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Proem

My privilege offers little experience with the loneliness of severe illness without reliable support. Meaning I have fantastic support. I seldom experience profound loneliness. Hope and support go together. Hope and support provide a foundation upon which to build spiritual health. Spiritual strength



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hastens recovery toward best health. Much support comes from caregivers, be they family, friends, or professionals. Caregivers are necessary for best health for those of us with disabling chronic or acute illnesses. Hence, the second episode in this series about emerging adults with mental illness centers on a mom, parent, and caregiver: Erika Blair, mother of Emeka Chima. I'm grateful to Erika and Emeka for their willingness to share their journey with us.

Challenges of multi-media. A note to followers. 01:14

I realize that my inclusion of video in my production channels can create some dilemmas for readers and listeners. You can't see the videos and might miss guests' body language, scrolling images, and print. I try to stay aware of these dilemmas. When I started my podcast, many blog followers thanked me for my years of content creation and prepared to move on. Not wanting to lose a loyal audience, I created article-grade audio transcripts. Verbatim audio transcripts underwhelmed me, so the effort to edit for readability was worth the many hours' effort to edit for readability. I use the app, Grammarly, to help me. Now I spend much of my time learning the nuts and bolts of video production, with help from my grandson and thoughtfully using alt-text for images, so followers with limited sight can appreciate those images. For those not looking at the video version of the podcast, please let me know when something in the audio doesn't make sense because you're missing something. Help me learn. Email me at danny@health-hats.com or go to my website, health-hats.com, and leave a comment.

Podcast intro 02:48

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen a two-legged cisgender old white man of privilege who knows a little bit about a lot of healthcare and a lot about very little. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.

Health is fragile 03:22

Health Hats: Erika, thanks for joining me. I appreciate it. When did you first realize that health was fragile?

Erika Blair: Oh, when did I first realize health was fragile? I realized health was fragile from a young age. I've had a lot of health issues growing up. So, I've always known that. Is this specific to my son?

Health Hats: No, I was asking about you.

Erika Blair: I've always known that health is fragile. I had a lot of GI issues growing up. I had a lot of surgeries from a young age, more than many people.

Proud of your son 04:19

Health Hats: That must be challenging. You must be proud of your son.



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Erika Blair: Very proud of him. He is not only a great help and support to our family and me, but he has so much to give to others, which is very inspiring. I am so honored to have him as a son.

Getting to diagnosis 04:50

Health Hats: Emeka welcomes you to speak with me about your journey together. But there must have been a transition from everyday parent-child tension and conflict to the kind of teamwork that seems like you have. Can you tell us something about that evolution?

Erika Blair: We must step back to when he was first diagnosed with schizophrenia and had his first onset, his first psychotic episode. It happened as a teenager. Even before that so, he was diagnosed with autism as a child. I always knew there were some social and sensory things. So, I took him to therapists, and I knew something because he was always very sensitive to light and sounds and very precocious when it came to academics. He was reading and doing exceptional math at two, like computing big numbers. And he was reading the chapter book Harry Potter by the time he was five. But socially, he would just get so sensorily overloaded. The schools would never do anything because he was so academically exceptional. But I knew there was something more than just academics. I knew there were some other things. He was diagnosed with, at the time, [Asperger's Syndrome](#), now with [DSM V](#) Asperger's now falls under the autism spectrum disorder.

Help in school 06:33

Erika Blair: When he got to high school, he was always academically gifted and musically. He started playing cello at a young age, played in the youth symphony orchestra, and took high school-level classes by middle school. By the time he got to high school, with all the social pressures of high school, you're taking all these college-level classes academically. He was taking calculus as a freshman, but the social aspect was just so overwhelming for him. And I think something happened because that social piece was always a challenge. I could never get an [IEP \(Individualized Education Plan\)](#) even though I fought for the schools. They would never give him an IEP, even with Asperger's. Because they felt nothing impacted him academically, he never got any help from the school system. But he did end up having a psychotic break. Cause I think it was the combination of the school pushing him academically and then trying to fit into social norms as an awkward teenager. It was tough.

