



## Practical tools for living with chronic illness

**Guest: Sarah Ramey**

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**Alex Howard - [00:00:15]**

Welcome, everyone, to this session where I'm really happy to be talking with Sarah Ramey. Firstly, Sarah, welcome and thank you for joining me.

**Sarah Ramey**

Thank you so much for having me. I'm excited.

**Alex Howard**

So we're going to get into some struggles here that I think a lot of people with fatigue related conditions struggle with. They are often the things that people don't talk about, things like endless suggestions from friends and family. Have you tried this? Have you done that? To go into doctors and then simply not understanding even not believing your experience. I think all of this can leave people feeling frustrated, isolated. So I'm really happy we're going to be getting into this.

Just to give people a bit of Sarah's background. Sarah is a writer and musician known as Wolf Larsen. She graduated from Bowdoin College, received an MFA from Columbia University and has worked for President Obama. She is a recipient of a Whiting grant and has been featured in The Paris Review, Ms. Magazine, Salon, The Atlantic, The Washington Post and The Washingtonian. Her book, '*The Lady's Handbook for Her Mysterious Illness*', was a starred selection for Publishers Weekly, Curtis reviews, and Booklist and was chosen as one of the best books of 2020 by BookPage.

Sarah has been living with severe, serious chronic pain and illness for 17 years. So, Sarah, maybe we should start there. Tell us a little bit about your journey, your story, with chronic illness.

**Sarah Ramey**

Yeah. So this is always like the hardest part for me, because it's a long story and I don't want to tell it and nobody wants to hear it.

**Alex Howard**

We want to hear it but I understand.

**Sarah Ramey**

Basically, in a nutshell, I guess 18, it's 18 years now, I was in my senior year of college and I was perfectly fine, very healthy. And I had, sort of in a nutshell, I had a surgical procedure, it was a urologic procedure that went wrong. It was like a botched urologic procedure that I became septic afterwards and I developed very, very, very severe pelvic pain.

And then after that, you know that was sort of this big incident but nobody was thinking of it as the triggering incident. It was just an incident. It was a bad thing that happened. And I was hospitalized. And we didn't know at the time that the procedure had been botched, we just knew that I had become septic afterwards and nobody really knew why. But we just figured that I was 22 or 21. And then I just, I lived. I didn't die. And so I was going to just bounce back and everything would be fine.

And it was the opposite of that. And this is so common for people with ME/CFS or any fatiguing problems that, sometimes it slowly creeps up on you, that's true for a lot of people, and other people it's like a big wrecking ball comes in, whether it's a car accident, or COVID-19, or a virus or whatever it is. There's a lot of different triggering things for...

**Alex Howard - [00:03:28]**

But it's a very clear event that triggers.

**Sarah Ramey**

Yes. And this was that. This was, it was probably not the, well, who knows, whether it's the combination of... The thing that happened was very painful, whether it was that or it was the sepsis like because that's incredibly traumatizing to the system.

So regardless, I go back to college, they sent me back with a PICC line, which is like an I.V. that you carry around with you of antibiotics. And I did not bounce back. I didn't get better. And I started getting worse. I was sleeping constantly. My muscles ached constantly. My digestion just went out the window, my colon stopped functioning properly. It was just like I went from being, it really was the definition of day and night. It was like being absolutely fine to suddenly so many problems, not just like one problem.

**Alex Howard**

But often you have a cascade of problems, right, that something knocks something else out of balance and so on.

**Sarah Ramey**

Yeah, exactly. But we did not know that at the time. And so, and my parents are actually physicians. And so, at the time it was very clear that something was wrong and that I needed to get to the bottom of it. And so I went to a million top shelf, best doctors in the country to try to figure out what's going on, because it was obvious that something was really wrong, because I've been so fine before and then so not fine afterwards. But as they, and this is also very common, as they ran all the tests and they all came back normal, negative, normal, a new sort of diagnosis started to emerge, which was that, well, maybe I wasn't sick at all. Maybe I was just depressed and that I just needed to go on antidepressants.

**Alex Howard**

And it's that weird thing that you're praying for a test result to come back with something wrong, right? It's a really hard experience.

**Sarah Ramey**

It is and it's like, but it's something I think about all the time. Like having a diagnosis is such a privilege, having no idea what's wrong with you and having all of the people that you have probably grown up with, like trusting the most, like your physicians, not being able to sort you out is very destabilizing and scary and disorienting, like it really, it's hard to describe unless you've been through it. It really, because it's just, the way I sometimes describe it is, it's like calling the fire department and they're like, no, we're not helping.

