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Introducing Melissa Reynolds 00:51

I'm part of a project with academic, clinical, and technical experts examining the puzzle of pain management and opioid use. While participating, I often see Melissa Reynolds's words in my mind's eye. She lives with, struggles with pain. She's so sensible about pain. I met Melissa Reynolds virtually. We've never chatted voice to voice, only asynchronously online. Melissa writes about Fibromyalgia, chronic pain, and pregnancy, separately and together. I read her faithfully and comment more than I do with most. She has inspired me from the start. Please allow me to share Melissa's wisdom with you here.

Health Hats: Good evening here in Boston and good morning in New Zealand, I'm speaking with Melissa Reynolds, who's known in cyberspace as Fibro Mama. Melissa, I think we met through the Chronic Illness Bloggers' Facebook page. You were looking for people to review your book. And this old white man agreed to review your book on Fibromyalgia and Pregnancy. This fellow has never been pregnant and doesn't have fibromyalgia. But I was taken with your book. And I've been following you ever since. I'm drawn to your no-nonsense and practical approach to pain. Things you've said resonate with me, I've stolen from you; nothing works for everyone; everything works for someone, and nothing works every time. You need many pain solutions in your toolbox. That's done it for me. I'm excited to be talking with you.

Health is fragile 03:14

Where were you when you first realized that health was fragile?

Melissa: Well, I'm not sure it was any one place, because it came on over many years. I don't think I realized until I was about 23 that it wasn't normal the way I was living. How hard it was. That's when I started to really fight my doctor for a diagnosis. So somewhere around then and I must have had some epiphany about it not being normal.

Health Hats: Before you had your issues, was there something that might have happened in your family or in your circle, your world where you were thinking about health and the tenuousness of health before it affected you or was it when something affected you?

Melissa: I was so young. I think it had to be from within before I realized. I knew that I had had pain for a long time. At my last semester of University, I got very sick with a bad bug. After that, I had extreme fatigue, and I realized that it wasn't right. It has taken until now; I'm slowly realizing all of the little things that contributed. So, the fact that I wasn't eating optimally, and I was very, very busy. I had a couple of jobs while at University. I helped out with my brothers at home because they are quite a lot younger than me and just the confluence of events. It didn't lead to best health. Yeah, so it's been an ongoing epiphany, I think.

What is *healthy*? 05:06

Health Hats: Now you're older, and you've been through what you've been through. What does it mean to be healthy?

Melissa: Given my context of growing up with chronic pain and fatigue, healthy is living the best you can within whatever your confines are and finding those key things that everybody should live by and following them as best you can. Those things like good sleep and good movement and good nutrition. And I think it's just treating that balance between your context and what it should be. You have to take your current context into account all the time.

I'm in a relationship with my clinician 05:53

Health Hats: I imagine that you and I could talk for several hours on the subject of pain. But what I want to do with this time that we have together is to pick your brain about the relationship between a person with chronic pain and their clinicians. And think about helping how people manage that relationship, so it's the best relationship possible. So, when I say clinicians, I'm thinking doctors, nurses, pharmacists, social workers, acupuncture, massage. People who have licenses as opposed to laypeople. So, what's been your experience managing those relationships?

Melissa: It hasn't been entirely positive for a great many years. For many years, I was ignored and treated like a hypochondriac or like my symptoms were made up. Actually, I was telling them classic Fibromyalgia symptoms. It took me a long time to gather any clinicians that I could trust. Most of my work has been done in isolation from them, which is a shame. Because it could have been so much faster. But even the clinicians I've touched base with since I have brought myself to this level of wellness have been disappointing, which really upsets me for everybody else. But the ones that I have had a good relationship with I'm so thankful for.

Health Hats: And what is a good relationship?

