Episode 9 transcript

ME/CFS

K = Kris Rudin
R = Robyn King
S = Stephanie Shockley

[Opening theme music]

S: Welcome to The Accessible Altar, a podcast of conversations at the intersection of faith and disability. I'm Stephanie Shockley

R: And I'm Robyn King

S: And we're your hosts. Today we'll be in conversation with Kris Rudin.

R: Kris is here to talk with us about ME/CFS, something she does a better job of explaining than we will, how that has impacted her faith and faith journey, and offer at least a small insight into what ME/CFS might bring to the conversation around long COVID.

[music interlude]

K: My name is Kris Rudin. I'm 65 years old, and I grew up in Montana, as an athlete, and I was a life long athlete. Had a very healthy lifestyle, never smoked, never drank, never did drugs. Exercised all the time. Was into competitive sports my whole life, including well into adulthood. In fact, in my 40s I got into cycling and hired a professional cycling coach, and I was training with the end goal of hopefully qualifying for the senior Olympics by the time I was 60 or 65. That was kind of my goal. And so… I had gotten married when I was 35. And my husband and I used to do lots of cycling stuff together, we used to do races together. And I had a successful career as a software engineer, owned my own company, and, all of that disappeared in the late fall of 2003 when I got an ear infection, and got vertigo at work, couldn't sit

up, and missed about week of work, couldn't train on my bike. But you know, after a few days it got better, about a week after it got better and I did a work out with my coach, and I noticed in the work out that my legs felt really odd, but I thought, you know, I've been off for a week, so whatever. Well, two days after that workout I couldn't get out of bed. I felt like a truck had hit me, never felt so sick in my whole life. And that began the journey of trying to figure out what was wrong with me, trying to get a diagnosis… I'm sorry, I'm sort of going into this, you know, long story of how I got to where I am, so it's not a brief introduction. But I, long story short, it took me 13 years to get a diagnosis. Not through lack of trying. I flew all over the country seeing specialists and having all kinds of tests. And nobody could figure anything out because all my tests were normal. And I just continued to get worse. I was able to work until year, let's see, until 2013, so 10 years in, I finally had to stop work. Because I just couldn't keep going to work. I had already given up all my hobbies. I had stopped going to church. But long before that I stopped singing in the choir, because singing was too exhausting. I gave up my volunteer opportunities. All I did was work, and rest. And then in 2013 I couldn't even work. So I've been off of work on disability since then. And my condition has continued to deteriorate, although I did get diagnosed, finally. A wonderful local doctor diagnosed me. Knowledgeable, kind, compassionate. He's someone I thank God daily for, because so many people with my condition have doctors who don't believe them. Still, today, doctors don't believe that ME/CFS is a real disease. But I have a doctor who does, and he is trying to treat me, but there are no FDA approved treatments. Basically it's symptom management, and I just continue to decline. I am to the point now where I have to spend all day lying down. I can prop myself up a little bit, but if I sit upright my heartrate soars to dangerous levels. I haven't had a shower in three years. I have to use baby wipes to clean myself. I mean, my husband takes care of me. And so I went from someone who worked out four hours a day to someone who can't sit up. And that's this disease.

R: You sort of laughed as you said that but I can also hear some the grief that is in that transition.

K: Yes, a lot of grief. I've seen a therapist for many years. I started seeing one early in my illness when I was still undiagnosed, and it was clear that I was not going to get back on the bike. And so I saw her for several years, was on an antidepressant for a few years. But then I felt like I got a handle this so I stopped seeing her. And in conjunction with her we stopped the antidepressant and I was fine. But after having to quit work and still just not finding any answers it just got bad again and so I started back into therapy, probably a year or two after I stopped work. And my therapist has been indispensable. She's another one that I thank God daily for. Indispensable in helping me find my new normal, and accept that this is my life and it's not the life I wanted, it's not the life I hoped for, it's the life I have. And so how could I make this life as good as it can be. But the grief never leaves, of course. If I could get on the bike today, let me tell you… [sighs] If I could go for a walk today… [laughs]

R: So I want to come back to some of that like, finding joy in the life you have. But first you mentioned in the middle of that story being officially diagnosed with ME/CFS.

K: Yes

R: Could you sort of

S: That was going to be my first question, just sort of a, like, you know, what are the key things that we

R: What does that mean

S: What does that mean, the key things we should know

K: Sure, yeah. ME/CFS, it's ME slash CFS, is the abbreviated term for Myalgic Encephalomyelitis slash Chronic Fatigue Syndrome.

Chronic Fatigue Syndrome is kind of a bad name because lots of illnesses can cause chronic fatigue. Depression causes chronic fatigue. Multiple sclerosis causes chronic fatigue. Chemotherapy causes chronic fatigue, right? Chronic fatigue is a symptom. It's not a disease. Myalgic Encephalomyelitis is slightly better, it still just describes a symptom, and what it means is muscle aches with neuroinflammation. So brain and nerve inflammation. And it is a disease characterized by fatigue, but the hallmark symptom, the symptom you must have in order to be diagnosed with ME is called post exertional malaise. And that means a worsening of your symptoms after some kind of activity, whether mental, emotional, or physical. That your symptoms will be worse for days or weeks afterwards. And they can actually test for this and show that this happens in ME patients and not in any other kind of patient. They do a two day treadmill test, sort of, where they do the treadmill one day and they check all your readings and your oxygen levels and you lactic acid and all the things in your muscles that are working and your oxygen uptake and your heart rate, blood pressure. And the second day, they do it again. And without fail, if you have ME/CFS, you probably can't even barely do the treadmill test. You can do probably a quarter of what you did. If you walked for 4 minutes on day 1, you might be able to walk for 1 minute on day 2. And all of your readings are sky high. Everything is worse. And so they can clinically prove that people with ME have problems with exercise, that exercise is actually harmful. Which goes, flies in the face of all accepted medical knowledge. Everyone says exercise is for, it's good for your emotions, it helps you, you know. In ME or ME/CFS, exercise is harmful. And that's, I think, one of the most important things to get out there for people to understand. If you have a friend with ME/CFS, you just can't tell them to go, you know, push though, I know you're tired, we can talk for another 30 minutes, I'm sure we can, you.