First psychotic break 07:36

Erika Blair: He had his first psychotic break. That was very devastating. It was scary because we didn't know what was going on. It was scary for him. He was terrified. Scary for us as a family. And that's when he was first hospitalized at about 16. It went on and off for about a year, in and out of the hospital with psychotic breaks. He didn't know what was happening. At first, they just call it psychosis. And then, I guess, after a certain number of episodes, they gave the diagnosis of schizophrenia on top of the autism.

When we finally had a diagnosis, they kept trying different medicines. A lot of medications would not work. They tried everything. He would still have so many symptoms. It was scary for him. And then he would come home and have to go back to the hospital again, and he missed birthdays and holidays. As a



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parent, it was challenging to see your child go through that; he was such a wonderful child. To see a child suffering like that is the most heartbreaking thing. It was complicated. I was also pregnant at the time with twins, so it was hard on my pregnancy. But I just made an effort. I wanted to get him better and get him help. That was my focus. That's all I wanted to do.

Finding integrated help for the family 09:03

Erika Blair: So, I did research. I was looking at programs. I found [Johns Hopkins' Early Psychosis program](#), which Dr. Carolyn Howe ran. And I saw that early psychosis programs in my research provided the best outcome for those newly diagnosed with schizophrenia and psychosis.

Health Hats: Were those services for both him and you? Like parents and child?

Erika Blair: Yes. He was hospitalized, in and out, for a year. Different medicines did not work. They worked to a certain degree, but they did not stabilize him. So, we got him into the early psychosis program. He was released from the hospital and brought into the early psych program. The way the early psychosis programs work, it is not a hospital. It's not an inpatient program. It's like a more holistic approach. So, the patients come one day a week to meet with the psychiatrist for medication management. You also have a recovery coach, somebody that meets you. They would work with him in the field. So, they would meet him at school. And then, the employment support coach helped train him in vocational and professional skills. Then the parent component. Parents would come every other week. Overall, a more collaborative team approach to recovery. And the focus is on recovery. And that's why you have a recovery coach, too. Once he got in that, he got on clozapine. After that, he never was hospitalized, knock on wood, again. It's a very supportive approach. You're looking at helping the person from every aspect to reach their full potential.

Goal-based care 10:44

Erika Blair: It's goal-based working with the recovery coach to set his goals - what he wants to achieve for himself. He set where he sees himself in the next year. Where does he want to be in two years? You make strides towards those goals. And as I said, it's collaborative. The parents are involved, so you do have the parent meetings, you're involved. And I think that it's a very successful program.

IEP finally 11:18

Erika Blair: Let me take a step back. When he finally got the diagnosis, after all the years of fighting for IEP for him, he finally got an IEP for school.

Health Hats: What does IEP stand for?

Erika Blair: It's called Individualized Educational Plans, supportive services for school. Keep in mind that he was already a sophomore. He was 16 when he had his breakdown. So, he missed the school year



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because he was in and out of the hospital. Because of that, they thought now this was impacting his education.

Finally, I fought the school system. I advocated for him getting him an IEP. Then he was able to get private placements for high school. It was a private high school called Hannah More in Baltimore. [Shepherd Pratt Hospital System](#) runs it. It was for students with IEPs who had emotional disturbance and autism. Emotional disturbance or autism. So, he was able to get support while he was in high school. And he did that for a few years.

Transitioning back 12:17

Erika Blair: At this point, he already had enough credits. Remember, he was always taking high school classes and only needed two high school credits to graduate at this point. He was about 17 at this time, and he was classified as a senior because he still needed two classes. But because he only needed two classes, they let him do dual enrollment. So, he was also enrolled at Baltimore City Community College. And they allowed him to take classes he didn't have to pay for because of his IEP. The school system pays for everything.

