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Proem 00:53

Often, lately, listening, and reading about people coping with Covid19 makes me weary, weary, weary. Pent up grief, draining sadness. I’m building more Covid-free time into my days, especially first thing in the morning and the last thing before I go to bed. Instead, I’m reading Lord Peter Wimsey short stories by Dorothy Sayers, a Jack Reacher tale by Lee Child, and Avenue of Mysteries by John Irving. Mindless, not mindful. Thankfully, talking to my friend, Sara Lorraine Snyder, enervates and uplifts me. Not mindless, not sad, hopeful. If you follow my podcasts, you might remember Sara from my podcast series on [Young Adults with Complex Conditions Transitioning from Pediatric to Adult Medical Care](#). We heard from Sara and her mom, Alexis. I’m grateful Sara agreed to satisfy my curiosity and share her experience in the Covid19 world.

Managing uncertainty and life change 02:20

Health Hats: Sara Lorraine Snyder. I love that I'm talking to you again.

Sara Lorraine Snyder: I enjoy talking to you as well. How are you?

Health Hats: I guess I'm a little frazzled. My stress threshold is lower, higher, - I don't know which it is - meaning that sometimes I feel like I'm going to cry over something stupid.

Sara Lorraine Snyder: I feel that, too. That's what everyone's feeling like these days.

Health Hats: I was talking to somebody earlier about managing uncertainty. One of the things about people like us who have a chronic thing going on is that our sense of what to expect in the future is a little less certain than the average person who just assumes that everything's going to be hunky-dory, like forever. We realize, well, not so much. I may have more resilience because I'm accustomed to it. But still, this amount of uncertainty is crazy-making.

Sara Lorraine Snyder: Yes, definitely.

Health Hats: So, how has this Covid19 insanity been affecting you?

Sara Lorraine Snyder: Definitely had its ups and downs. The way that I reacted to quarantine and isolation was different from a lot of the people surrounding me. I think in the immediate when it first arrived in my town; I was freaking out. I was so upset because 'I'm never going to see my friends ever

again. Everything's going to change.' For the first week or so, I was not at my best. But then as time went on, I adjusted, and I got used to it. I guess I accepted that this is what's happening, just taking everything one day at a time. I feel like a lot of people at first were accepting of it. 'This will blow over soon,' and now everyone's feeling the stress of it all. Because school's canceled, everything's closed for an indefinite amount of time. I reacted in the opposite way. I was upset and then fine. And everyone was fine and then upset.

Health Hats: That's interesting. Some of the milestones for you are off. Weren't you going to the prom with your boyfriend?

Sara Lorraine Snyder: I was.

Health Hats: That's a big deal.

Sara Lorraine Snyder: Yeah. A lot of things got messed up. Junior prom and senior prom have both been canceled. Graduation's up in the air for my senior friends.

Health Hats: Was there a period before there was a quarantine, and schools were closed where you and your mom and dad were trying to figure out what this meant for you? Did you have to take different actions because you're more susceptible?

Sara Lorraine Snyder: Not really. It was weird when Covid19 first started spreading on the other side of the globe. Everyone here was just, 'Oh, it's not that bad. It's just like the flu, and not a lot of people are dying.' I was one of those kids that thought everything's fine. But then as time went on and the virus progressed, and it traveled over to the US, we still didn't understand because the virus hadn't picked up to the point where it was as catastrophic as it would be for a person like me, yet. So, it didn't start to affect how I was going about life and planning things until it was knocking at our door.

Health Hats: Are you doing different stuff in terms of seeing your doctors, medications, and - do I remember correctly - infusion?

Sara Lorraine Snyder: No.

Health Hats: No. Okay. So how has that stuff changed?

Sara Lorraine Snyder: Luckily, I haven't had a lot of doctor appointments scheduled during this time, so there was nothing that we had to cancel or do over telehealth. All of that is okay. It's more the parts of normal life of seeing friends, going outside, that have changed.

Health Hats: So, are you going outside?

Sara Lorraine Snyder: We try to go for a walk around my house once a day. But the weather is not always the nicest. So, there are some times where I don't walk for a week.

Health Hats: Oh, my goodness. That must feel weird.

Sara Lorraine Snyder: Almost two weeks. It is weird, especially since going outside and being in nature is something that I've enjoyed since I was a small child. I'm not seeing any of my friends in person, so that was a shift as well.

Health Hats: I miss hugging people.

Sara Lorraine Snyder: Yes. I agree. I can't even love my cats anymore because, apparently, now they can get it.