S: Yeah, I waiting for someone to recommend yoga, right?

K: Oh yes.

S: I feel like that's the sort of go to thing for any…

R: the classic "my friend tried yoga."

S: Yeah

K: Early on in my illness I actually did try yoga. And it was impossible to do. I didn't have the muscle strength for it. I didn't know what was wrong with me at the time, I just knew that I felt worse after yoga and not better. So yes, post exertional malaise is the hallmark symptom. And the other biggie is unrefreshing sleep, that no matter how long you sleep, you will wake up in the morning exactly as exhausted as you were the night before. Which is brutal.

R: I have some sleep issues and I gone through periods like that, and oh, yeah, that is so brutal.

K: It is. It is, it's really hard on your body. I've had this illness so long that I can actually, that I'll recognize good sleep, versus not good sleep. I can tell the difference, mostly in my brain, how my brain functions, the clarity. Brain fog is another common symptom of ME/CFS, where your brain just doesn't work. And so I can tell I've had a good night's sleep – my brain fog is less. So, yeah. And the other really interesting thing about ME/CFS, other than the post-exertional malaise, other than the PEM and the unrefreshing sleep, the symptom spectrum is huge. I'm not talking severity, I'm just talking about the kind of symptoms you have. Some people have endless migraines. Some people have sore throats so bad they can't talk. Most of us have swollen lymph nodes in our armpits, groin, neck. Lots of people have digestive issues – IBS, gastroparesis. Lots of people are in terrible pain all the time – muscle and joint pain. But it's all over the place. Pain is not something, thank God, that I deal with much. I have mild, very mild muscle ache, and I really just don't even notice unless I stop and think about it, but other people are desperate to find some kind of pain relief because they live at a pain scale of 8 out of 10 24/7. And so it's really odd… I actually

met people with ME/CFS when I was looking for a diagnosis but my symptoms were so different that I thought "well, I don't have that…" Well, I didn't know that symptoms were different for everyone. So that's the other really interesting thing – no two ME/CFS patients present alike.

R: Not to excuse the long delay in diagnosis, but I can see how that would make the process of diagnosis so much harder

K: Yes

R: Because you're trying to limit out all the things that those specific symptoms might mean.

K: Exactly. It is, it is harder. And now, you know, knowledgeable doctors at least now will hone in right away on the PEM. And if someone comes in and they've got this weird, you know, set of symptoms that seem sort of all over the place affecting all kinds of systems and fatigue is one of them, a good doctor will go "let's do a two day, what's called a CPET – cardio-pulmonary exertion test or something- let's do a two day CPET and we'll see. And boom! There it is. PEM, and you can be diagnosed.

R: I feel like in… most of this I know because we've been loosely connected through church circles for almost a decade now.

K: A long time, yeah

R: But, so I've had some very rough following of this through that connection. But that move from chronic fatigue to ME is fairly recent. Finding that ability to have any sort of diagnostic indication.

K: Yes, yes. And right now the CPET is really the only one. And it's, not everybody, you can't get that done at lots of places. And to know what to look for specifically to indicate the actual physiological PEM, that's difficult to get a doctor to even A. know about it and B. be able to order one and you be able to go get

one somewhere. And of course, the other thing that that test does is it causes PEM.

R: It causes PEM.

K: And it will cause you what we call a crash, which is bad PEM. And every time you crash, you basically do permanent damage to yourself. It's like you take one step forward and if you crash you go two steps back. And you work really hard by resting and resting and resting and you take one step forward and then you go a little too far and you take two steps back. And that's what happened to me, because for so many years I didn't know what I had, so I just kept trying to live a normal life, pushing through, and I just kept getting worse. And sometimes you have things that happen that you have no control over that will cause a crash. November of 2020 I got an abscessed tooth. Went to the dentist, and he put in, he did a root canal. He wanted me to come back in 10 days to get something permanent put in or whatever. Well, in a week I was having pain, a bad taste in my mouth, I had to go back in in a week. So I saw the dentist, and then one week later, I saw the dentist again. Now, Robyn knows I need two weeks between outings. But I went and had to go one week, and then I had to go the week after that to get the root canal permanently set. And then I still was having problems and I had to go again. So I ended up going out four weeks in a row, and I crashed so badly that I ended up being sound and light sensitive, which is something that happens to severe ME patients, I had to exist in a dark room 24/7. I couldn't listen to music, I couldn't listen to audiobooks, I couldn't use my phone. I was completely cut off from all my friends who live in my phone. And that lasted almost three months before I could start tolerating a little bit of light and sound, and gradually work my way up. And it finally, that whole crash didn't really end until I got that tooth pulled. Because I was still having problems with it. So I got that tooth pulled and things got better. But, that's how fragile people with ME are. Simple, things, root canal, oh, no big deal! Oh, you have to go back in again, no big deal!

R: Happens every day.