Health Hats: That's a great deal. One of my sons did that too. He did his senior high school year at the community college. So, he got dual credits.

Erika Blair: It saves a lot of money

A word from our sponsor, Abridge 13:00

Now a word about our sponsor, [ABridge](#). Record your healthcare conversations with doctors and other clinicians with Abridge. Push the big pink button and record. Read the transcript or listen to clips when you get home. Check out the app at [ABridge.com](#) or download it on the Apple or Google play store. Let me know how it went.

Freaking out together 13:44

Health Hats: It seems like you were blessed in the relationship between you and your son. This whole experience was like freaky together as opposed to freaky apart. Is that true? Do I hear that right?

Erika Blair: Yeah. It was scary for both of us, but my goal as a parent was just to get him to recovery. Get him well, to get him help. And he was scared, so I wanted to help him. I needed to do everything I could to find resources. And all I did was reach out, research resources, and get him help. I have a technology background. I was working at FDA at the time, even though my focus has always been on medical technology and medical research. I'm big on looking medical research and seeing what is successful.



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Questions for professional helpers 14:51

Health Hats: So, you were familiar with how to go out and learn more? Wow. I wanted to ensure that when I started talking with administrators, teachers, and doctors for this series, I came from a place of lived experience knowledge. As I start talking with doctors and people who administer inpatient and outpatient programs and community services, what do you think I should ask them about? I predict they're going to talk about resources and staffing. I'm expecting, I don't know, but that's what I think. But what do you think I should be talking with them about that would interest you?

Do professionals have lived experience? 16:19

Erika Blair: When you're going out to the community with the lived experience? I think it's essential to look at the staffing, having people who have had that lived experience who are providing professional services for newly diagnosed patients and providing that support. I think that's asking because the doctor, certain doctors, and counselors have often not been to the experiences themselves. They're trying to offer advice, but what better advice can you give somebody who's newly going through this experience than somebody who's been there themselves and has been through that? And so, I think that's a good thing to ask. Do you have people on your team who are on your support team or staff team who have lived experience? That's an important thing to ask.

Giving back 17:14

Erika Blair: And that's what Emeka is doing now. Even before Shephard Pratt, when he was first diagnosed, he was hospitalized for a month at Shephard Pratt, an inpatient hospital in Baltimore. And then, as I said, he went to a high school that Shephard Pratt ran. Okay. He got graduated from college and has his degree. He's now employed and working as a peer support specialist through Shephard Pratt. Oh, that's great. He is currently on that team. As I said, he had an interdisciplinary team of psychiatrists, recovery coaches, and employment support who worked with him. He is now a part of that team, but being somebody who's been through that experience, I think it just brings so much more insight for newly diagnosed patients. Yes. To see, okay, wow. I can set my goal. This is the outcome.

Hope 18:10

Erika Blair: There's hope. It's okay. Yes, there is light at the end of the tunnel. There is recovery because you're at a moment when you're first diagnosed, and you're just feeling so helpless, and as a parent, you're like, wow. I'm in so many parent groups for parents with like schizophrenia. They don't see that there's any hope or any outlet. They just see the moment now. They don't think their kids can attend school, get jobs, and be productive citizens. But when you see when you're, and it gives people hope, wow, this is possible. Yeah. So, that's one thing I would ask if you had people who do have lived experience on the team.

Family on the team 18:49

Health Hats: We had a family member who had profound depression, and one of our challenges was that we could not figure out how to be included on their team. Do you know what I mean? It was like their treatment; their support system was extra. Extra meaning not with us, okay.



Erika Blair: They didn't include the family in the treatment plan.

Health Hats: That was hard because we didn't know how to act. We wanted to support the program. And it sounds like you landed in a program where you were part of it.

Erika Blair: Yes. And that's a big thing about the Early Psychosis clinic. The parent family support is a significant component. That is a component. Is that part of that collaborative team? Yeah. And again, I guess that's something you, it's an excellent question to ask too. Is the family part of that recovery team? Is that part of the team? That's very important because then everybody's on the same page. Everybody's working together for the same goal.