**Alex Howard - [00:05:57]**

Your house is on fire and they're like there's no fire. It's really hot in here right now.

**Sarah Ramey**

It's really bad, you have to come and they're like, no I don't buy it. Hang up. It's really scary to have your health go up in flames and to have the firefighters say either I don't know how to help you or I'm just not going to help you because I don't believe that your house is on fire.

And so that's kind of what, so the first phase, we're really trying to figure it out and they couldn't figure anything out. So then it went into the next phase, which was, you must be depressed or malingering or something like that, prescribed all kinds of antidepressants and anti-anxiety medications, things like that, which made things much, much worse.

Sometimes, I'm not anti antidepressant, sometimes those can really help people. It's just in my case, they really did not. It made things way, way worse and I became very suicidal. Just all the stuff that was, it was horrible. And at the same time I was getting much sicker. And this is over the course of several years.

**Alex Howard**

And I think that's scary when you see a constant decline and you go, well, where does this end? What's the bottom point of this?

**Sarah Ramey**

Yeah, and how can I not be getting better? And they don't know, it's one thing to have a diagnosis, but, well, this is just what happens for this. And you can pull in support and people understand and they can be with you on your decline, but when you don't know why, it's very difficult. We'll talk about this later, but it is quite difficult to get support from the people that you need if your house is burning down.

Yeah, and so I declined for quite a while and went to a million doctors and then I ended up defecting into alternative medicine. At a certain point I was like, this is not just not helping, but I think it's harmful to me being told that nothing is wrong when it obviously is wrong. I was in a horrific amount of pain. I couldn't wear pants, couldn't keep up with any of my friends. I wasn't, at that point, bedridden yet, that would come later, but like was really limited with my energy and my digestion didn't work and my muscles ached all the time. I was sick.

And so, being told that I wasn't sick was, I finally just sort of woke up and I was like, wait a second, this is bad.

**Alex Howard**

But there's something about honoring the lived experience in your body over the opinions of people that are not living with that feedback. And I always think that your body knows more than the doctors. The doctors might have a theoretical understanding, but if that doesn't meet your lived experience, your body's right, they're wrong?

**Sarah Ramey**

Yes. That is 100 percent correct. And, of course, like they do exist in the world, you know, malingerers or hypochondriacs. But those are the rare exception. It's not like that, because I can understand whatever if you've never seen this in your life as a doctor and you just get this one free patient, that is this way. I can sort of understand coming to that conclusion. But I know and you know, there are so many of us.

And so to have this many patients that are telling the same story that I'm telling, I'm sure that you

have told doctors, to see that many patients and just decide that they're all making it up and that there's some secret society that we've all gotten together to be like...

**Alex Howard - [00:09:26]**

I mean, if you're going to make something up, there's better stuff to make up as well right? Actually society gives you some care and love as opposed to the realm of rejection and judgment.

**Sarah Ramey**

Right. I would make up something that had great palliative care and was covered by insurance, and my family and my friends are really nice to me, and I was able to go out on disability. That's what you would make up, not is.

Anyway. So that's why I defected into alternative medicine because at the very least, the floor is a lot higher in terms of at least they usually believe you, they want to try and help you, they want to care for you. And this matters. I mean, just in terms of at least putting a stop to the, what I feel is like psychological torment of being told that you're not sick when you are. That just to me is like deeply unethical. Like, that should stop. There shouldn't be a debate about that, but there is of course.

Anyway, so I got into alternative medicine and I did a bunch of things that are the standard things, like I changed my diet and I did yoga and I got into meditation, I did acupuncture, that kind of stuff. And that really kind of stabilized me for a while. I didn't get better, but I wasn't declining anymore and that felt better. And then, kind of the long and short of it is, but that didn't last forever. I had a huge collapse in 2013 and was at the farthest end of the ME/CFS spectrum. And it was like, I had to be fed broth and bathed by my mom for two years. I mean, it's just horrific. And then have gotten treatment like through functional medicine and low dose naltrexone and a bunch of different things that helped me at least get out of the pit of the upside down. It's like where it's just so bad. It's not even, I think, understandable to most people, like how you can be that sick and still not getting medical care. It's just, it's bad.