K: Yeah. You don't even think twice about it. You go get your root canal, you go back to work, you know. People with ME, we're so fragile, we're living on the bubble, one thing, one bad night's sleep, I mean it just doesn't take much.

R: I know you have built a community and you have family, your husband and your sister, but I imagine you lost a lot of people in the process because, sitting here, like, I know this is true, I believe you, but I also know that it sounds a little ridiculous.

K: Yeah, I honestly don't know how many of my former friends, former coworkers think that I'm just some sort of crazy woman. Because I'm very honest on Facebook. I post about ME, I post about my struggles with ME. When I was in that horrible bad crash I had my sister post updates for my friends. And I have had several people say "thank you for doing this because I had no idea and my neighbor has this weird thing, and I think it's what you have, and I didn't know…" So I know some people get it. But I am sure there are people who didn't really know me, who I just worked with, or just went to church with…

R: You just disappeared from their world.

K: I disappeared and I pop up on Facebook and I post all this weird stuff about some bizarre illness that sounds impossible… I'm some sort of hypochondriac weirdo. And I'm sure there are people that say that. But I have not had anyone say that to my face.

R: Ok. I'm glad.

K: Yes. I've had some doctors, most doctors actually believed that there was something wrong with me, but they just didn't know what it was. I am one of the lucky ones in that regard. Because medical PTSD is rampant in

R: Mhmm…

K: In every illness community it's…

S: I've noticed that there are particular categories of chronic illnesses, like if you go on, if you're in contact with people on twitter, for example

K: Yeah

S: There are particular categories of really complicated chronic illness where people have just been through hell and doctors don't listen to them, and they get written off over and over and over again.

K: Yeah

S: And this is one of the illnesses that tends to be on the list.

K: Yes. The illnesses on that list, like ME, fibromyalgia,

S: POTS

K: Polycystic ovary disease

R: PCOS, yeah

K: All seem to affect women…

R: Yeah, I was going to say, some migraine presentations

S: Uh huh

K: Yes, migraines, and so, yeah, we get told we have depression or anxiety or we just need to find a man, I mean, there are people who…

R: To try yoga

S: To try yoga

K: Take a vacation

S: Eat organic food, cut out gluten

K: Yes

R: Yeah

K: So, thankfully, I didn't run across any of those doctors. And thankfully I haven't had any acquaintances or anything say to my face, well, you just need to do this, you know, if you just got up and got active you'd feel better. No one has ever said that to me, personally. But, I do know lots and lots of people for whom it's a daily thing. Their spouse gaslights them, doesn't believe them, doesn't support them. And then their family and their pastor and their friends and they're all by themselves and no one believes them.

R: You mentioned pastor and I want to turn the conversation that way. You talked, in your move from pre-ME/CFS to full diagnosis, you stopped going to church, you stopped being able to do choir, were there times when the Church managed to respond well to this change in your life?

K: Um, yes. When I had to stop choir, that was not, nobody, that was just like "oh well, she's not doing choir anymore." I mean, you know, people come into to choir and out and whatever, and I didn't make any big announcement, I just said I'm not going to do this anymore, so, oh, ok. But when I really had to stop going to church, especially after I had to stop work, the, I was not, at the time, I was not going to an Episcopal church, it was a non-denominational church. And the pastor at the time would reach out through email frequently and see how I was doing and how are things going. They sent me flowers once saying you know, you're not forgotten. That was really sweet. But then they

forgot me. You know, after probably a year or two of me not being at church it just kind of petered out. People who I thought were my friends at church, unless I reached out to them, they didn't reach out to me. With two exceptions – there's another woman who also has a chronic illness. And she has still, to this day, remained in touch with me. And a married couple who have brought me meals, especially when occasionally Randy used to have to travel for his work, and so they would bring me meals on nights that he would not be there. And the husband would drive me to me appointments. He's retired so he could take me to my appointments. And they were the only two people from that church who stayed and still stay in contact. I'm not in contact with the pastor or anybody else.

R: I'm sorry.

K: [wry laughter] Yeah. It actually kind of worked out ok in a sense because if I were suddenly physically able to go back to church I wouldn't back to that church. I've deconstructed quite a bit. While that church, for a non-denominational, sort of evangelical church is fairly progressive in some senses, in many other senses it's not. And so I would not go back to that church anyway. Not because I hold any enmity or bitterness, it just wouldn't be a good fit.

R: Wouldn't be a good fit.

K: Yeah

R: What does church look like for you now?

K: It's mostly non-existent. I have, in the past, I would watch some streamed morning prayer services from various churches around the country. You know, I'd go on YouTube and find a streamed service, and I'd get my prayerbook out and do a morning prayer. And this would not be live, because I'm not awake for morning prayer, right?

R: Yes

K: My morning starts at noon. So it's a recorded thing, but that would be something that I would do. I have developed a sort of a community of other Christians online. I'm a member and an admin of a Facebook group, can I plug it?

R: Yeah

K: Christianity without the insanity. And I've met people there and become pretty good friends with people there, and we have a pretty supportive community. I read Richard Rohr's daily messages, and there's a community on Facebook that does discussions there. I follow Bishop Steven Charleston on Facebook and I have a couple of his books. So I read his daily devotionals. So for me, church is an extremely individual thing, except for the discussions sometimes on Facebook and interacting with people there. So it's been a very different experience. A not really communal experience.

R: You describe it as not really communal, and I understand that, but I'm also struck at all of the different points of connection you have within that.

K: That is true.

R: Sort of a diffuse community.