Melissa: It's that willingness to work with you. To believe you wholeheartedly and the willingness to say, "I'm not really sure what to do. But I'm really happy to figure this out with you." My current GP has good experience with fibromyalgia and chronic pain and good experience with alternative therapies. He never really had anything specific for me to try, but he was so supportive. I remember when I brought him my research about low dose Naltrexone. I brought him these reams of research and was prepared to talk him into it because I've done so much research. He was like, "sure, great, can I have a copy of this

research?" And he was so happy to have my research. That's just been how our relationship worked. When I was pregnant last year and had severe pelvis issues, I went to him. I said, "look, this is really really bad." He knew what my context was. So, he knew that when I'm telling him, it's bad, it's pretty bad and he put me off work immediately. I didn't have to fight or go through those awful processes I see women in my group having to go through just to get some recognition and support. So, that's kind of intangible. I don't know how a doctor would learn that sort of thing.

Health Hats: I have a neurologist with a rap, "I know about drugs and therapeutics for MS. But I don't know crap about you. My job is to learn about you and what's important to you." When I met this guy, I thought I had died and gone to heaven. When he moved away, I was devastated. I auditioned some neurologists and fired some when it didn't work out. I fired them and went on to try somebody else. You didn't go directly to the ideal GP?

Melissa: No

Health Hats: Was it hard for you at first to say, "forget it, he's got nothing, or she's got nothing. I've got to go somewhere else?" What was that process like for you?

Melissa: Again, it took a long time. I didn't realize that I had permission to do that. I thought the doctor was going to be the one that fixed me. And because the doctor had nothing, I just had to live like that. My first GP saw me on and off for years and years and years and didn't do anything. When I took her the article about fibromyalgia that someone had sent me, she checked the tender points. "Yes, fibromyalgia," and didn't do anything else. The only other thing I recall from her, was when I was saying "I have this idea that if I could reduce my work hours, I might create some space and feel a bit better." She always discouraged that. She said, "no, you'll just have less money but still be in that much pain. You'll be disappointed." She was so wrong. That was the best thing I ever did. When I made my big move, my big shift and started working less, I had a GP who wasn't dismissive. But again, she just didn't get it. I only left her because I moved and so I accidentally had to change doctors, and I knew that this doctor was not right because I went to her and I said, "look, I've got severe fatigue. I've got a little baby to look after. What on Earth can I do, and she said, "have more salt." That's when I changed GPs and found the one I've got.

Health Hats: If you're anything like I think, it's not just a GP that you see. There are other clinicians that you see whether they're medical people or not medical people. How have you built relationships with them or found them?

Melissa: It is a long process of trial and error, trying to figure it out. So. And that's the unfortunate thing, and that's why I share everything on my blog because I don't want it to be such a long, painful process for others. But I slowly learned what worked for me and what I needed. So, after many years of going to many different physical therapists, for example, I learned that I needed a specific type of treatment and I didn't actually learn until 2017 that it was my facial pain syndrome and trigger points. But there are these two trigger points right up in the base of my head that if they don't get treated, I get severe headaches and very sick and dizzy. I learned by accident what I needed. So, when I was auditioning new physiotherapists when we moved, I knew what I was asking for. When I would meet someone and they were resistant to me telling them what I needed, I knew that they weren't for me. I would call and I'd be like, "okay, I need to be really sure that what you're doing is not this." For example, have you ever heard

of dry needling? That intramuscular needling is what I need, but a lot of them jab it in. Or push it in and purposely jiggle it around for a spasm, which flares up your central nervous system, which I do not need. So, I would be very clear on the phone that this is not what I need. I need them to just put a needle in and leave it, gently. I need gentle treatments. Many people I called and checked. Then I'd go in and see them. That's not what they would do. But then I need a physiotherapist who was willing. She wasn't trained in that, but she was willing to give it a go. So, she was an acupuncturist. I said, "but I want you to put the needle into the trigger point." So, she learned about those trigger points and put them in for me, and that started to make a real difference. But when she left, a more experienced physiotherapist came, and so she was not only willing to do that, but that was already was her practice. We can do it together, what I needed her to do. For the last two years, I've been seeing her, and it's been just amazing. I tell her exactly what I need. Every time I go, we have like a Congress of what I've learned and what she's learned. It's been empowering and very exciting. But all that knowledge is hard-won and took a long time.

