

# Nursing with Fibromyalgia

The (limited) research, my (small) surveys from real mamas and my (three) experiences.

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### Disclaimer

**N**one of the content specified in this book is to be treated as medical advice and not as a replacement for a professional healthcare physician. I am not an expert in Fibromyalgia, Chronic Fatigue Syndrome or Myofascial Pain Syndrome – I am an expert in *my* experience. I share my experiences and research to help you be your own advocate and to make the experience of this illness more visible.

You will note the expectation that you will perform your own research, I give you places as a starting point so that you can go into discussion with your doctor informed.

Like many areas of living with Fibromyalgia, I have found there to be little information on nursing with Fibromyalgia. In fact the post on my blog, from which this eBook is compiled is the most comprehensive information I have ever found.

## The Research

There are a few articles, [like this one](#) on Fibromyalgia Symptoms that mentions research but provides no links, "Numerous studies have been done evaluating how fibromyalgia influences breastfeeding. These studies all indicate that it is very hard to breastfeed with fibromyalgia."

The Fibromyalgia Health Center on WebMD posted [an article in 2004](#) referencing a new study about nursing with Fibromyalgia. This study was very small, with just nine mothers included:

"All nine women felt that they were not successful in their attempts to breastfeed, and felt frustrated," Schaefer writes. Difficulties included muscle soreness, pain, and stiffness; fatigue; a perceived shortage of breast milk; and sore nipples."

The article lists a few tips from the study which includes **good nutrition, proper rest and paying attention to where and how you are nursing.**

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### Other posts you might like:

[\*Early Pregnancy Symptoms and Fibromyalgia \(2018 Edition\)\*](#)

[\*Navigating Pain Relief in Pregnancy with Fibromyalgia\*](#)

[\*Necessary Baby Items for a Fibro Parent\*](#)

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## The Survey

Please do remember that we are all unique, how we experience fibromyalgia and how we experience pregnancy or nursing. My story will not reflect yours. Before I give you my experiences, I'd like to show you some information from a survey I undertook when I was writing my book [Pregnancy and Fibromyalgia](#).

In response to the question, did you manage to nurse? 40% responded that they did for 12 months or more! 20% managed for both 12 month and 6 month periods (that's 40% for 6-12 months!). 15% didn't manage to nurse. 5% exclusively expressed. There were 20 respondents, so the sample size was small, but these are encouraging results.