K: Yes, yeah, it's a distributed community

R: Yeah

K: And it's one that I interact with very, what's the word, it's not like you and I are interacting right now, in real time. Someone will post something, and I will see it hours later, and I will comment. And then…

S: Uh, what's the word… um, asynchronous?

K: Yeah

R: Yes

S: Is that what we're looking for? Yeah, okay, it took me a minute there.

K: The communication is not happening at the same time. And so it still feels like to me, sort of an individualized spirituality, yet, I am, as Robyn says, I am still connected. And I will fight to the death to say that online connections are as real as in person connections.

R: I will not fight with you… I will fight on your side, but I am not going to disagree with that because absolutely.

S: Yes, yes, we are absolutely, we are absolutely here for that. Um…

K: Yes

S: I mean, Robyn, when's the last time we saw each other in person?

R: Um, 2008?

S: So there you go.

R: Yeah, it would have been my seminary graduation, May of 2008.

K: Wow.

S: Yeah. So, you know…

R: Yeah

S: Yep. And I think about how much of this is possible because of all the different ways you can connect with people online.

K: Yes

S: Whether it's Facebook or it's zoom, or it's any of the other myriad of things

K: Absolutely

S: So much is possible

K: Yes. And that's been an extreme gift to me, being at home. I mean, I really cannot leave my house and we live semi-rural, so people don't just drop by, and besides I can't really handle people just dropping by. So, to be able to stay connected to the world through the internet, the magic of WIFI- my goodness! People do sometimes ask, "Aren't you lonely? You're stuck at home all the time!" And I'm going no, I'm not lonely, at all. I have friends, I have so many friends. I can pick up my phone and send a text or send a message to someone and I'll get a response immediately. If I need help, if I'm struggling and I just reach out to somebody and say "hey, having a tough day, are you there, can we chat?" Boom! Somebody's there. So I'm not lonely. At all. And I'm so grateful for the technology that enables this. And it enables the spiritual connection. I mean, I would not have gone through the deconstruction that I went through without having Richard Rohr's daily emails. And then the discussion group. And discovering Bishop Charleston. And some of the other, Thomas Merton, and some of the other people that Richard Rohr refers to and so it just spread out into more reading and more mind-opening things that enabled me to walk this path of deepening my faith while being stuck at home. And that's kind of a miracle.

R: Yeah

S: There's… I almost feel like, and I don't know, let me know if you think this makes sense, but there's almost a desert spirituality to this… I think?

K: Yeah

S: There were these wise people, but they were, in their case they were choosing it, it wasn't because of the restrictions of an illness, but these wise people in their little places, you know, living separately, but they had connections, they communicated with each other in certain ways, you know,

K: Yes

S: they, there was a community of people even while they were hermits, and this desert spirituality that was developed in that particular situation.

K: Yeah

S: And I'm just getting a little bit of a desert spirituality vibe from this, like how do you under, what most people would consider impossible conditions, how do you find your way spiritually, and stay connected with a community?

K: Yeah, I really like that idea.

R: I agree. I had a similar thought. But I also want to say you not only continued to find spiritual nourishment and community but you are saying you deconstructed, so you changed spiritual communities. So you changed, which…

S: Yeah, actually, yeah

R: That's hard if you're able to go to places in person

K: [laughs] Well, one of the gifts of this illness which I hate to think that this illness has any gifts at all, because I hate it, but

one of the gifts is time. I have time to read, I have time to listen. You know, those three months when I couldn't even read or listen, I had a lot of time in my head. I've had time over the years, you know, away from church, away from the influence of a religious community to, to have to really look at myself and say alright, what do I really believe? What do I want to believe, what do I feel like I should believe? What do I, where do I want to go, what do I want to stand on? I mean, I had to examine myself, because I didn't have anyone to help me examine myself. And it probably helps that I'm a little bit introspective anyway, despite the fact that I was, you know, a jock and an athlete, I was

R: You were also a software engineer

K: Yes

S: Right, exactly, I was going to say

R: You can be both

S: Yeah

K: I was both. And so, but yeah, I recognized that if I was going to grow spiritually, it was on me. Because certainly at the beginning of my journey at home, I don't think zoom had been invented. You know, there was very little connectivity. Facebook was there, but it wasn't really big yet. So there was just a lot of I had to do it on my own. And so I did.

[music interlude]

R: I don't expect you to have brilliance on this, but I'm really intrigued, and not because I don't think you are brilliant, I do think you are brilliant, but I've been keeping a loose eye on the science, and I don't think anyone has brilliance on this yet other than to sort of look at it and go like - I think there's something in this long COVID/post-viral illness/ME/CFS pandemic that there's

something in that mixture that will continue to clarify out for people.

K: Yes. Yes. I think that for the ME/CFS community, and this is going to sound really harsh, and I don't mean it that way, but the pandemic was a blessing in disguise. Obviously, obviously, the millions of people who have died, that is tragic, and the cost of it, you know, lost productivity, and people being sick, and medical bills, and, I mean, that's horrific. But from the scientific standpoint because the pandemic forced the medical community to really focus on this whole post-viral thing, that wow, maybe this really is something real, and because it all happened at once, at least the US government said we've got to put some money into this and figure out what's going on. And so the president pledged I believe 1.1 billion dollars in research money for long COVID. Well, you know, in the ME/CFS community for decades, we've been practically doing bake sales to raise a few extra thousand dollars for a researcher to do one more little trial or something. I mean it's nickels and dimes. And so all of a sudden we have a lot of money coming into this, and I think we're going to see some real traction as far as understanding about the mechanism of what is happening in the body in these post-viral cases. Why are some people's bodies not just going "oh, I have a virus, I'm going to be sick for a while, here's a fever, here's a runny nose, okay, cough a few times, and a week later we're better." Whereas a not insignificant percentage – 20% they're saying – it's varies, between who you talk to – but a not insignificant number of people, their bodies do something completely different. And it messes them up for the rest of their life. At least for now. We have no way of interrupting this or stopping it. Because we don't really know what's going on. We can see now, we're finding a lot of evidence, medical evidence, increased cytokine production, cytokines are an indicator of inflammations. Problems with neural conductivity, neuropathy. Heart problems, orthostatic intolerance. I mean, there's all these things that we can see have gone wrong, and so far, for ME/CFS, you just treat the symptoms. Oh, you have orthostatic intolerance, here's a drug that should help your blood pressure

