

# 16, Sophomore, All-in Transitioning from Pediatric to Adult Medical Care

03/17/2019

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## Podcast introduction

Welcome to Health Hats, empowering people as they travel together toward best health. I am Danny van Leeuwen, a two-legged, old, white man with privilege, living in a food oasis, who can afford many hats, and knows a little about a lot of healthcare and a lot about very little. Most people wear hats one at a time, but I wear them all at once. We will listen and learn about what it takes to adjust to life's realities in healthcare's Tower of Babel. Let's make some sense of all this.

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## Sara Lorraine Snyder 00:49

“If you were playing with the team for football or whatever and then they come you come in the next practice and half of your team is completely new people that you don't even know and then you don't know how to effectively work with that team so that in the end of the day you can win or like achieve, whatever you need to.”

## Series introduction 01:18

Welcome to the Health Hats podcast series about young adults transitioning from pediatric to adult medical care. In this series I will interview young adults with complex medical conditions, their parent or guardians, point-of-care clinicians caring for these young adults, and whoever else I find of interest in this fascinating, frustrating, heart-breaking, and inspiring world.

My first interview was with Jill Woodworth, a mother of four children (ages 14-22), three of whom have Tuberous Sclerosis. This second podcast of the series is with Sara Lorraine Snyder who you heard briefly and eloquently a moment ago. I'll let Sara introduce herself. Our next two podcasts will be with Sara's mom, Alexis, followed by the two of them together.

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## Introducing Sara Lorraine 02:48

**Health Hats:** I really appreciate you taking a few minutes with me. Tell me a little bit about yourself.

**Sara:** First off, my name is Sara. I'm 16. I'm a sophomore in high school and my entire life I've lived with chronic medical issues. It's just consists of on a daily... I guess, fatigue and stuff. there's a lot more to it than that, but I don't it's not really the purpose of why I'm here today. Yeah.

**Health Hats:** Okay and you're a musician.

**Sara:** Yeah. I am a musician.

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## Who's driving your car? 03:25

**Health Hats:** Yes, that's great. So, if your health was like driving a car who's driving your car?

**Sara:** I'd say it's pretty like let's say it's a long road trip and it's pretty split between me and my family especially my mom because she's the one that's always looking out for me and making sure I'm getting all the care I need in order to be successful in daily life and attending school and stuff like that.

**Health Hats:** Are you learning to drive?

**Sara:** I'm not I'm not learning to drive. Legally I could be learning to drive but haven't started yet.

**Health Hats:** Are you learning to drive your health?

**Sara:** I am learning to drive my health because I've just been in this the health world for so long now, that I'm learning the ways and how to advocate for myself so that I'm able to one day do when I'm not living at home or just out in the world able to do it on my own.

**Health Hats:** How's that going?

**Sara:** It's going pretty good. It has its ups and downs. But yeah, It's definitely harder than it probably looks from the outside because like there's always things that can go wrong. There's always complications and stuff. But yeah, it's interesting.

## What does health look like to you? 04:57

**Health Hats:** It is interesting. I agree. Sara, what does healthy look like to you? That make any sense?

**Sara:** You mean like a healthy average person or do you mean my health?

**Health Hats:** For you? Like you were just saying there's ups and downs, and which is the human condition, there's always ups and downs. And so, if healthy is an up and not healthy as a down, what does healthy look like for you? Days when you feel like it's going good?

**Sara:** Probably being able to get out of the bed in a reasonable amount of time because mornings are always the hardest for me with fatigue and stuff and being able to like do more extracurriculars that day being able to go out after school and stuff without having to come

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home and rest so that I can do my homework and all that and have the energy to give my work my all. Just like throughout the day not feeling drowsy or anything. I just forgot what I was going to say.