And so I'm out of that now. But I still have something called complex regional pain syndrome, which is very painful pain syndrome and ME/CFS. It's not as bad as the bad place, but it's still very limiting. And then other things like POTS and MCAS and those are, like most people like me, we have a whole bunch of acronyms.

**Alex Howard**

So particularly in that darkest place, that couple of years where your mom was having to sort of, effectively be your carer. How do you find meaning? You know, there will people watching this or listening to this that are in similar levels of severity, let's say. And each day can feel like a mountain one has to climb. How do people, what helped you in terms of finding meaning in those really difficult places?

**Sarah Ramey**

Yeah, so a couple of things. The first thing I just want to acknowledge is that it is, that is a terror, it is really bad. And it is not something that you can kind of paint with pastel paint.

**Alex Howard**

Make it look all pretty and nice.

**Sarah Ramey**

Think about it in the right way, like it's actually a gift. No, it's not. But that said, I think still trying to claw some meaning back actually is, for me it was vitally important. And so for me, the main thing was, normally the things you need when you're sick, medical care, of

course. But, you know, we'll put that to the side in this case because that's so hard to find for these illnesses. Connection to the other people for me is the most important thing. And when you're bedridden and you can't open your blinds because the light makes the illness worse and all this stuff, it's very difficult to connect to people and it's very easy to just kind of let all of it go to just fall away from everyone and have no connection whatsoever.

And I did that for a while. And then, I was suffering so badly because I was so isolated and I hadn't seen anyone but my mom in over a year, it's just crazy. And so, I reached out to some friends. I actually, I reached out to one friend and said, I can't do this, but I need you to reach out to some friends and pull in like a support group for me that is on Facebook so we can kind of have a group together and I can't do anything, you guys have to be the support, whether it's like cat videos.

**Alex Howard - [00:14:21]**

There really is a place for cat videos in life, right?

**Sarah Ramey**

Yes. Yes. This is good. I'm a cat person.

Even the smallest things to have, it was very embarrassing to be like, I need you guys to focus on me, because I'm the person that is always like, I can do it, I'll do it myself. I can do anything by myself. And I just realized that if I kept being that way, that I was going to have, I really was going to have some very severe psychological problems just because I had no connection to people anymore, and so I kind of had to humble myself and reach out to these people and to ask them to do anything that they could think of to keep reaching out to me over a long period of time, even if I couldn't even really reach back very much because I didn't have the strength to even take messages or anything, that they were still there really meant a lot to me.

And it's one of the things that I feel so grateful that I did that, that I sort of had that conversation with myself and was like, you have got to suck it up and ask for help from these people.

**Alex Howard**

Thanks a lot of courage, particularly in such a difficult place.

**Sarah Ramey**

Yeah. Especially when there's no, I still didn't really know what was wrong or have a good diagnosis to give people. I'm now much more comfortable with the diagnosis of ME/CFS, but at the time I still felt that that was so stigmatized that I didn't want to say that to people because I felt it would push them away even more. I don't do that now because that just reaffirms the stigma, I've been much more clear about activism with my friends around. Like this is a real diagnosis. Here's what you need to know about it. Here's what the CDC says, etc. But at the time, I didn't have the energy for that.

**Alex Howard**

There's something about what you're saying around finding meaning through connection that even when you're so limited in what you can do, there is still that place that you can have connection, which gives some sense of, joy might be the wrong word, but some sense of purpose in the midst of that hell.

**Sarah Ramey**

Yeah. So that it's not just like unabated suffering. There's some sort of glimmers of light and connection from your friends. I just think it's important because you take it for granted when you're healthier, that those connections, they're just kind of there. Even if you could do more, when you have been so cut off by this illness, you really do have to be a lot more conscious about that. And I think be

willing to ask somebody else to help organize that for you, because that's really common. A really good friend of mine has breast cancer right now. She's not organizing her support group. Her sister is. And that person has brought us all together to support her and that should exist for these illnesses. There's no difference.

But a lot of times, friends and family don't know that you need that and you kind of need to say that to them and be willing to speak up for what your needs are and to know what you would like. I've had people say to me, oh it would be such a dream if my friends wrote letters to me that would make my life but I can't ask for that. I'm like, why can't you ask for that? Just ask, just do it. And some people won't but you're strong enough don't let get in the way of asking for the easiest thing, which is somebody to write you a letter, like that is such a, if somebody asked me that I would be so excited.