stabilize, you know, that kind of thing. But now they're actually seeing this in real time, so to speak. And so people that are a lot smarter than me are, you know, looking at very specific things in the body. Mitochondria, the immune response, the nervous system response… So we're seeing some things come out now, that people are trying some interesting drug combinations. One group of researchers who came from the ME/CFS community and shifted to long COVID because that's where the money was, they're doing some stuff with some anti-cancer drugs and I was about to go look it up, and I can't remember, there's one other… they're comparing an anti-cancer drug, just a standard anti-cancer drug, with another very common anti-something drug, and seeing some good results in lowering the cytokine response. So, you know, there's really some hope that with this focused effort on long COVID, that we will get some trickle down, we in the ME/CFS community will get some trickle down. Because the two are practically identical in nature. I think I mentioned last time that anyone who has long COVID meets the diagnostic criteria for ME/CFS.

R: In the last couple of weeks I've seen some of the people with long COVID, mostly people I've followed on social media, become officially diagnosed with ME/CFS.

K: Yes, that's quite common, that's quite common. Because, because doctors don't know what to do with either, right? So, yeah, and because ME/CFS is really only a diagnosis by symptom, that's the only way to diagnose it, that's the official way to diagnose it. You know, you rule out all of the other things, and then if you have these symptoms, the boom! ME/CFS. And, well, people with long COVID have ME/CFS. Long COVID people do tend to have more lung problems than the typical ME/CFS person, and there tends to be some different kind of cardiac behavior in long COVID than in the typical person. But all the other symptoms, it's the same…

R: Yeah. They're the things they're talked about.

K: Yeah

R: One of the things I think that is sometimes unique about disabled communities and chronically ill communities is how easy it is to be accepted within them. Are you seeing that among people who have contracted long COVID being welcomed in and around ME spaces.

K: Um, mostly yes. The typical response I'm seeing in my ME/CFS groups on Facebook and in a specific and in a specific group for ME/CFS and long COVID – the typical response is "we're so very sorry you're here, it really really sucks, and here's what we wish we knew at the beginning, and so we're telling you, please listen. Um, there is an undercurrent of "oh, you have the same symptoms that I've had for 20 frigging years, and all of a sudden you are accepted by the medical community, you are accepted by the research community, where have they been for the last whatever decades when we've been screaming and crying for any kind of relief."

R: I saw somewhere and I'll have to see if I can find it and we can put it in the liner notes for this, but the gist of it grabbed me because it was saying, you know, the lack of research into ME/CFS and other post-viral infections is really a disservice to people with long COVID, like, we could have been much better prepared for this.

K: Yes, that's brilliant, that's entirely true.

R: We had all of the pieces lying around in different communities

S: Right, because there was long polio, right, and I have a, I know of a, I have a friend who has long mono.

K: Mhmm…

S: And that's been around for years. It's not…

R: Yep

K: Yeah

S: It’s not a surprise that viruses leave damage

K: Yeah. Right. And that some people’s bodies respond in atypical ways. That’s been known for years but it’s been ignored. Literally ignored. And not just ignored, but in many circles, denied. Oh, ME/CFS, it’s all in your head. If you just wanted to be better, you’d get better. If you weren’t afraid to exercise, exercise wouldn’t hurt you. I mean, patients have been literally told this, and yes, if we had known, if the medical community had accepted this, especially, I think, in the 80s when “yuppie flu” became in the news and was just dismissed as, yuppie flu. Maybe if the researchers had taken this seriously, if governments had taken that seriously, we would have been completely prepared for the fallout from COVID. We would have said oh, here’s what we need to do, right away, we know the genetic make up of people who tend to respond poorly to these kinds of viruses, so here, take this and this and this. You know, I mean…

R: Yep

K: Could have been so much more proactive.

R: Well, and I’ve also seen, and I don’t want to go too far down this, because there’s other things I want to talk about, but I mean, I think California just denied like a record number of disability claims…

K: Oh!

R: Because the system is not taking into account two years of a mass disabling pandemic

K: Right, right

R: The whole system could have been prepared to find ways to make society a safe place for people with long COVID to live.

K: Right

R: Or at least a safer place.

[music interlude]

K: The problem with chronic illness or any long term disabling condition is that the Church is not set up to handle that. It's really good at crisis – oh, so and so had a baby, meal train, here we go, or so and so had an operation

R: Yeah, heart attack, operation

K: Yeah, right, right. There's an immediate response of caring from the community – oh, we care, we love this person, we're going to help out them and their family. And then they get better and we're done. But when you get a long term condition that very well may require meals maybe not every day, but a couple of meals a week would really be a huge lift to someone with a disability, and that's just not something that most churches do. And that's sort of a failure in the Church, I don't know, architecture, structure, whatever, in how churches do church.