## Accepting me for who I am

**Health Hats:** Okay, we're talking about what healthy looks like. In my experience, so I'm old. I'm in my 60s and so teenage years are like well behind me, but I do remember a little bit about those days, and I felt like being a teenager in and of itself was kind of lonely. And then now that I'm a person with a chronic illness. I have multiple sclerosis. And now even though I have a great family that are very supportive. I am part of different communities whether their social media communities or life communities that are very supportive. I still feel like there are times having MS that it's kind of lonely. I'm wondering for you, how do you stay connected to, try to manage loneliness that comes with having something you're dealing with all the time?

**Sara:** I think in my classmates' perspective and especially like people that I'm friends with at school. I think my school is a very accepting community of everyone. So I don't really find it a problem with feeling lonely at school because like even if you don't have immediate friends at school everyone accepts everyone for who they are. That's something I'm very grateful for because I don't have to go through the hassle of feeling lonely or eating alone and stuff because everyone's just able to look past the fact that I'm different and like include me and I think it also helps that I've always been a very social person and just like want to be everyone's friend because I know everyone has their differences and stuff. It really doesn't matter at the end of the day as long as everyone's able to have good conversation and have fun. And I think that's how my school is, too. So, I don't really have the loneliness battle that some people do.

## Looking forward to adulthood 08:23

**Health Hats:** Oh, that's great. It's great that your school is like that. Yeah, that's a gift. Oh, my goodness. When you look ahead to what, you said you're 16, so if you look ahead to becoming an adult what are you looking forward to?

**Sara:** Probably. I mean, it's like this is kind of like a bittersweet thing more like Independence and stuff and more relying on myself. But the bitter part of that is you're not always going to have someone there to like to lean on for stuff necessarily and also with schools and stuff and the stuff that you're learning. There's a lot more options than like high school because you have

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to learn like math and science and all of that stuff but like when you're in college or after that it's kind of like you're taking the wheel on that type of stuff.

## How do you manage? 09:20

**Health Hats:** Yeah, so you're taking the wheel sort of managing yourself where you're headed in the decisions you're making about your life. Okay, that makes sense. Let's think in terms of more tactical. A part of living with illnesses is there so much to manage, whether it's appointments or paying for everything, insurance. Let's so the start with the you know, it just the logistics, appointments and getting the stuff. So, how is it that you're seeing the that transition of that you're coming out of a pediatric care world and going into an adult care world? How does that look to you?

**Sara:** I think it's little scary but also kind of supporting the fact that you're taking the wheel and you're being more independent because like an adult medicine they're not only doctors and staff aren't always going to exactly, like what your parent help you when you're trying to explain what's going on or symptoms. You've been having? But I think it's going to be. Good because like by the time you're an adult you should be at the age where you have consciousness of your body and what's going on. So it's really like a test to see how well you can take care of yourself in some way, I guess.

**Health Hats:** Mmm-hmm. Test. It's always a test. Isn't it? I feel like for me I feel like it's always an experiment, sometimes stuff works and sometimes it doesn't and then okay, it didn't work. What do I do now? Alright. I used to work at Boston Children's. One of the things that I noticed is the challenges that people who had Pediatric stuff happening to them that were being treated comfortably in the Pediatric world than there are some things that the adult world just was not equipped to handle because they were you know, so unfamiliar with it and what I probably know more about is people who have had sickle cell where that was very comfortable in the Pediatric world. It was really hard to find adult doctors and nurses who were familiar. is that something you're dealing with?

**Sara:** A little bit. I think because on the outside I look like the average person who's able to like function in a normal way. Sometimes it's challenging for new doctors, especially to understand all of the pieces and like hey, this is actually going on because they're well on the outside, you look good, but that doesn't mean on the inside everything's good.

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## How would you advise other young adults? 12:51

**Health Hats:** Right right, right. Okay. Yeah. Yeah appearances are deceiving. I feel like you know people tell me oh, man, you look so great. I do look good and I'm basically doing good, but it doesn't mean that I don't have my issues on the inside. If you were thinking about other young adults that are trying to manage the transition to the adult medical community. What would you what would you advise them?

**Sara:** I think to just you know your body the best so if someone comes along and disagrees or like challenges what you're saying you feel just to have patience and just like put yourself first and don't start doubting yourself or feeling like you're not being taken care of. Yeah, you know what I mean?

