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.

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.

My now almost 4 year old has a compassion and understanding that many adults lack, she understands some people need to rest more because their bodies are fighting an invisible battle. She asks with curiosity rather than judgement. **The struggles are well worth the rewards!**

Super moms do not exist so if you are feeling too fatigued or too sore to go to play centres, it's ok to stay home. There will be another day to go out when you feel up to it.

Parenting with Arthritis

- ✓ Physical Care of Children
- ✓ Dealing with Fatigue and Flares
- ✓ Impact on Children
- ✓ Parenting Resources

Discussion

The resource is a first step in developing comprehensive, evidence-based information for people living with arthritis to support them in decisions regarding pregnancy and in carrying out parenting tasks. It is important that more research be done about the use of medications during pregnancy/breastfeeding and short and long-term outcomes in children.

The resource will be regularly reviewed to ensure the most recent and accurate information is available to patients. Next steps include a review of the resource by health care professionals to increase the overall reliability of the resource and to promote uptake with patients and the broader arthritis community. Ongoing efforts will be made to promote the resource and use will be monitored through social media, website metrics and surveys.

Conclusion

CAPA developed a resource for people living with arthritis regarding pregnancy and parenting. CAPA aims to raise the profile of this issue and help people living with arthritis engage in dialogue with their healthcare providers during these critical life events. It is expected that use of the resource will enable shared decision-making, improve communication with health care professionals, and reduce stress for people living with arthritis and their families.

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References

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