### **Alex Howard - [00:18:03]**

But I think often also friends feel powerless and to actually have something they can practically do to help is often a gift to them as well.

### **Sarah Ramey**

Yeah, exactly.

We also, one thing that we did, which is much easier now because of COVID, we did a lot of group movie watching like we would do, now there's like ways to actually do that and all be on the same chat and everything, but that was really helpful to me to feel like I was doing something even though I was just still lying there and was just passively taking it in. My friends were there, I was listening to their jokes about this bad movie that we were watching, it mattered.

And so that connection to me was really, really, really important. There are other things that I did to try to change my mindset around the meaning of what was happening to me. But I have to say that establishing these thin filaments of connection back to the outside world is actually the thing that was the most important to make me feel like there was worth left in my life, because that can really feel like there isn't any reason for you to be alive in those really, really dark moments where you're basically unable to move. So that for me was the most important thing.

### **Alex Howard**

And I know that you talk about the heroine's journey. Say a bit about that and also how it's different to the hero's journey, that Joseph Campbell sort of modeled that we're perhaps a bit more familiar with.

### **Sarah Ramey**

Yeah. So, in terms of like a theoretical framework for thinking about meaning, was the most important thing that I did. And so I was writing this book about mystery illness, I was writing ' *The Lady's Handbook for Her Mysterious Illness* ', but I had to, I had written like a whole, I wrote two full manuscripts that I had chucked.

### **Alex Howard**

No perfectionist here.

### **Sarah Ramey**

Yeah. Yes. But they were bad. They were just, I couldn't understand why they felt wrong to me. And when I became so sick in 2013, I was thinking through, because I was like, well, that manuscript is not going to work because, and I was trying to think through why. And I was thinking about how I had kind of modeled sort of the narrative arc on the hero's journey, which is, I love Joseph Campbell and I love thinking about well how do stories actually work? Because they don't just come out of nowhere. There's often a structure that is really resonant for people across cultures, that's what the hero's

journey is. It's like he went through all these different cultures and was like, actually, if you look at this story from this culture, and this story from this culture that are completely different, the structure of that story is actually exactly the same. And you see it in like every Harry Potter or Lord of the Rings or any superhero story. It's all the same origin story and arc.

And I was thinking about that and about why that wasn't working for me. And it became really obvious. It was because I couldn't complete the journey. I could not slay the dragon, I could not win. There is no way to win because the harder that I tried, and I did so much stuff to try to get better, I mean, like the most aggressive health seeker you've ever met of just trying to do anything. I tried everything in return for a steady decline in my health.

And I was like this story that I've been telling about myself, I am a failure of this story and this is why it feels so bad. And so, I was just lying in bed, this is for months and months, and so I was trying to, I just had a lot of time to think, and so I was like, well, maybe there's another story but I don't know what it is. And I thought about that for a long time. And then just one day I was like, I wonder if there's a heroine's journey? And so I just Google it and it comes up and there's like a bunch of books, but there's this one called 'The Heroine's Journey', and I get it and I read it and I literally underlined every single line.

### **Alex Howard - [00:22:14]**

I love it when that happens. Basically the whole book.

### **Sarah Ramey**

Yeah. So I was like, let's just bold and underline the whole thing. And so, what 'The Heroine's Journey' is, is instead of it being this difficult but grand journey there and back to slay the dragon and save the world, it's basically the inverse of this. It is the journey into hell. And it is the story of Persephone and the story of Inanna. And there's all these, just as the hero's journey, there's basically this story of the descent into hell exists in all cultures.

And so start reading about this, I was like, the journey into hell, that's me.

### **Alex Howard**

That's my story.

### **Sarah Ramey**

But of course, it's not enough, like it's not enough for it to just be like, oh, I'm in hell and this story is in hell. The actual story is of Persephone, she gets abducted into hell, it's against her will. It's not her fault. And, I won't go into the whole mythological structure of it, but basically, in the end, she eats some food from the underworld and this means that she's released to the upper world and gets to come back to the upper world and it comes back to life. She's the goddess of spring, because what happened when she got abducted is her mother killed all the crops in the upper world. And this is why Zeus brokers a deal with Hades to bring her back to the upper world so that winter can be over and the crops can come back.