Early intervention 20:15

Health Hats: What advice do you have for parents living with a young adult with psychosis or severe mental illness? What do you recommend?

Erika Blair: I recommend getting early intervention services, getting help, and getting support immediately as soon as possible.

Health Hats: So, like you smell something wrong rather than there's some like a full-blown crisis.

Erika Blair: Yes. If you know that something's wrong. Yeah. Get help. The way they call it early psychosis is just within the first year or two, I believe. So first few psychotic episodes. So, once you realize there is psychosis in play, and psychosis can occur with not just schizophrenia but people with profound depression, bipolar, and anxiety. Different things can manifest psychosis. But once you see the psychosis, just try to get the support that addresses the need for help with people with psychosis. Yeah. Every state in the United States has early psychosis programs that you could look up in your city and find out. In these programs, they do offer social groups too. Also, I think it is good for individuals to realize that they're not alone.

Health Hats: Social groups. Like in person or virtual or both?

Erika Blair: Yeah. Partial. Virtual or in-person, or both. So, the early psychosis groups do offer some social skills groups. Emeka was always in programs that offered those services where he was with others with a severe mental illness. They would discuss different topics, do movie groups and outings, and go to the beach. During the pandemic, there was so much isolation, and everything shut down. That was hard for him because he was so used to going to these social groups in person. Yes. And that all closed down. That was a tough time. Because it was so much isolation, he found something called Students with Psychosis.



Students with Psychosis 22:29

Erika Blair: Students with Psychosis started as an in-person group. I think it was created at Penn State University. It was an international group for college students with psychosis at the time. It was initially called Students with Schizophrenia. Now we know psychosis not only has just a schizophrenia factor. There are so many different factors. It's an umbrella like autism is the umbrella. So, they started online services with the pandemic. He found this group and joined its online services as a student leader. Cause he was in at the time in college. He was a college student. Then his college was all virtual. He was just going to college in person, and your whole world shuts suddenly. And for him, it was so important to have that social aspect. That's always been part of his recovery because he needs to connect with people. So, it was tough cause your school is shut down, and all your classes are now virtual. You don't have your social skills support. But he found the students with psychosis, and they had different programming types of groups every day of the week. They had open mics. They would have silent dance parties online, virtual, through various web platforms, either Google Meet or on, Zoom or Instagram lives. He found a whole tribe of people internationally whom he could connect to. They were also college students going through the struggle he was going through, the challenges he was going through. They realized they were not alone and could support each other. They can encourage each other. When midterms are up, they would have little sessions to help people, or when finals are up to support each other. Cause stress can trigger psychosis. So, all the time, when you're in midterms and when you're a college student, any added stress can be havoc on your mental health. So, it would just be this outlet of students going through different things, and they would come together and support each other. He loved that. He found himself, became a leader, and started as a student leader. Now he's a secretary on the executive board, helping with planning the programming. I would say for individuals, finding groups like that is. Finding other individuals who are going through what you're going through. The point is not to feel that you're alone.

Positive support for parents 25:02

Health Hats: Before we wrap up, what should we have discussed that we didn't talk about?

Erika Blair: I'm trying to think. Where do parents turn? I guess that's the thing. It's so hard when you're in this situation. You don't know where to look. And as I said, that's probably the most challenging thing. Yeah. For parents, I would say, first, finding support groups. There are Facebook groups. There's NAMI that has groups, the [National Association of Mental Illness](#). They have parent groups. One caveat is to be careful because you'll see so many people, a lot of negative things, and there's not a lot of hope or success stories. So that'll bring you into a deeper hole.

Health Hats: That's so smart. I agree. I have found that I'm involved with different groups of people with lived experience, but if it smells negative, I drop it. I'm pathologically optimistic, and I want to stay that way. I don't want to mess with it.