**Health Hats:** I do I do. That's quite that's some wisdom there. Yeah. How much did your mom have to do with this confidence you have in yourself?

**Sara:** Probably a lot because over the years just watching her schedule appointments and like make sure I have everything I need and make sure all my prescriptions are going through and dealing with all of that chaos, you know, it's sometimes really stressful and stuff. But she does it all anyways. So, I'm just learning from her to have the strength to be able to face all of that stuff head on and face doctors who might not be like a good fit for you so that you're able to at the end of all of this be on a steady road so that you're going to be maintaining your health in the best way that's possible for you.

## First discovering health issues 15:03

**Health Hats:** Mmm-hmm. That's great. So. If I asked one of the things that I'm going to do is have this conversation with your mom and then if you're up for it, I would love to have a conversation with the two of you together. Yeah, because I really think going from the center out, there's you and what you have to deal with. There's your mom and how she's supported you and then there's the relationship which is wonderful and challenging and whatever. Okay, where were you or what was happening can you paint a picture of when you first realized that you know you were a person with health issues? it's not like, you're one year old and you realize you're just, living your life. But when did you... like what happened or how tell me it? Can you tell me a little bit about that that?

**Sara:** Yeah so, I don't think I realized I was realizing that I was different. I actually thought it was really annoying but now looking back on it I'm oh yeah that makes a lot of sense. But it was on

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the playground. And I was probably in second grade, first grade. I was with my friends and every day at recess we'd play tag, and all of the kids could like run and run and run and I'd have to take lots of breaks to catch my breath or rest my legs for a bit. And now I'm realizing it was because my health was definitely more fragile, and I definitely needed more time so that I was able to continue throughout my day without completely like crashing. But yeah, like I said before I didn't realize that's what it was. I was just like wow, this is really annoying. Now I can't catch that kid.

## Transitioning from pediatric to adult medical care 17:13

**Health Hats:** Yeah, I'm just thinking about what would make it easier for you to manage this transition from the pediatric medical world to the adult. What would you like to see that could make it easier for you?

**Sara:** I don't know. Probably just because in Peds, all of the doctors are very like caring and give you your time to speak and make sure that you've got everything and that they can help you in the best way possible. I think it's probably patience. For the doctors to have patience to be willing to take in everything you're saying because I feel like with kids it feels like a lot more important. If that makes any sense? And then in the adult word world, it's just like. Oh, okay. Well, you're an adult now you're doing okay. So just come back and see me in a year, but there's definitely more to it than that. So, like I don't know what the word to describe that is exactly. But yeah,

## Do you have a primary doctor? 18:33

**Health Hats:** Do you do you have a primary care clinician now that you anticipate you'll be able to see for more years. Who are you? Yeah. Oh, that's good. It's so hard to it's hard to shift.

**Sara:** Yeah, especially when you have so many doctors. Like I have like thousands. No, but I have a lot of doctors. So, like that is definitely a lot of shifting because most of them are at Boston Children's so like that's a children's hospital. So. Just like the jump from that it's like you're almost losing everyone that you've developed relationships with over the years. So, it's easier to talk to them about your symptoms and stuff. And then you're just jumping and like you have like a whole new team. Yeah, that's like. It's kind of like if you were playing sports, I don't know if this is a good metaphor. If you were playing with the team for football or whatever and then they come you come in the next practice and half of your team is completely new people that

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you don't even know and then you don't know how to effectively work with that team so that in the end of the day you can win or like achieve, whatever you need to.

**Health Hats:** Yeah, that's a good metaphor. When you said yes about the primary care physician. Now who's your - I don't mean who, meaning Dr. Jones. Yeah. Who's the central clinician that you have? Is that somebody at Children's?

**Sara:** There's kind of a tie between someone who's at Children's and someone who's at another hospital who's actually is a more recent doctor. Okay, but it's working out really well and they're really trying to take all of the pieces and make sure they make sense and see if he can get anywhere with the symptoms that I have.