But then she becomes this cyclical goddess where she is in the upper world part of the time and in the underworld part of the time. But she also becomes a guide for other souls as they descend into the underworld when they have died. And then there's this sort of journey through hell where they basically have to sort through are they ready to go on to heaven? Do they have to return to the upper world to do more work? But basically it's this journey into the darkness and she becomes their guide.

And it's the same thing you see in the Inferno where Dante descends into hell but he has a guide, Virgil and then Beatrice. And this is a concept you see in so many different stories. And it is exactly the same thing that I see in the journey of, like everybody in your summon that has been abducted into hell, but then goes on this sort of quest of learning.

And the way that the heroine's journey is constructed is there's the descent. There is the descent and then there's this search and then there's the return. And this is something that you see, and this happens over and over and over again. And this is something that you see a lot of in the chronic illness world is there's the descent into hell. But then you end up, over time, learning an enormous amount and usually in repeated cycles through the underworld, kind of over and over.

And what so frequently happens is that when people get better, and even if they don't, even if they get somewhat better, they start to become the guide through how to help, like you. Like start to help other people make their way through the darkness because the gift that they have now is not like fighting and slaying dragons, it's knowledge, and it's also being able to see in the dark, which is a skill. It's very scary when this has first happened to you, you can't see in the dark and everything feels upside down and crazy.

The other more westernized version of the same story is Alice in Wonderland. Down the rabbit hole.

### **Alex Howard - [00:26:19]**

But it strikes me, sorry to interrupt you, but the hero's journey can be a bit of a, 'look at me what I achieved. I am the hero'. Whereas what you're describing here in the heroine's journey sounds more empowering in a sense. It's like I've been on this journey too, here's what I learnt, I wonder if that can help you. There's something about it which feels more helpful in some way.

### **Sarah Ramey**

Yeah, well, I think it's really, it's the archetype of the healer. And like that is the other big story. It's not just like one narrow story. It's like, there's the grand story of the hero is like an important story, I think especially in days gone past where there was a lot more war and conflicts and things like that. But the other side of that is like, it's interesting. So if you think of like a soldier where their story is the hero's journey, that's often applied to that type of life.

But when a soldier has PTSD, they switch stories and it becomes this descent into the underworld where all of a sudden they can't overcome this problem that they're faced with. It's this thing that they actually have to learn to work with and to have all of this internal work and be in the darkness and not be able to just triumph and succeed and kill the darkness.

That's one of the main differences, is the darkness is not like this thing that you can just eradicate, which I really think modern medicine is wrongfully constructed around this idea of like, well, we just have to find the bug or find the gene and then destroy it or give you the medication that fixes everything. Instead of being like, going into, what I think of as the descent into the underworld is the descent into the root system and the descent into where things are unwell, that you have to go down and look at the roots.

Like so much of the medical help that helps people like us always talks about how it's like root cause medicine and it actually goes down into what is actually going on here? And it's usually not just one singular thing. It's something that you really have to look at the ecology like what is happening down here that is complex and difficult? And it's going to take many cycles to sort through and look at. And it's not just this miracle pill.

### **Alex Howard**

And it's not the sort of binary cured or not cured. It's an unfolding journey in a sense.

### **Sarah Ramey**

And there's a spectrum of, you know. Yeah, exactly. It's not binary, it's a lot more complex. And so anyway, reading about that for me was like so relieving because I was like, I'm not a failure. I am a queen of the dead. And that felt really important to me. It sounds a little silly when you say it out loud like that. But to have a narrative, I think that we underestimate how much we're actually telling

ourselves stories in the back of our minds and if you're telling yourself the wrong story, that you're just failing out all the time. I think that that can be quite damaging. And that was happening with me.

And so to realize that, well, I'm just sort of in this like, very garden-variety, like healer mode where I'm not going to know everything, but I have learned a lot and I'm going to be able to share that with people and help people some. And that's enough. That's enough. And you don't have to save all the people that have ever been sick with this disease, which is like, that had been my framework was like, I'm going to figure this out. I'm going to completely solve it. And that obviously doesn't work.

### **Alex Howard - [00:30:16]**

I really like that model, I think. And I think it's much more fitting for a lot of people's experience.

Something else I want to talk to you about that I think a lot of people struggle with is when someone is suffering from a chronic illness, people around them read articles, hear things on the radio and through the best of intentions of wanting to help, you end up with this endless list of recommendations. It can be really frustrating for people. How did you find that and what helped you navigate through that?