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Erika Blair: Yeah, especially the Facebook groups, you'll find a lot of negativities where you don't see any hope. You will hardly see any success stories, to be honest. And when you do, is that possible? Like they won't.

Health Hats: I can see because people are suffering and they're feeling they're suffering and, that's, but I yeah. Anyway. Okay. This is great. Hey, thank you very much. Thank you much.

Erika Blair: Bye.

Reflection 27:09

As I reflect on this conversation with Erika, I'm struck by how proud she is of Emeka. She made such an effort to advocate for her son. She emphasized finding professionals with lived experience. She appreciated the integrated team. She values positive support and a sense of hope from other parents. The organizations I've worked with had leaders, in and out of the C-suite, clinicians, and peer recovery specialists with lived experience. I've spoken with others that struggle to build that kind of team, don't have peer specialists, and may or may not have Advisory Panels of people with lived experience. In my own family, we've experienced mental illness. In one case, the institution's licensed professionals provided little sense of hope. If one of the aides hadn't told us privately to hang in there, I'm not sure what the results might have been. Another time we couldn't become part of the team, but in fairness, our family member didn't want us to. Parents, family, and caregivers have such a brutal row to hoe. What experience have you had? What wisdom can you share? Help me learn. Email me at danny@health-hats.com or go to my website, health-hats.com, and leave a comment.

Health Hats presents the next episode with Annie Schneider, an emerging adult with her story about major depression, followed by an episode with Matt Neil, a high school teacher. Watch/listen/read here next. Show notes with an article grade transcript and links can be found on my website health-hats.com/pod.

Annie Schneider 29:19

I remember things were not right when I was 15, over ten years ago. I was not my best self in just a lot of ways. And I was struggling a lot. And I think my parents noticed it first. But eventually, I very quickly saw a lot of it. I was unfocused in school. I had a quick temper. I just had a lot going on that was not healthy. And, of course, many people, when we're teenagers, you have mood swings and all kinds of ordinary things. We're humans. We're all humans. But I was not like other 15-year-olds. So, it turned into a lot. I had a lot of preoccupation and obsession with negative thoughts and negative thought patterns and was unfocused in school.

I found out from my mom later on. She, of course, didn't tell me at the moment. Later on, I found out I just had a very glazed-over, glazed-over look on my face and in my eyes a lot of the time. I know it sounds cliché and kind of dumb, but I didn't have much of my spirit. I was a shell of myself starting at 15, at least. That was when it became like a healthcare journey to recover and get well.



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Matt Neil 30:23

I have a group of kids at our school called the Ambassadors running our new student program. About six years ago, our principal came to me and said, we have this population of students in our school that are being missed. I think they are lonely and dropped into our school community. Even though we're all very well-meaning, they're not supported. Will you do this? I said I would love to do that work. Our group takes a heart-centered approach. We just want to scoop these kids up and bring them on board. We have 78 current members. Every student in that group is teacher recommended for their ability to work with others, their kindness, their heart, and their willingness to improve the lives of others. When a new student comes in and gets a tour of the building, that's a detailed tour and the opportunity to connect with people. They get somebody to eat lunch with, and they get a check-in at the end of the day. And those three points of contact, as opposed to no points of contact, before making the student feel welcomed into our school community. And then the goal is to have that student remain a contact and a first friend for those students in our building.

Podcast Outro 32:13

I host, write, edit, engineer, and produce Health Hats, the Podcast. Kayla Nelson provides website and social media consultation and manages dissemination. Joey van Leeuwen supplies musical support, especially for the podcast intro and outro. I play bari sax on some episodes alone or with the Lechuga Fresca Latin Band. I'm grateful to you, who have the most critical roles as listeners, readers, and watchers. See the show notes, previous podcasts, and other resources through my website, www.health-hats.com, and [YouTube channel](#). Please subscribe and contribute. If you like it, share it. See you around the block.



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