[Who can you coach? Doing the work? 14:44](#)

Health Hats: So, how do you advise people who are early on. I guess what I'm asking is what you already blog about and write about. But how can people proactively learn to be Captain of their own ship and manage their pain? It seems to me that some trial and error is part of learning, and you need to do that for yourself. But there's something about a supportive community that gives you the courage to try to speak up and try stuff, and not be satisfied. So, what have you learned as you're working with younger people? I don't know that I necessarily mean younger, but I mean newer in the journey. How do you advise? What do you recommend to them?

Melissa: It's really hard. Because if I'm coaching someone, I get the ability to talk to them and ask questions. Really dig into it. So, it's much harder when I'm just writing on my blog. The first thing you need to do is be really aware of where your pain is originating because you need to be aware of what is going on so that you can then figure out what might help it. For example, for fibromyalgia, they say there's no physical cause for the pain. You can't feel why there's pain or where there's pain and therefore treatments aren't supposed to help.

Whereas, in my facial pain syndrome, you have actual trigger points. You can feel them. The therapist can feel them. The therapist can see when you are having a spasm. So, it's quite a different ballgame. Actually, the one thing I love about the facial pain syndrome is it's a little bit easier to treat. You can know where you need to go for the pain. You know where it's originating, but you have to be aware of what your pain is; what is causing it. Then you can figure out what might treat it, but unfortunately, it's not as simple as saying, "Okay, well I have a trigger point. So this will work." Because the physical therapy and the physical treatments of your pain is just the tip of the iceberg. If you want anything to work, you've got to be working on perpetuating factors. You've got to be working on the central nervous system dysfunction. You've got to be sleeping. Nothing is going to help if you're not sleeping. So, unfortunately, there's no easy fix. It's really hard to tell people early on, "I'm so sorry, but there's a ginormous puzzle of things you have to do with each of those puzzle pieces.'

Health Hats: I appreciate what you're saying. In my language, I would say, "I want to love myself. I want to be at one with the pain. I want to explore it as much as I can. This is me. I'm good." Language is so inadequate sometimes to describe pain. Like you just said, whether there are triggers, whether there

are other factors... Very fortunate for me, one of the things that works more than anything is drink more water. I can't stand it how much that works: one out of four times, one out of three times. That's just so simple.

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Most important person on your team: You 18:58

I think that one of the things that's really hard... I don't know about the medical system in New Zealand. I don't know much about it, but there just isn't time to do that work with a licensed professional because they get paid by the unit whether it's the visit or the session or whatever. Solving a puzzle, which is what it is, takes more than the time there is. Was that an issue where you are as well?

Melissa: Yeah, I think even if they had time, I don't know if they would necessarily be able to do it anyway. I don't think they have the knowledge. Wherever your healthcare system is, you have to be in charge of utilizing your doctor and your professionals as well as possible. That's why I think the two most important people in your healthcare team are you and then potentially a coach or someone like that who can help you project manage the whole thing. Because it is a project.

Health Hats: In my language - I don't mean my language English versus whatever - I think about a care partner. For me, that's my wife. I agree that those are the two most important people in my health team: me and my care partner. Because when I feel like crap, I'm useless. When it comes to me in general, I'm way better with other people than I am with myself. Who else is on your team that isn't a professional? You have a coach. I have a care partner. I guess I have a bunch of coaches.

Melissa: Which isn't necessarily someone who calls themselves a coach, right? I don't have a coach for the fibromyalgia because I haven't met anyone more experienced than myself in this area, I need them to be experienced. So, I dabble with coaches in a different way. I've never actually had a care partner. I've needed that. I've been it. I've been my team the whole time. Sometimes, I sub in a consult with my GP or maybe a physiotherapist, I've tried a naturopath. That didn't go so well.