### **Sarah Ramey**

Yeah. So I think, number one, you have to have a friend that you can vent with a little bit when that happens, before you set up boundaries with people, which I'll talk about in a second. I think it's very important to have like one other chronically ill friend where you can just feel like ugh. I can just share the you know, when somebody does, because it happens a lot it happens to me a lot because I wrote this book and everybody is like, oh, an illness. Let me pop into your DMs and tell you what you should do.

I do think you have to be able to kind of let it go. Part of it is just being able to just be like, I don't have to do that, this is a stranger or a person that doesn't know anything about me, because it does get to you. I mean, it really gets to me. It hurts my feelings. Like when a friend or somebody like that is like, oh, have you tried crystals?

### **Alex Howard**

Because I think also what happens is people often feel, as a result, they feel unseen because they feel like that person is projecting onto them. And apart from the fact it can be irritating, it's a sense of can you not see how much I've already put into this? And there's something about that that I think hurts as well.

### **Sarah Ramey**

Yes, that is exactly correct. And so I do think it's important to at least sort of attempt to not be so attached to that feeling. It's hard, but I think that that's part of it. But I think more important for me has been, I wrote up basically like, care and feeding of Sarah Ramey, for friends and family. That was like, here is what I need you to know, here are all the things. Here's what's going on with me. I have these syndromes. Here's what it feels like in my body. I need you to know that I have tried whatever has popped into your mind that you're thinking about suggesting to me, I guarantee you that I have tried it or I know enough about it, that it's, I'm not going to do it.

And please don't, unless it is... So the way I usually say it is, because I don't want to say don't ever make a suggestion to me because, you know, maybe somebody has something that could be really helpful. What I always say is. Number 1, stop and think before you fire off your suggestion, please consider not doing that, number 1. Number 2, if you are going to suggest to me you need to do the work to tell me, here's how you would access it, here's how expensive it is, if you need funds, maybe I can donate to help you. Because you have to understand that you're telling somebody to go spend a ton of their own money, you know.

**Alex Howard - [00:33:35] .**

And then you're judging them when they don't.

**Sarah Ramey**

Yeah, exactly. That's why I say to people, I'm like, if you want me to do that, did you want to contribute to my GoFundMe to support that? Which usually repels suggestions. And they don't want to suggest it any more. But I just say it's OK if you really, really, really want to make this suggestion, but I need you to understand that if you're going to make it to me, I want you to say it in the following way. I want you to say, I know this is really irritating. I know that this must be adding to an enormous pile that you're dealing with. But it's so important to me, this seems so important that I really want to share it. And if you don't want to do it or can't do it, no problem.

So I've done several letters to friends and family and posts on social media that basically say that. In terms of how to deal with people's suggestions, as I really am clear about, pretty much don't suggest anything unless you really feel passionate about it. And if you're going to do that, I request that you do it in this way that is with some humility that you're not just like dumping it in my lap, that you say that you're dumping it in my lap.

**Alex Howard**

I really like the fact that you're describing, taking the time to educate people, because I think part of the breakdown here is people are well-intentioned and we end up angry and frustrated and pissed off. And actually taking the time to say this is why it feels this way. It's almost like what one would do in good marriage counseling. It's like express how you feel and why you feel that way, ask for what you want and what you need. As opposed to just being in victim of being frustrated. I think it's a really practical, helpful way of approaching it.

**Sarah Ramey**

Yes. And that dovetails with, like just generally one of the most important things that I've done, and you kind of have to do this every few years if you're sick for a long period time, is to write a letter to your friends and family that says, here's what's wrong, here's what I've been trying and here's the support that would be helpful. Here's what I really need and I really appreciate you still being there for me even as this drags on forever.

And that is, I will say if you're too sick to do that, I have been in that place and I didn't reach out except to bring in my friends and that Facebook group. But I think it's really worthwhile asking a friend to do that for you if you're too sick to do it yourself, to just ask somebody to do it. They would do it. I would do it. If you needed me to do it, I would do it for you. And I think there's a lot of people that way.

Because I think, what can happen is you get too defeated, you stay either a victim or you're just too sick and you don't reach out and then people don't know how to help you and then they don't because they're busy and they're going on with their lives. And they don't actually realize how sick you are or how difficult it is in this prison that you're in. And there's no way for them to know unless you build that bridge out to them in some way. They don't have a way to get to you and they don't even know that they are supposed to. And that sucks. Like even just talking about it, I remember that feeling of hurt of like, they should know, they should be reaching out to me and they should know that I'm missing. But they don't.