R: I mean, you describe that and especially listening to you talk about our ability to respond to an acute crisis and our, sort of the Church broadly, and our simultaneous inability to understand a sustained thing. And I hear echoes of that sort of, this is a little jargony here, so bear with me for a second, but that medical model of disability. Where something happens, it gets fixed, and normality is reasserted. And all the like air quotes around normality.

K: Yes

R: Which is so woven into our society and therefore also our churches.

K: Yes, yes and I think there is also a well-known psychological, what would you call it, term, called compassion fatigue, which is real. I understand that. I get it. I see people in some of my groups, the same person posting the same, "oh, I'm struggling, I'm struggling" over and over and over again. And I'm in a great place to totally understand because I struggle every day. And yet, I think, "oh, she's posting again!" And I have to literally force myself to, you know, to step back and be intentional and go, oh, she's suffering, how can I help? And so compassion fatigue is a real thing. I mean, I understand. I don't have a solution.

S: I think, I think that's something that, maybe requires, like you just outlined, an intentional choice to be very very aware and to not, to find a way around it. I remember, when I was working as a hospital chaplain, I'll tell you, not always, but often the cases that were the most emotionally difficult to handle, were the situations where I'd meet with a patient and they had a situation that just went on and on and on and they were suffering in a way that there was nothing, even your presence felt absolutely inadequate – because, let's say they were sick and they had been homeless and it was a compounding, a thing that was compounded by multiple things, and there was immediate anything anyone was going to be able to do. And that was always harder because you just really realize I think your own limitations as somebody who's trying to provide the compassion.

K: Yeah, mhmm…

S: It would be harder than like a sudden crisis, a car accident, a whatever, because you knew the kind of intervention that would generally be supportive of those families or those patients. Yeah, just… humans aren't good at the long term.

K: No, I don't think so.

R: And churches, I mean I have seen this again and again in my years of ministry. You have like the three people who cared deeply about X, and I promise I'm not thinking about any specific thing, just like, this is the archetype of what I've seen. And they do X and they do it well, and they meet a need and then X needs to look different, or they don't want to let it go and be done it. So there's not always good leadership transitions that are built into church communities. So when those people get burnt out or tired or move so many things fall apart.

K: Yes

S; You know what I'm thinking about, actually? I'm thinking about, I think it was… when we talked about Gabe about pandemics, and he talked about HIV/AIDS, and he was talking about how, the communities that wanted to support people with HIV/AIDS started off buddying people up, where there'd be like, a person with HIV/AIDS and then somebody who'd be there to offer support, a lot of practical support. And they quickly learned that there was no way that was going to work. Because it was just overwhelming

R: People burned out and

S: And they wound up coming up with teams of like ten people and they put together a care team, and that was a model that was used in a lot of places so that there was coordination, there was support, and no one person felt that they were the only one that was making sure that things that needed to happen, happened.

K: I think that, that model has to be in place for churches to be able to minister to the chronically ill and disabled community. To have a team approach, because otherwise yes, there will just be burnout, there will be compassion fatigue. And that's just, that's not good for anybody. That's a poor situation for the giver and the givee, both. It's a bad situation. But, I don't think most churches are really set up for the long term kind of care.

S: I'm wondering about, and Robyn keeps going back to the concept of bad theology. I'm wondering if, you know, if this is a situation where theology, where action follows theology. So, if our theology of illness, of disability, of chronic illness, of the kinds of situations that aren't necessarily going to be resolved with medical model, magical solution, or whatever, our theology isn't great, if we don't teach people how to, how to understand from a theological point of view

K: Yeah

S: a long term, chronic illness, then they're not going to know how to respond from a practical point of view either.

K: I think you're a hundred percent right there, because especially with chronic illness, but even with some physical disabilities, there is this theology that many people have that well if we just pray about it it will go away. You will be healed. Your leg will be straightened. You know, your hearing loss will be restored. And so there's prayer, and there's anointing, and laying on of hands, and you know, all of this happens, and the person doesn't get healed. And so, how does theology categorize that then. And I think, I know, that in some cases it turns extremely toxic and blames the patient, blames the individual, well, you're not healed from your chronic illness because you're not praying enough, or you're not praying the right way, or you have some hidden sin that is blocking God from moving in your life and you need to examine yourself

R: I was going to say, we're just back in the middle of the Book of Job. No, no, no, really, this all happened because you sinned.

K: Yes. And that's extremely common.

S: Yeah

K: in certain Christian circles, that we'll say. And if they just step back and think how that makes the individual feel. Here is this person who is suffering, deeply, let me tell you, they're suffering, and let me tell you, they have prayed, believe me, they have prayed six ways from Sunday, I mean, they have prayed, they have desired healing, they have done everything right. And yet they are not healed. And then to have someone they turned to for help say, eh, it's your fault!

R: And it doesn't have to be that blunt, there are a million ways people convey that

S: Yeah, I was thinking it's not always that literal

K: Yes

R: Ways that people convey that without being so overtly rude. Well, you, you, sometimes it's just an attitude of like well clearly you're not telling me the truth, because obviously that would have fixed it.

K: Yeah. Well, you know that God healed so-and-so, you know, look in the Bible and Jesus healed this and Jesus healed that so you know, what is it exactly, why aren't you being healed? And so that is you know, extremely toxic, and it is very present, and there are people I know of in the ME/CFS community who have therefore turned their back on God and religion and churches and everything and are militantly atheist… which, if you're an atheist, great, I got no problem with that, got no problem with that. But these people have been hurt and so they've been hurt by the very people that are supposed to be drawing them in. And that are supposed to be providing comfort. But I think lots of people just, lots of pastors in many churches are just not well trained, theologically and so you get a lot of toxic behavior in this area.