Art and music in Covid world 09:09

Health Hats: Oh, you're kidding. That's seriously annoying. Have you found new ways to do stuff that you usually do since this pandemic began?

Sara Lorraine Snyder: I don't know if it's a new way of doing it. Well, some of it's new, but it's doing more of it. I play way more music and do a lot more art than I think I ever did in "normal" life.

Health Hats: Playing music, meaning listen to music or play the guitar or both?

Sara Lorraine Snyder: Both. All of them, but especially playing guitar. I have been able to be a part of a lot of virtual events. I am participating in a virtual music festival.

Health Hats: Seriously? How's that work?

Sara Lorraine Snyder: Everyone sends in a video, and they're making episodes and releasing them every couple of weeks. Mine's going to be in the next episode, so it'd be dropping in a couple of weeks, which is very exciting.

Health Hats: It's a series of solo performances?

Sara Lorraine Snyder: Yeah, it's a series, and in each video, there's probably five to ten performers. There are a lot of us. It's all the kids from my high school. All of us that make music and go to shows together. It's fun to see everyone that way.

Health Hats: I've been getting together with this guy that's in the blues funk band I play with. He's been using Audacity (a sound editing app) to lay down some tracks. He plays percussion and has a synthesizer. I've been trying to learn to use my Bari sax as a bass instrument. He sent me this Audacity file with four tracks, a click track, and then four musical tracks. Then I'll lay down, a Bari bass part and an improv part. I'm a little nervous about it, but what's the worst I can be – terrible? So, we'll see. It is kind of interesting. What else are you doing differently besides the music?

Sara Lorraine Snyder: I've also been in a couple of virtual open mics and poetry readings and lots of virtual art. I've had time to look into colleges. I had a college interview last week, and I have another one with the same college this week.

Health Hats: Wow.

Sara Lorraine Snyder: But as to going about things differently - normally, I never go to stores. I never go anywhere with people. I'm in the house, basically 24/7, with lots of handwashing. If I touch anything that's been out of the house and sanitizing my phone and my parents' phones.

Health Hats: So, are you getting along with your parents?

Sara Lorraine Snyder: It's going better than a teenage kid stuck at home with just their parents could expect. It's going pretty smoothly and weird because we haven't spent this much time together since I was a baby, and I don't remember that.

Health Hats: It's my wife and me here. We're getting along great, thank God. Wouldn't it be weird being stuck in a house with somebody you don't really like or that you found annoying? That would be tough. You said you were doing, poetry and art. Do you have any clips of you reading your poetry that you'd like to share that I could put in the show notes?

Sara Lorraine Snyder: I don't have anything published, but I do have videos and recordings of mine.

Health Hats: If you don't mind, I will share them in the show notes, and people would get a sense of your many talents

Sara Lorraine Snyder: For sure.

Long term changes in habits 13:59

Health Hats: Cool. What do you think, this is the only been six, eight weeks? Do you believe that there's stuff that's changed that you would want to keep doing once things opened up again?

Sara Lorraine Snyder: Hm. I think, well, I know that I'm going to have to now always be more careful about washing hands more so than I ever was, and all of that sanitizing things because this isn't just gonna up and leave one day. It's gonna have a season. Yeah. But we can only hope that it's going to be nicer next time. So, I'm going to have to make, you know, be more cautious about making sure everything's clean, washing hands before you do anything. But as for just things that I've started to do. I mean, I always play a lot of music and do a lot of art regularly in life to keep up my happiness. So, I will still make a lot of music.

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High school to college 15:54

Health Hats: I'm sure I've asked you this before, but I don't remember. So, what are you going to study when you go to college?

Sara Lorraine Snyder: I want to study to become an expressive arts therapist.

Health Hats: Perfect.

Sara Lorraine Snyder: It combines everything. I'm speaking with a college that has that program this week. I'm chatting with some of the faculty in part of the program to learn more about it. It's fascinating.

Health Hats: I think when you have lived experience, passion, and curiosity, that's a magic combination. Good for you. So, how are your friends managing?

Sara Lorraine Snyder: They're doing okay. My closest friends that live near me are all seniors, unfortunately. So, a couple of them said, 'this is what I've been waiting for my entire life. I'm so excited to be a senior.' So, they're bummed out right now, which is sad because we can't do anything about it.

Health Hats: So, no partying?