And there's all kinds of people in our lives that are suffering right now. And we don't know. And we're not bad people because we don't know that they've got this thing going on that is invisible to us, you know? So I think that that's always important for me to keep in mind and remember that I need to, as you say, educate other people about what's going on and what helps and what hurts. I think it is important to be able to tell them, don't say these things because it hurts me. And they may not know.

It's the same thing with grief. I think people who have just had somebody die suddenly, people say the worst things but they don't know that they're hurtful to other people and it's helpful to them to

have, usually not the person grieving but somebody else say, like, here's what's helpful and here's what's not helpful.

**Alex Howard - [00:37:57]**

One of the other big challenges, and you spoke to a bit earlier, is doctors. The medical experts that one goes to for help, fundamentally not believing what's going on for someone. You did speak to a little bit earlier but maybe we can spend a bit more time there. How does one handle that? How does one sort of learn to advocate for their own experience?

**Sarah Ramey**

Yeah, so this is the hardest thing, I actually think, because the dynamic between doctor and patient, especially with this family of illnesses that has, it's getting better, but is so stigmatized and doctors really, there's like a real antagonism there where they're just like, ugh, this type of patient They don't like this type of patient with ME/CFS, fibromyalgia, POTS, MCAS, like this whole family of fatigue related autoimmune type illnesses. If you have a proper auto immune disease, that's different.

So I think the very first thing, because this took me so long to actually do, is before you deal with your relationship with your doctor, because there are interventions that I can talk about that can be helpful, but sometimes they're not. Sometimes they don't go well and they're not well received. And so before you get there, I think the most important thing is to forge just like an unbreakable alliance with yourself that you are not going to let this person tell you that you're not sick when you are sick or tell you that you're invalid when you know that you are valid. That it may hurt and that your feelings may be hurt, and I don't want to diminish how difficult it is to spend money and time and your precious energy going to a doctor for them to treat you poorly. It's awful.

But the most important thing is that you don't get turned against yourself because that is extremely common. That happened to me. Happens in alternative medicine as well. You get a lot of like, well, maybe it's your mommy issues or daddy issues or whatever it is. And you learn to like, you learn to just be like, oh, if I'm not getting better, it's because of this limitless list of emotional problems that you just haven't sorted out yet.

**Alex Howard**

By the way, most of the population have, right? That's one of the points I make. So I have to resolve all of my emotional issues to get well? And I'm like, there's lots of well people with lots of emotional issues.

**Sarah Ramey**

Exactly. So that can be very frustrating. And it becomes sort of this parasite in your mind. It's very difficult to eradicate that. It's not, if you're so sick, that it's not you, that it's just you're sick and there's something wrong. We haven't figured it out yet.

**Alex Howard**

And you're exposing the incompetence of their understanding and the lack of insight potentially of their model. And I also think people say, well, I didn't want to upset them, I didn't want to be rude. And I say, well, if you were taking your own 5 year old child that you knew had a broken leg, for example, and they would say, no, the leg is fine, it's not broken. And you knew your child was suffering, you wouldn't leave that room until they paid attention to it. And that's the level of ferociousness that one needs sometimes.

## **Sarah Ramey - [00:41:19]**

That's such good advice. And I think that that's really important. It's very healing to hear that coming from a man because I actually think men are a little better about this than women. Women sometimes can be, can just collapse on themselves and want to be too polite or too nice or something and actually need to be more aggressive and more forceful, not aggressive but more assertive with this person that is wrong. It doesn't matter that they have a white coat and that they have degrees in the law. They are wrong.

And I think it's important as a patient like this to really understand the larger superstructure around these illnesses. They have not been studied or funded and understood at a medical level. And that is why the doctor in front of you doesn't know what's going on, why he doesn't have a test to run for you. It's not because you're so unique. It's because they haven't done the normal, robust study of these illnesses that would develop the tests that they could run and say, oh, here's what's going on, you're a classic case of blah blah blah. And so they don't really have, they sort of do, but they don't really have that level of testing.

As soon as they do, all of this skepticism will go away. And nobody will apologize. Nobody will say, wow I was an asshole to those people for 20 years. They'll just start saying, "yes Miss Ramey you have blah, blah blah. And here's what we're going to do". And it's just going to change.