R: So, you are one of the people who has been tagging me in posts about disability theology for, I think years, it's fairly safe to say.

K: [laughs]

R: So I know that you have some passion and are aware of that as a field.

K: Yes

R: When did that, was it some of these stories that brought that up on your sort of radar, or did you stumble across that somewhere else?

K: I think it was both a personal reaction and then reading what people in my community would post about their experiences, it just really got me thinking about this, well, why are Christians saying this to people, why do they believe this, what is it about their belief system that can't deal with an unhealed physical condition, or a mental condition? What is missing in their theology? Because, well, I guess you could say it came out of a real sort personal selfish thing, because people's theology failed me, and my own theology failed me, you know. I mean, I was asking why am I not healed, what is wrong, what is wrong? And I, a friend gave me a book and I think it's called Glorious Ruin by [Tullian] Tchividjian addresses this specifically, about what happens when God doesn't heal somebody, what does that mean. And he, you know, his point was that the physical healing isn't the necessary outcome. That sometimes what we just need to understand is that suffering exists and to be present with people's suffering, that these cases just sort of end of being, yah, I'm broken physically, and I'm not being healed, but I'm still trusting God, I still believe God, I still worship God, I still, you know, walk with God, and that becomes more important than physical healing. And I kinda liked that partly; I still say, you know, why am I not healed, why did this happen to me, but my theology has changed to realize that suffering is just part of this world. And everybody suffers just in different ways.

R: I mean, even Jesus

K: Yeah, oh yeah, absolutely. And so, I can look at someone who's totally healthy, and they're out there posting pictures of their latest hike up on Mt. Spokane, or you know, skiing in Grenoble, or whatever, you know, and think, and be really jealous, and think, aw, you know, that could have been me, that should be me, why isn't that me? But in some cases I know some of their deep suffering in other areas of their life. Their suffering just isn't as physical as mine, or physically the same way, but it's certainly crippling emotionally, there's other things that they are dealing with. And so, so I'm still working on re-aligning my theology on God is not a gumball machine, that I put in prayers and I get my little shiny gumball, but that God is a co-sufferer with us. God knows suffering, because God has suffered, as you said. So, and that for whatever reason, and I do not know this, and I will ask God when I get to heaven, there is suffering in this world. For whatever reason, there is suffering. And everybody suffers. And I just happened to pick the short straw and get my physical malady that causes me to suffer. But I haven't lost my beautiful, wonderful husband, I mean, he wasn't taken in some you know tragic car accident or something, you know. I didn't suffer that way. I didn't suffer from abusive parents or alcoholic parents. I didn't suffer that way. So, my theology is changing from a view of God is there to end your personal suffering to God is there to be with you while you suffer. And I don't think most people, I don't think that's what most people hold to in their theology, that if you just pray enough you can get healed.

K: That's where my personal theology has moved, and I will say I think it is a truer answer, but some days it is definitely the less satisfying answer.

K: Absolutely. Yeah, I really do wish, geez, of course I wish I could just pray this whole illness away, are you kidding me? I would like to pray half of my illness away.

R: Yeah

S: And everyone who has ever suffered certainly feels the same, you know.

K: Yes

S: It's so woven into the human condition and one of things I've been asking, I've been discussing with my parishioners lately, we've been talking about a lot of these topics, actually, and one of the things I ask them when they talk about miracles, or people say they've, somebody's had a miracle, or whatever, I've said well, I've worked with thousands and thousands… I'm a parish priest now, but I was a chaplain for a good number of years, and I worked with thousands of families that never got their miracle.

K: Right

S: What's different about them? Why didn't they, what do you think happened that was different for them, why didn't they get their miracle? I'm on the side of all the people who never got their miracle.

K: Yeah

S: Because, that's most people most of the time.

K: Yeah

R: Yeah

S: We have to have a theology that is more robust than "pray really hard and maybe you'll get your miracle." Because that doesn't apply to most of us.

K: Right, right. I think if, if we have a view of God as a God who suffers with us, then we understand that there is something holy about being with someone in their suffering, just being with them, holding their hand, letting them cry on your shoulder, crying with them. Just being with them in suffering is a holy act,

because that's what God does. God holds us in our suffering, God holds our hand, God weeps with us. This is my belief. And if we can see that, then the presence of God is made manifest in sharing one another's sufferings. Instead of saying that you shouldn't be suffering, because that's what basically they're saying when they're saying well I'll pray for your healing, I'll pray you get healed, that just means you shouldn't be suffering. And, well, nobody wants to suffer, but everybody does suffer.

R: The concept of toxic positivity comes me, that insistence that you have to be happy.

K: yes

S: Right

K: Yes, absolutely. Toxic positivity is, toxic.

S: Yuck. And have to be happy not for your own sake truly, but for the sake of those who just don't want to know that there aren't people who aren't happy.

K: Exactly, because you need to be happy because your suffering makes them unhappy.

S: Makes me sad, makes me uncomfortable.

K: It makes them uncomfortable. So you shouldn't be suffering because it makes me feel bad. And that's the complete opposite of what we were just saying, of God being a god who suffers with us, and that there's holiness in the shared suffering, and it makes, if we recognize that, that suffering is inevitable, suffering is a part of life, and that shared suffering is holy, if we embrace that, then the person who is suffering feels seen, feels validated, feels accepted. That there's not something wrong with them because they're suffering.