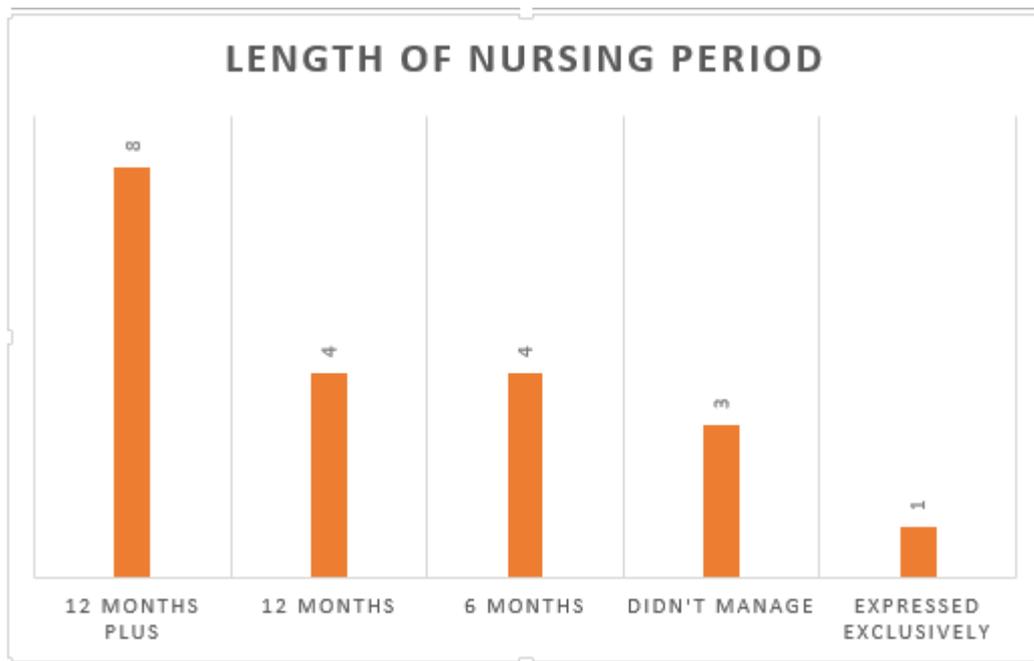


Figure 1 Survey Results: Length of Nursing results from survey

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*Some advice from a respondent about nursing:*

*"The two hardest things for me have been lack of sleep, and being forced to sit in the same position for long periods of time while nursing, or while my son slept. I kept five different pillows on the couch, and used them to prop myself and him up at every angle. Really helped."*

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## My Experiences

Having had three children now, I thought I would share my experience. As with all areas of this illness, my experience may not be the same as another's with Fibromyalgia, so my difficulties do not translate to all women with Fibromyalgia.

I found nursing extremely painful with my first two children, I had cracked and sore nipples from the second day cluster feeding with both babies. Both times, it took a long time for them to recover. Expressing was less painful, but still resulted in sore breasts.

The differences in situations were extreme.

### Baby One

With Nu, we found he was excessively windy and by week two we were going back and forward to doctors at the afterhours centre. At last, at week three, we were sent to the hospital and there they found that he had pyloric stenosis - a thickened sphincter that wouldn't let food out of the stomach to be digested, so it was forced back up and out of his mouth in projectile vomiting. After several days in hospital

and a small operation, we came home and found that he doubled the amount he was taking at each feed. My supply couldn't keep up, despite pumping three hourly the entire time he was in the hospital, my supply decreased in real numbers and relative numbers. I managed to keep him exclusively on breast milk until eight weeks. At this point whenever it was time to express, I would cry, so I knew it was time to finish up. I was just tired and sore and Nu was not a very settled baby and so cried the entire time I tried to express.

I was so relieved when parenting no longer needed to include my breasts. I am proud that I managed to give him such a good start in life, but I also wish I had given up sooner, but the pressure on mothers to breastfeed is enormous, even my expressing rather than feeding directly was seen as failure. My doctor and my Plunket Nurse were both supportive as they understood the Fibromyalgia and how hard I had tried.

### Baby Two

With W I managed to persevere a little longer. My right breast got so sore and cracked from the second day cluster feeding that when I first tried to express, I expressed blood in the milk, it was a frightening sight! I persevered with the one side for another week before that became too sore (this guy is a rough feeder and liked to pull away with it clenched between his gums). I expressed four hourly during the day and once in the middle of the night (that was hard to leave baby sleeping after giving him a bottle and stay awake). My supply stayed static no matter what I did to try to increase it, so by week four, I was only just producing enough from both breasts for one feed. Luckily I had a lot of frozen milk from the first weeks of expressing.

**This time I knew it didn't have to be all or nothing (this is an important message for all mamas, you can mix feed!),** I had more knowledge and therefore more power. I also ignored any messages of my being deficient or not trying hard enough. I managed to add in a physical feed each evening after he had spent the previous few hours having more regular bottles in his nightly cluster feed, this meant I didn't have to worry about him not getting enough and he got some comfort from it at the end of a long day. It hurt, but swapping which breast I gave him each night helped me to cope. I worked with my midwife to reduce to a few feeds a day of my milk and add in formula for the shortfall. My plan was to give him whatever breast milk I could, for as long as I could.

As we know, plans do not always work out. Little W developed reflux and vomited my milk and got very sore. Through long weeks of trial and error we found that I could feed him directly (my measly 40 ml or so) followed immediately by a bottle of thickened formula, reducing the vomiting to spills and the gas pains greatly decreased. At seven weeks I was still managing to mix feed, with the miniscule supply I produced.