**Health Hats:** Oh, that's good. And so, and then the adult referrals will some come from that primary doctor and some from your current specialists who are handing you off.

**Sara:** Probably what's good is I think the newer doctor is also seeing adults too, but I'm not I'm not sure. But the new doctor is not just at a children's hospital. So, there's probably more of a possibility that I could continue seeing him.

## How're you going to pay? 21:28

**Health Hats:** How are you gonna pay for all this shit?

**Sara:** Hopefully insurance, but you know, you never know where life takes you. If you win the lottery. But. Yeah, everything now is paid for by Insurance thank God. Hopefully that's how it will continue to be. But yeah,

## What about college and music? 21:57

**Health Hats:** So, are you thinking now about college?

**Sara:** I wasn't but in school we have this it's basically home room, but we only go once a week. It's called advisory and every week they've been putting us on college websites and seeing like what college is best suit us. So like now I'm like kind of forced into thinking about college even though I really don't want to be. But yeah, I have a general idea of what I want to do with my life but not exactly.

**Health Hats:** Yeah. Do you do you see trying to make money in music?

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**Sara:** I do because one of the things I'm interested in would be taking music and putting it to use to make people happy or feel better. So, one of the things I've been talking about with my parents and actually some of my physicians who said that it would be a really good idea is being a music therapist. Yeah, and there's a bunch of colleges around here that have good programs for music therapy. So that would be really fun. But I'm not quite sure yet. Yeah.

**Health Hats:** Well, it's early days yet. But yeah music therapy, art therapy. This is sort of meaningless, but in my career, I've been really good at my work. I'm a determined amateur musician that I have more determination than talent and it's so interesting to be doing something that's not work that I'm not really good at but I really see how music helps me. So, for example, my neurologist, I have MS, and my neurologist says that whenever I see him, he asked me, have you fallen and are you still playing the saxophone? And his rap is that. Yeah, so I play a baritone sax. So that's a big horn takes a lot of wind and he said without playing the horn I would have more much more trouble breathing because the MS would affect my breathing muscles and that it's a big horn with big heavy keys I play five, six hours a week and so my hands my dexterity is better and it's good for bring, you know brain pathways, and so he says, I got nothing you know to offer you that comes close to the benefits from playing the saxophone. Which I love that. First of all, I love that he says that, and it makes me feel like I'm playing music that I'm fair at but it has benefits and I think that so I really see that it uses such a different part of my brain, just to play And anyway, so well, hey, I really appreciate that you're spending this time with me and that you'll chat with me again down the road. Yeah. I'm talking with another young lady the middle of next week and I also know her mother and so I'm thinking of trying to do the same thing, and then putting all that together into one episode.

**Sara:** Yeah, that would be cool.

**Health Hats:** It would be interesting. I'm excited about it. So I'll let you know and the next thing I'm going to do is reach out to your mom again and schedule. So we know each other through, you know work that we do together and so, I appreciate that she's introduced me to you and that you've agreed to chat with me and if there's ever anything I can do for you. I'm here.

**Sara:** Thank you.

**Health Hats:** So, take care.

**Sara:** Thank you.

**Health Hats:** Okay. Have a good day.

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**Sara:** You too.

## Sara's all-in 26:13

Sara's all-in. One the one hand, she doesn't have a choice. It's the cards she was dealt. On the other hand, she's blessed with a strong family, a welcoming school, self-awareness, and curiosity. I'm fortunate to have met Sara.

Next podcast you'll meet Sara's mom, Alexis Snyder. Here's Alexis:

"the healthcare system isn't always so empathetic. No matter what age you are. And I think that the players in the Healthcare System needs to remember that again life is a transition. And not everybody it's not so black and white the transition process from adolescence to young adulthood or young adulthood to adulthood. There's no definitive time period. And I think the health system to organize itself needs a needs a cut off and they need a definitive period of time. Not everybody matures at the same rate. Not everybody is ready at 18 to take on a larger role."

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