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*What I'd Start with
Upon Diagnosis*



First Steps

By Melissa Reynolds



Melissa Reynolds

First Steps: What I'd Start With Upon Diagnosis

When you are first diagnosed with a chronic illness such as Fibromyalgia or Chronic Fatigue Syndrome, your brain has rather a lot to process. If you're buried too deep in pain and fatigue, the enormity of the challenge may not hit you immediately.

You, like me, may have been diagnosed after a long battle in which you have learnt to push through and assimilate the challenges into your life. Potentially making yourself even worse. Or you may have been struck down, as if by a lightning bolt of pain and fatigue.

Here are a few key things that we need to do when we're diagnosed, or ready to process.

Research

You are your advocate, medical coordinator, cheerleader and guru. You need to guide your doctor. You need to track your progress. Get a book, or open a digital file and write it up. Keep articles that you come across. Because when you're ready you need to experiment. Your doctor can only take you so far. Be sure to get a referral to a rheumatologist, this doesn't seem to be a guaranteed thing where I live, but it seems important. After several years, I was finally referred to one. Unfortunately, mine didn't seem at all keen to deal with me and referred me on to the pain clinic, which wasn't all that much better. However, if you are at the beginning of your journey, you may find it helpful.

Experiment

There are many types of treatments, medicines, supplements, alternative treatments, physical treatments and diets. We all have different chemical make ups, different genetics, and different triggers. This means we need to find our lifestyle that

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gets us as pain free and awake as possible. The complexity of this is huge, especially when you take in the fact that synergies, mixtures of things may be the solution. Your body may need a mixture of medicines, supplements, physical work and mental work.

Hit Your Lifestyle

You can't keep going in the same way. That way didn't work. Try to journal it out or talk it out, or whatever you do to think things through. You need to rebuild your lifestyle. Find what works for you, what your passions are (the non-negotiables of your life), and go from there. I spent a long time dreaming of working slightly less hours so that I could rest more and try to recover.

Find Your People

If there's no one in real life, find a virtual community. You need to be exposed to new ideas and you need to be able to ask questions. There are many people struggling along with chronic illnesses sharing their journey. Just try to keep it positive. Most

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people would have brushes with depression/sadness when they're in daily pain and exhaustion.

Here's some slightly more involved steps to try:

Testing of vital nutrient levels

Hopefully, you don't have to ask for this, but check that all of the thyroid tests are optimal (not just TSH); thyroid issues have been a big help for some of those fighting our symptoms, and supplement any areas you are low in. There's no point supplementing blindly. Iron is a good one to keep an eye on – for years, I was told that my iron levels were “normal.” It wasn't until I began seeing my most recent general practitioner that I learnt that the range of ferritin is large and I was at the very bottom of it. We have aimed for 60 and only by iron injections (in the butt) have I managed to get to that level, but it made a huge difference in my energy levels. This is something I have to monitor constantly.

Acupuncture

Or whatever physical therapy offers you relief. Recently, I have learnt (after over a decade) that my neck pain is caused by myofascial pain syndrome: severe, recurring trigger points. So acupuncture needles in the trigger points in my neck and shoulders really help me. For others, massage is a real relief. Some swear by osteopathy and others chiropractic. You can learn to do a lot for yourself but a good treatment with a compassionate, knowledgeable practitioner is a blessing. My physiotherapist is the only person I tell most of my daily symptoms to, it's a gift to speak it out loud and have someone understand.

Prioritise Sleep

However you need to get it, do it. I have written several posts on this on my blog and have a chapter in this book on sleep. I really hope your doctor recognises the importance of sleep in the

body's ability to function. Look up the sleep chapter to see why it's so important and some things that may help.

Gentle exercise

Keep moving even when it seems near impossible. If stretching is all you can manage, do it. If you can walk down your hallway and back, do it. If you can do a series of yoga Sun Salutations, do it. Movement keeps the muscles moving and strong. It's much harder to bring the muscles back from atrophy than it is to keep using them. But don't for one second think I mean you should be launching into graded exercise therapy and pushing your way up to functional improvements to the detriment of your quality of life. See my chapter on gentle exercise for more information.

Start meditating

This is crucial to me as I cannot nap; I cannot fall asleep without amitriptyline. If you can nap and dislike meditation, then nap (sleep hygiene suggests only a 20 minute power nap between 23pm). It took me awhile to get into meditation; I had to learn to

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slow down and give over quiet reading time to true rest. But it's made a huge difference as I discuss in the chapter on meditation.

See food as fuel

There's a lot of conflicting advice about food. After much experimentation and research, I believe in eating nourishing whole foods, limiting processed food and only eliminating foods that are truly bad for you (MSG, etc.) and things you're intolerant to.

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Ready to Connect With Other Fibro Fighters?

What Works for Fibromyalgia Facebook Group

Fibro Mama Pregnancy and Fibromyalgia Group

Fibro Parenting Group

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Ready to Do Some Further Reading?

There are links to Goodreads, not sales links.

I have read the first three books two or three times each, at different times on my journey. Each time, I have taken something new from them. There is just too much information to take in at once, and we cannot fight everything all at once.

Here are some resources:

- [From Fatigued to Fantastic](#) by Dr Teitelbaum
- [The FibroManual](#) by Dr Ginevra Liptan
- [Suffered Long Enough](#) by Dr William Rawls
- [Take Back Your Life](#) by Tami Stackelhouse And

check out my own books:

- [Pregnancy and Fibromyalgia](#) by Melissa Reynolds
- [Melissa vs Fibromyalgia](#) by Melissa Reynolds

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An excerpt from *Melissa vs Fibromyalgia:
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About the Author

Melissa Reynolds has fought Fibromyalgia since she was 14 years old. Only, she didn't receive a name for her invisible opponent until she was in her 20s. Unfortunately, the name of the illness did not come with help.

After declaring war, she went from miserable and barely coping with life to thriving in seven years. Using a combination of research and personal trial and error, she has managed to bring her pain and fatigue levels down and minimise the effects of the debilitating brain fog by using everything she has written about on her [blog](#). She is the author of *Fibro Mama Pregnancy and Fibromyalgia* and *Melissa vs Fibromyalgia: My Journey Fighting Chronic Pain, Chronic Fatigue and Insomnia*.

Melissa lives in Auckland, New Zealand, with her husband, two children, and her dog, Coop.