Sara Lorraine Snyder: No prom. Right. And no having lunch together every day and talking about our days. But as for my friends: one of them is taking a gap year, and one of them is going to college locally, but my boyfriend, on the other hand, is going to Ohio.

Health Hats: Yuck. That's not very nice of me.

Sara Lorraine Snyder: No, no, no. Yeah, I felt yucky at first trust me. So, it's hard just waiting for this to be over so we can go and live out the best lives we can before everyone goes their separate ways. But other than my friends preparing for college, accepting the end of their years, they're all doing relatively well and still being creative. All of us have a lot of creative outlets, so we're trying to keep our heads up.

Health Hats: Are there people in your circle or your adjacent circles who are having challenges with this?

Sara Lorraine Snyder: Well, one of my friends is a germaphobe, so she's had a couple of moments where she was like, see, I told you so. But as she has adjusted to the quarantine, she's been doing okay. One of my best friends that live far away, she was having a bit of a rough time, ups and downs, but that's normal for anyone these days. There's no one that I'm very worried about. If anything, if my friends were answering this question, they would all probably say they were worried about me and no one else.

Health Hats: Isn't that sweet. That's really nice. That means they give a shit.

Sara Lorraine Snyder: It's good to find those people.

Health Hats: It's priceless. So, what should I be asking you about this craziness?

A leg up with lived experience 19:48

Sara Lorraine Snyder: Something that I can add is that as a person living with a disability, we're already used to the world being able to hurt us or bring us down. Whether it's from other people judging or saying things or your body being funky and doing not the best things - not behaving in an optimal way. So, I guess just knowing that now there's something, especially for people like me living with lung conditions and whatnot. Knowing that there's something that can very well take us out if it so pleased. It feels not real. It feels fake. How is this possible? This is like every sci-fi movie that I binge-watch. How is this happening? At the same time, everyone's getting used to it, which is almost more alarming than the fact that it exists in the first place. We're all saying 'just wear a mask, and when you go out, don't touch anyone. It's a very strange time.

Health Hats: Yeah. I think that we're in the middle of it. Let's deal with it is resilience. But then as it starts to get so long, that it's hard to keep the positive up or things are getting better and then people are feeling weaker. In my experience, working as a nurse, one of the things that I find is as people start to get better, that's the riskiest time because they let their guard down and they overdo it. They don't realize that healing takes time. This has been traumatic. As things start to get better, then people

overdo it. Or all the freak out that they've been suppressing, trying to keep a stiff upper lip, then it all comes out. I was talking to somebody who I interviewed maybe a month before I interviewed you last time who talked about the medical PTSD she had gone through being in an ICU and having organ failure and being on a ventilator - all the PTSD she had to deal with. We were talking, and she's thinking that the next epidemic is people recovering, which is stressful. Maybe I'm an idiot, and you can call me on it in a year when we talk again, but I feel like we're more used to those ups and downs. We go through these crises, and then we find a new equilibrium, and we suffer a little bit just getting back to that new equilibrium and think, 'Oh my God, what happened to me?' And then you're afraid this is going to happen again. And every little symptom is like a significant flare when it isn't, we have experience with that, so it doesn't seem so weird to experience it again. Anyway, Sara, I love talking to you. I'm glad you're doing as well as you're doing. I know we're going to stay in touch, so thank you.

Sara Lorraine Snyder: Thank you for inviting me.

Health Hats: Sure. Hug your mom for me. It kills me that I can't hug my grandkids, my sons. That's the worst. I'm glad that's the worst. I'm not wanting for food; I'm not wanting for income, housing. It's the hugs.

Sara Lorraine Snyder: Wanting for hugs.

Reflection 25:16

A month ago, I said this on my podcast. It's worth repeating:

Sixty-one million people in the US have different abilities than you, temporarily able-bodied people. We have a 15-minute advantage on you. We know how to deal with unwelcome, strange circumstances. We know how to ask for and offer help. We know how to build a team. We know how to navigate from a chair, a bed, a fog, in pain, with canes. We know how to live at peak performance with a dizzying array of conditions, circumstances, and confusions. We have a 15-minute advantage on you. Don't underestimate the importance of fifteen minutes. You need us. We want to share and teach. We have much to share and teach. We are not expendable. When you have the opportunity and bandwidth, reach out to the less able-bodied. Spend some time with us. Connect, listen, learn, and appreciate. You won't have far to look for us. We're everywhere. We are in this together, me and you and the world.

Stick around and listen to [Fred Small singing the Talking Wheelchair Blues.](#)