But it's important I think as the patient to understand that, that is why they are treating you this way. It's not because there's something wrong with you and you're being irritating or you're being, you know, sand in the gears for them, which is how it can feel.

But I do think, like you were saying, in terms of being assertive with the doctor, this can be tricky because I think that it's, it really depends on, because sometimes you really need that person to not become alienated from you, which is sometimes a risk if you say like, hey, what you just said to me, that is wrong. I am sick, etc. Sometimes people take that very poorly and they're like, well, then, fine, get out of my office. It's like I'm not going to help you.

I've had a couple of doctors be really unreceptive to learning about, if I bring in something about ME/CFS, I'm like, hey, the CDC just updated their website. It used to be really scant information about ME/CFS, now it's really robust. I just thought I would bring this in. And they're like ugh, and they're so upset with me.

## **Alex Howard**

We had someone post in our online community a few days ago, they were at rage by seeing a doctor who wrote in a report, suffers from so-called ME/CFS. Like it's not even a legitimate, I mean they were so angry.

## **Sarah Ramey**

It gives me rage just hearing about it.

So it's delicate. And this is my main point here is that some doctors, especially if you're focusing on not on the ME/CFS, but in my case, like, you've got really bad pelvic pain. I need that pain doctor that I have found. And it doesn't matter that they don't believe in ME/CFS I need them to be helping me with pain. And so I'm not going to push back with them on whatever their bad attitude about ME/CFS is because I really need them to continue helping me with my very severe pain problem.

But somebody else like an internist or something like that, I think it's important to push back or to send a letter, I've done this, there's a letter in my case that's been the most effective thing. I think that's maybe easiest because I'm a writer. But just to write like a gracious letter that just says, I know that there's a lot of stigma around this illness, but I would like to work with you and here are a couple of materials that I think could help you understand me better and just use the most sort of mainstream.

**Alex Howard - 100:45:37**

Don't overload them. Pick a few carefully chosen pieces.

**Sarah Ramey**

I can understand a doctor being like, oh my God, this person Googled their illness and brought me this blog about whatever. So I think it has to be contextualized a little bit with the express purpose being like, I really need help and I like you and I want to work with you, but I need to make sure that you want to work with me and can work with me. And please tell me if you can't, because I'll go work with somebody else.

**Alex Howard**

There's something I think what you're saying that's also really important about picking your battles. And sometimes you need to say yes to yourself, you have to say no to somebody else and you have to fight that battle. And other times you have to let things go that you actually want to fight the battle because fighting the battle is going to become a roadblock to something that's important. And that takes a certain level of, I think, awareness and judgment about how to navigate those dynamics.

**Sarah Ramey**

Yeah, I think so. And it's again, it's it's really difficult. It shouldn't be this way, but it is. And so I think that just learning, I think it is important though to learn that you can, sometimes it is worth pushing back. It's sometimes the most worth pushing back if you're not going to see that doctor anymore. To write them a letter and to really say like this was unacceptable. And this was, again, being sure that you are not going to need them again.

**Alex Howard**

Don't go back for a repeat prescription a week later.

**Sarah Ramey**

I wouldn't write a mean letter to anybody but an assertive but still, a generous letter that just has, I am really sick. I really hope you learn more about this. Here are a couple of resources that I think could be helpful to you the next time somebody like me walks through the door because we need you. And I hope that you come along on this path.

**Alex Howard**

That's beautiful. That's beautiful.

Sarah, I'm mindful of time. There's so many more things I'd like to ask you, but I think we've also covered a lot. For people that want to find out more about you and your book and your work. What's the best way for them to do that?

**Sarah Ramey**

You can go to my website, which is just [sarahmarieramey.com](http://sarahmarieramey.com) it's my whole name. And it's got the book or you can go to [wolflarsenmusic.com](http://wolflarsenmusic.com). I'm a musician and that's there, but that's also my main website. You can get the book anywhere you get books. You should support your independent booksellers. They need our help, but it's also available on Amazon and everywhere else.

**Alex Howard**

Brilliant. Sarah, thank you so much. And I really appreciate, not just your vulnerability and your story, but also the practicality of your suggestions. I think it's going to help a lot of people. So thank you so much.

**Sarah Ramey**

Thank you so much for having me.