S: Thinking about, we're coming up on Holy Week, and I'm thinking about Jesus in the garden, and the disciples falling asleep, instead of, you know, all he asked was for them to stay with him, watch with him, keep vigil with him

K: Yeah

S: For just a little while, and they couldn't do it.

K: That's an excellent example, that's an excellent example. Because yeah, it is difficult to see, especially people you love, of course it's difficult to see them suffer, of course you want their suffering to end, of course you do, but when it's not a viable option for that suffering to end, then I think what we're called to do is walk with them through that suffering

R: Or even, I mean, I want to say even if their suffering is going to end

K: true, yes, yes

R: I mean, I'm thinking of like both stories from my own life, but also the quintessential thirteen year old, for whom everything is just horrible right now. And the last thing they want is the adult who's like "well when I was your age it was terrible and then I grew out of it."
Like, that's not sitting there with them and being like yeah, no, this is hard, and it's horrible, and even if it's probably going to end, it's going to be hard and horrible for a while first.

K: Uh huh, yep, yeah, no, valid point, valid point. I think really if we can see one another's suffering, acknowledge it, you know, it helped me amazingly to find this one doctor who finally diagnosed me after 13 years, who didn't just say, oh well, all of your tests are normal, I can't help you, goodbye. Literally, I can't help you, good bye. To be seen, to have this doctor say I see this, I see what you're going through. I believe what you're going through, and in fact I think what you're going through is called ME/CFS

and I going to do my best to help you through this, we'll do what we can. It's a lifelong disease, it's incurable, but we'll do what we can. I mean, that just was, that was amazing. I mean, to get a diagnosis of well you have this incurable condition, there's really nothing we can do.. but it was amazing, because he didn't just dismiss me.

R: He saw you, and he cared.

K: Yep. He saw me, and cared and he still sees me and still cares to this day. And it's the most amazing thing, to have this person see my suffering and want to help. Even if that's just listening to me say this is terrible, I've felt terrible for three weeks. You know, it's amazing to have someone see you.

[music interlude]

S: Thank you for joining us for this conversation about faith and disability. We encourage you to find local conversation partners to discuss everything we've talked about in today's podcast. And we hope it's been helpful to you in your conversations about faith and disability.

Robyn, as we wrap up this conversation, are there any things that stand out to you from this conversation?

R: I had, I still remember the feeling I had as Kris started talking about being forgotten by the church she had been attending. Because I know I have seen that happen as people's priest, as they have sort of become less and less engaged and I have accepted that they were drifting off. And sometimes that is how people are sort of choosing to make that exit, it has made me wonder about all of those again. It has also made me wonder, and sort of reconsider, how attentive to be as we, God willing, are sort of emerging from sort of the deep depths of the pandemic and are able to gather again, what conversations to have and how to keep track of people who maybe we haven't see because the pandemic made it hard for them to be visibly attached to the

Church, especially given, the I think, I hope, very well known, especially after this conversation, uptick in conditions like long COVID and ME/CFS. How about you?

S: I thought a lot about the conversations I've seen in a lot of online clergy spaces or online church spaces, sometimes also articles posted in large publications about the issue of livestreaming. Some people theorizing that, well, if we just stopped livestreaming, people would come back to church. People responding to the anxiety about attendance numbers. That conversation has been really frustrating for me. Before, because there have always been people for whom being present in the pews on Sunday morning was really difficult. But this conversation is a good reminder that there are people out there who are not able to necessarily be with us in person and we don't know their hearts and minds. Especially if we've not followed up with them. But we don't know their, whoever they are, we don't know their hearts and minds and we don't know about their faith journey, and they may be doing the very very best that they can, under the circumstances that they're in, to maintain their own personal faith.

R: And I think it's definitely worth saying, because no one can see it, but I'm nodding in agreement to all of that, that while conditions like long COVID and ME/CFS are certainly two reasons why people may not be able to make it to a physical building on Sunday mornings, there are a host of other reasons, mental, physical, comfort level, that people may not be able or willing to do that yet.

S: And before COVID there were many reasons as well, before COVID.

R: Yep

S: We were saying earlier off mic that when you know better, you do better, and we know now that we can make our services accessible in that way. Livestreaming is easy, and that we can do

it. And that it means a lot to people, even if we don't always know exactly which people those are, or how it's being accessed, it doesn't matter. It's important that it's available.

The other thing that really stood out to me is we were very much aware as we were talking with Kris that a very significant amount of her available energy on the days that we spoke with her was being dedicated to this conversation, and that it was a big priority for her to help not only for her story to get out there but for people to know more about other people like her dealing with the same condition or with similar conditions. And she was really gracious with her time and energy because she was trying to help not just herself but everybody be heard. People who don't often get asked about their experiences, particularly with this condition, she clearly wants them to have, to have like more of a presence and a voice, because often they're not able to.

R: And a huge part of that is somehow she has managed to continue to love a Church that has not always known how to love her well. And would love to see more connections between her ME/CFS community and her church community. But this whole episode is a huge gift of her time and energy.

S: We're very appreciative of that, and I hope that those who listen to this podcast, I hope that this will be helpful to you as well. Whether you know somebody who's dealing with ME/CFS or something else like it, or whether you yourself might be in that situation, or even if you just file it away for the next time you speak with or encounter a situation where somebody is facing something so exhausting that they feel like they're being left behind by everybody else, keep in mind some of what we talked about.

[music interlude]

R: You have been listening to The Accessible Altar: a podcast at the intersection of faith and disability hosted by Robyn King and

Stephanie Shockley. We record on the tradition land of the Leni Lenape and Treaty 6 territory.

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[closing music]