Health Hats: A naturopath?

Melissa: Yes, I've tried all sorts of things, but basically, I'm the project manager and I sub in people sometimes. But ultimately, it's all on me and always has been. That's why I trained to be a coach. I know that back at the beginning when I started to fight when I realized I wasn't that person for me. It took me several years to become that. If I could have had that several years ago, it would have been a much shorter fight. It would have saved me a lot of time and energy and vulnerability and just plain being miserable. That's what we need. I don't care what they're called. Whether it's a care partner or a doctor or counselor. Anybody who's trying to help you. Help you see that we've got lots of strands here. We've got to work through it. I'll keep you to keep going. But I think ultimately no matter who's on your team you've got to be the main person, the cheerleader. No one's more invested than you are.

Keeping track of what you've tried 22:55

Health Hats: Yeah, so we've been talking about relationships in this. What about data? How do you use information, whether it's your medical information or tracking stuff?

Melissa: So, in terms of tracking my health and my doctors: at first, it was all very accidental. I'd get blood reports, and I'd keep them and look back at them. Then, I started formulating my own kind of sheets to track my progress. Then I realized that they probably will be useful if I turn them into a bit more of a pretty version. And so, I have some of them free on my blog and some of them I sell in an Etsy store. It's just that you've got to watch the data and track it over time and notice how things change. Because there's so many strands and so many things to try and so many areas you have to keep an eye on it. You will have to write down a list of everything you've tried. Because when brain fog is an issue, you can't remember. I've tried right tons of things. I do not remember how they worked. But also, there's things I would like to retry now that I'm in a better position with my health because they might be able to actually work because more subtle things are helping now that I've made some real progress.

Health Hats: Like sleep?

Melissa: Yeah, sleep is humongous. I could talk to you for hours about sleep. Once you start sleeping, you can chip away at the more subtle things. It's amazing. I will go over way off course if I go there, but yeah, you do have to keep an eye on it. I've been watching the research for a long time. I've been reading a thousand things of the times you've just got to write it all down and keep track of it.

Health Hats: Do you do that on paper? Have you used spreadsheets? You said you sell something on Etsy and on your website. I will put your information on the show notes.

Melissa: I made templates. It got more formal as I had more energy. At first, I was just kind of wading in the water, and then I would start writing things down. As I had more ability, I was able to write things down. Then I started playing on the computer, and it became a little bit more formal, like the templates and things. But mostly I am a pen and paper type of person. I've tried all sorts of apps and things to track stuff. I'm not a big fan of that. Same with project management software. I just like a good checklist on a piece of paper.

Health Hats: Well, that's technology. I think I in our email exchange setting this up, I told you that one of the gigs I have is with people who are developing clinical decision support tools to help with the process. I'm underwhelmed. I call myself an informaticist. That means I'm familiar with how people electronic tools. I've been the project manager for several electronic health record implementations. I download, I'm going to say hundreds, but I'm probably exaggerating, tens of apps to try them out. I'm with you. I have a spreadsheet, an Excel spreadsheet. That's the best thing. But I don't keep track of what hasn't worked. I do keep track of books I already read because I'll forget and start reading them again. I realized that I have to keep a list. But oddly enough I don't do that for symptom management, which seems kind of nuts now that I'm talking to you.

[You can make a difference for yourself 27:31](#)

What should I be asking you that I'm not?

Melissa: In terms of keeping track of things?

Health Hats: In terms of your odyssey of managing your pain. I don't want to talk for two more hours, even though I'd love it. My wife's going to be home soon, and I want to make dinner. If there were a couple of points that you thought ought to be in the podcast for people who care. What do you think?