Due to the very different positions in my health and a lot more knowledge and confidence, I believe it was slightly easier the second time around. However, by 12 weeks my supply had completely dried up. I was really happy that I had been able to provide him with these vital nutrients for that long. I was also happy to not have to deal with expressing, feeding and bottles - it had begun to feel like my whole life revolved around his feeding. And at this time my life turned to revolving around his sleep, or lack of!

# Pumping

One thing that helped me both times was my breast-pump. I used the Unimom Hospital Grade Double Expressing Machine (not currently available in US or UK Amazon) for these two.

For a big guide on [pumping for your baby see this post!](#)

I also only used Avent bottles because I liked the teat shape (it mimics the breast-shape) and found that helped my boys to avoid nipple confusion. We introduced bottles of expressed milk very early, so please don't worry when people talk about waiting until breastfeeding is "fully established" - because of all the women I have heard of who have done this, they never got their baby to take a bottle. This may be alright for you, but for me, I needed that ability to leave someone else to do a feed.

## Baby Three (2019 update)

I have finally got a more successful story for you! After a much more comfortable pregnancy (even with severe pelvis issues that resulted in my being put off work at week 23 and on crutches and is still causing trouble at nine months postpartum) nursing was not such a kick in the pants. I had gotten my health into a much better place prior to pregnancy and reaped the rewards in pregnancy and nursing. This was due to low dose naltrexone and my ability to sleep in more than one hour blocks. You can find my [post here about LDN](#).

My doctor and I agreed I would stay on it because the potential risks were minimal and the benefit of my sleeping and managing my pain were astounding. That was a personal decision, made by reading the research, listening to other women's experiences and talking with my doctor.

We did have a bumpy start with the nursing. For three months we battled thrush and it was so distressing as in those early months every time I nursed I would have to stomp my feet and grit my teeth with the initial pain. I had to really push for people to take me seriously and realise it was not just me (or the fibromyalgia). So please do explore continued pain when breastfeeding. If I weren't so committed to my personal goal of three months (at that stage) I would definitely have given up in those early weeks. I also got mastitis. I felt suddenly worse and I thought the fibromyalgia was just catching up with me, thankfully I went to the doctor and realised I had a bad case and needed antibiotics immediately.

We got through all of this and at about four months I realised that there was no trepidation about having to feed him and no pain! We nursed exclusively until he started solids and were still going at 9.5 months (August 2019). I have no end date in mind. We will see how it goes.

## My tips for nursing with Fibromyalgia are what most nursing women are told:

- Try to **rest** as much as you can
- **Eat** as well as you can
- Drink lots of **water**
- Make yourself as **comfortable** as possible when you feed
- Know that **whatever you manage to give your baby is awesome** and that you cannot fail. You will be a great mama whether you feed physically, by expressed breast milk or by formula. A fed baby and a happy mama are both minimum requirements. **(Your wellbeing counts as much as baby's and don't let anyone tell you otherwise!)**
- **Advocate for yourself** - check out any pain (do not just chalk it up to the fibromyalgia - sure, it might be, but check it out)

I'd love to hear about your experiences with nursing with Fibromyalgia, if only so that others have something to read when they Google about it.

## Where to from here?

Thank you for reading this ebook!

My book [Pregnancy and Fibromyalgia is the most comprehensive guide to pregnancy with fibromyalgia I have ever come across.](#)

Come and join [Pregnancy and Chronic Pain, Fatigue, Fibromyalgia Facebook group](#) and join the community of support for women who are considering pregnancy, trying to conceive, pregnant or parenting.

## About the Author

**M**elissa Reynolds has lived with fibromyalgia for most of her life. When she became pregnant with her first child in 2013 she was so disappointed by the lack of information available about pregnancy and fibromyalgia – so she began creating her own resources. MelissavsFibromyalgia blog, [Pregnancy and Fibromyalgia book](#) and [Pregnancy and Fibromyalgia course](#) are the results of several years of personal research, experience and informal surveys.

Melissa is an author, coach, mindfulness practitioner and yoga teacher, she lives in Auckland, New Zealand, with her husband and three children.