Melissa: Well, if there's one thing I'm ever allowed to tell people it's that you can make a difference and you can improve your life. And it's going to be through knowledge. You're going to have to inform yourself, and you're going to have to do some work. So, it's within your hands. It broke my heart when I did a poll and asked people if they had ever tried anything other than the medicines their doctor gave them. More hadn't than had. These people didn't even know simple things like using their heat pack or having an Epsom salt bath. All they had was this medicine their doctors gave them. It breaks my heart because what happens then when they're pregnant? The doctor said, "okay, you're not allowed that anymore. You're going to have nothing," and then they take them off it and then wonder why they were struggling. But you have the power if you've made decisions and done your research when you're in a better position to make those choices for yourself. Because I always say that the cost versus benefit scenario, especially when you're pregnant, as well with medicine - you have to be part of that equation. Your quality of life counts.

Health Hats: Your quality of life depends on it.

Melissa: Yes, your quality of life. You're not a martyr, and you deserve to control your symptoms, whatever the situation. Sometimes you might make a decision you're comfortable with, and that means you're living with more pain for a temporary time and that's fine. But if you've made that decision with knowledge and you're aware, and then you have also put in the other things in place. If you've gone through and worked on your natural pain relief mechanisms, for example, you will have made this such a difference to your quality of life because that power is crucial. Knowing that you have control changes the way you think of things. If you're sitting there thinking that things are being done to you and you can't do anything, it just is not going to help you. I believe it sinks into a bad cycle.

How do you define and measure success? 30:34

Health Hats: This neurologist that I loved - one of the things that he said was, "I need to know what's important to you." So, I went home and had a conversation with my family. Thinking about it, it was some pretty basic stuff: I want to progress as slowly as possible. I don't want to mess with my pathological optimism. I want to keep playing the saxophone. So, he said, "well, I can work with that." So, when we were exploring treatment options, he would say, or I would say to him, "Is that going to affect my pathological optimism?" He said, "well, it might," and I said, "then I want to try something else." He says, "I don't know that much about it. But if you come to me with something, we can do it." I think with what you're saying is, the feeling like I'm in control, this is okay. I can handle this. Now, this other, I can't handle, but this I can. I think that the control piece is important. I think what I hear from you is knowledge, experimentation, keep track of it.

Melissa: It's your choice what you're working towards. Whether you're working towards better functionality or symptom management. However, that balance; that's up to you. A lot of the research for a long time was all about functionality. People wanted you to be able to walk a certain distance. They didn't care if your pain was less. I fired a physio because he said to me that he had someone walking for an hour every day by the end of the year, but his back pain level hadn't changed. The physio decided that it was a success. And I said, "no." I do not subscribe to that. Does that person consider it a success? There's no need for him to walk an hour each day. For cardiovascular health is 30 minutes, that's enough. So why force him to walk an hour when his back pain is not changing. How do you define and measure success? So, I think it's up to us whether we are looking for what that ratio is? What that looks

like for us symptom level versus functionality? I think that's cool that you and your neurologist had that frame of mind. He's a good one.

Health Hats: Yes. I'm very fortunate. I have a really good team. I have a physical therapist who over ten years, I've probably seen her ten times. She specializes in Parkinson's and MS. After giving me an initial program, I don't need somebody. I can do my own program. But when I progressed, and I was falling more or whatever, I would go back to her and get a tune-up - review the program. I went from one cane to two canes. Now I use an electric wheelchair some of the time when I'm traveling. So, I've only seen her not that often, but she's a critical person. I know it's progressive and I'm going to need her again. Knowing that somebody understands you.

[You have to believe in yourself 34:23](#)

I wasn't going to ask you this, but I'm going to ask it anyway. I'm considering doing my next series of podcasts is what you're talking about - being the captain of your own ship. I'm appalled at how unready people are for that. Do you know what I mean? I don't work directly with people who are sick anymore. But I work with the people who help people who are sick. It is frightening to me how unprepared people are to be the captain of their own ship, the ship being their health. What's your experience with that? Is that part of the work that you, helping people get become ready?

Melissa: My aim through everything I write is for people to see what can happen when you take control. Basically, I give as many tips and tricks and things as possible. But all of the things I suggest, they have to do the work. Whether it is going to see a specific doctor, whether it is researching an option, drinking more water or stretching or going for a walk. It is things they have to do, and I try to make it clear that they do have to start doing the work. But I will not take the work to the next level. I won't work with a client who doesn't already fully believe that they have that power to change their quality of life and who hasn't already started. So, if they don't have a list of things that they have already tried. If they don't talk in those kinds of proactive terms, I can't work with them. They're not going to get the benefit. I can't. If someone is just going to listen and say, "oh yeah, that sounds good, that sounds good," but not do anything. Then they're not going to make any progress. That's just a waste of everybody's time and energy. I just want people to know that they can be proactive,

Health Hats: I have two thoughts. One is that I feel for doctors in some ways. I thought a lot when I was a practicing nurse. Those people who aren't taking charge, they're there. It's our job to take care of them. I agree that it's a two-way street and there's a clear role for everybody. The other thing is that this physical therapist I was telling you about. She told me a few years ago that she thinks (I might have these numbers wrong, but they're in the ballpark) that a third of the people she treats does anything she recommends after she recommends it. And I'm the only person after ten years is still doing what she recommended. I think that that is disheartening to hear.

Melissa: That's not us. I didn't realize it. I think I've been quite insulated because I'm only in very proactive groups like on Facebook. I only talk with the type of people I talked with. I didn't realize that the people I deal with and are proactively seeking solutions and helping themselves. I didn't realize we were a small proportion. I didn't realize how many people don't try anything.

Health Hats: It just makes me want to cry. That's a lot of needless suffering.

Melissa: I know right? Yes. It's upsetting because they stopped. You can't bemoan the doctor, but you've got to do it. The doctor can't do that work for you. So, it's always going to come to you. Whether you take the recommendation of your doctor or the recommendation of someone else, will you find it yourself? You've got to do the work, and you've got to realize that something is going on in your body and it's just not going to magically get better.

Health Hats: It's lovely talking to you. I'm delighted that I'm actually seeing you and not just that photo of you. I am going to email you and make sure I have the right information to put in the show notes so people can find your good work. Thank you for inspiring me.

Thank you. Yeah, so have a good one. You as well. Thank you so much. Bye.

Reflections 39:51

Fibromyalgia is an invisible illness. We all vary greatly in revealing the inside of our bodies and our minds, even to ourselves. We all have invisible selves. Many have invisible illnesses. Most of us (what goes on inside) is invisible to others. Most of us is visible to some if we're lucky and safe and **do the work**. "Do the work" as Melissa talks about, niggles at my mind. I want to respect people that don't do the work or don't know there's work to be done? I want there to be solutions for everyone – that's equity? Solutions to manage pain, to improve function, to nudge us towards best health. My goodness, but we're all so different. Not only is there **no one size fits all**, but there may also be many potential solutions for everyone. So, who's the audience here? A small proportion that needs to do the work and be captain, CEO of their health – there's no other way for them! Like Melissa and me and maybe you. Some who want to do the work – but maybe don't know how to do the work. They need a map, a guide, a coach, a partner. Then there's the largest percentage that doesn't know that they **can** do the work and be captain of their own ship. For the "don't know" group, we could plant a seed that might germinate under the right alignment.

Melissa can't work with people who aren't doing the work. That makes sense for her. Her kind of coaching is intimate. She opens her heart. It can be exhausting. I've been molding a new series for this podcast. How can you serve the "must," the "don't know how," the "don't know yet" audiences? How can we support them in the journey together toward best health? No matter their age, genetics, social circumstances, physical environment, medical condition...? Goodness, I feel like I'm a bit stoned saying this?! But I'm on to something.