Caring for Rare Podcast: Season 1, Episode 5 | Brought to you by Nutricia North America

Parents of children and children with PKU, MSUD and HCU share how they talk about their metabolic disorder.

TRANSCRIPT

KATE MILEY: Welcome to Caring for Rare: Stories of Rare Metabolic Disorders, a podcast that explores what life is like with a rare metabolic disorder. On this episode, we're talking with parents and kids about how they talk about their metabolic disorders. Though these disorders are rare, you can find community and support, you are not alone.

> JORDANN COLEMAN: We went from blissfully happy to it felt like everything was crashing down.
> LACY SHAFFER: I felt like a first-time mom again because now I have a child that has a disorder that the entire world isn't familiar with.
> COLE SULLIVAN: We've got to stop talking about what we can't do and start talking about what we can do.
> JULIE BOLDUC DEFILIPPO: Seeing Johnny hit his milestones was very reassuring.
> CARTER COLEMAN: You just can't have certain foods, but you can do normal stuff.
> JORDANN: I find it therapeutic to have other people that understand our life.
> SARAH SULLIVAN: We could do this, like this is something that we can do.

KATE: Caring for Rare is brought to you by Nutricia North America, a manufacturer of formulas and low protein foods for inborn errors of metabolism. We're proud to have served the metabolic community for more than 30 years. I'm your host, Kate Miley, a member of the Nutricia team since 2019.

KATE: In this episode, we talk to four families Nutricia has partnered with. I just want to note that this podcast may not be representative of all rare metabolic disorders, and this in no way replaces the care, advice, and medical supervision of your metabolic healthcare team. The following content is for informational purposes only, but we're hoping you'll find comfort and connection in these stories

KATE: Many children with rare inborn errors of metabolism are diagnosed at infancy or early childhood. The immediate focus is on adjusting to a new diet and medical care. But as these children get older, they start to notice that what they eat is different from their friends, parents,

and siblings — and they have questions. In this episode on how to talk with your kids about metabolic disorders, we're exploring what some of those conversations are like.

> COLE: We probably once a month or something have a discussion with the kids because they'll ask, "what does that taste like? That smells really good. Do you think I would like that?" And it's a lot of "well, your bodies are different. You have to get your nutrition this way and, and mom and dad's bodies are different, and we have to get the nutrition that way."

KATE: That's Cole Sullivan, his two children, 11-year-old Colbie and 9 year old Cayle, both have homocystinuria or HCU. HCU is a rare metabolic disorder where the body can't break down protein. Many people with HCU have to be on a diet low in whole protein and take a special metabolic formula. Foods such as meat, fish and dairy are typically not allowed. Colby was diagnosed at 3 and Cayle when he was 1. When they were first diagnosed, Cole and his wife, Sarah Sullivan, hid their own food from their children for fear of upsetting them.

> SARAH: I just couldn't eat in front of Colby or Cayle, like, something that I knew that I would normally share with them. I would go in another room or in the closet. I just couldn't bear to eat around them. It just broke my heart.
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> COLE: And we kind of had this, like, epiphany of, you know, as soon as these kids see the people that they know and love eating different foods - when they go to school, when they go to birthday parties, when they go elsewhere to people that they don't know as well they wouldn't be so honed in on what they couldn't have. It was just the norm. Mom and dad eat this food and I eat this food and it has actually paid off for us. They know that they are going to have different food than what mom and dad have.
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> SARAH: Once we kind of turned that corner I, I feel like we've traveled and we've done a lot of things and we don't let homocystinuria hold us back or our kids back in what they can do. And I think that that's proving to them for later in life that, yes, they've been delivered this chronic illness, but you can live with it and do a good job with it. It's always in the back of your mind, that they have these limitations, but we do our best to lead a normal life.
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> COLE: And our approach on this with the kids as we talk and we grow, is that everybody has something. You can't always see it on the surface. And the other thing that we try to instill in the kids is: You can't use this as an excuse, it's not a crutch, you know, you have to work hard in school. Everybody works hard in school. You can't use HCU as a reason you're not doing well. That's not a reason to get a pass. So we, we are working with them on the mental aspect of that.

KATE: Another important part of the conversation is about medical management, like blood draws.

> COLE: Our approach to it has changed over the years with the blood draws. They were hard for us in the beginning, and so we almost had to surprise the kids with blood draws, which wasn't great. But we had our favorite phlebotomists and we'd work around their schedule. But as the kids have gotten older and we've been able to rationalize with them, we will talk ahead of time and say, OK, well, you know, blood draw's coming up. We either have to do it this date or that date. What are you guys thinking? And the kids are now part of that process. They also want to know, hey, what were my levels? So in sharing with them, hey, here's your levels. And if it's high or something, we can point back to a time when to the kids and say, OK, well, remember, we kind of went over on that day or that day that could have affected this. So we're using that time as a teaching moment to the kids. But we're also including them on the decision making process as well. So now we just had blood draw the other day. They were like, well, OK, let's just go get it done, let's just go get it done and we'll be back in no time. I think Cayle's comment was I think we'll be gone for all of 15 minutes. I said, well, buddy, it takes a little longer than that. But his outlook was, yeah, we'll just go knock it out and we'll be back.
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> MUSIC

KATE: Jordann Coleman's 8-year-old son, Carter, has Maple Syrup Urine Disease or MSUD. Similar to HCU, people with MSUD are on a special diet with little whole protein and a metabolic formula. Carter was diagnosed in infancy. Jordann says they started talking to him about his condition when he was about 3.

> JORDANN: We started to tell him when he would ask about other people's foods, that when we say that he couldn't have them, that it would hurt his brain. And we didn't want him to get sick. So he had to eat the food that we gave him. And I would say probably by the time he had turned five, he had been hospitalized 10 times, so he had memories of being in the hospital and having IVs and being sick. And so when we've had other conversations about why it's important for him to stay on diet, why we need to take blood tests to test his levels, he has a memory. He knows that, oh, OK. That that experience was because my levels were high. So, um, he got older, we kind of expanded upon that just so he could try to understand the reason why he couldn't eat the same food as other people. And we have been very fortunate in that he doesn't really push the envelope as far as food is concerned. He pushes the envelope in so many other ways. But when it comes to food, he really trusts us.

Here's Carter, to explain his understanding of MSUD.

> JORDANN: If somebody was to ask you what is MSUD, what would you tell them?

CARTER: Uhh, let's see. It's like this thing when you're born you can't have certain foods.
JORDANN: Why can you not have certain foods?
CARTER: Because then it can damage your brain.
JORDANN: You're right, yeah, because it can damage your brain.
CARTER: And yeah, y ou can't have certain food, but like you can do lots of other stuff.

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KATE: Lacy Shaffer and Julie Buldoc Defilippo each have two children, one with Phenylketonuria or PKU and one without. PKU is another inherited genetic disorder that can be successfully managed with a diet low in whole protein and a special metabolic formula.

Lacy is mom to 3-year-old Aspen with PKU and 7-year-old Finn. Julie's son Johnny is 5, and his little brother David is 3. David really only wants to eat meat, something Johnny, with his PKU diet, can't have at all.

JULIE: When David started eating those foods, Johnny would ask a lot of questions. He felt isolated. So we just talk with him honestly about that and that it's okay to have those feelings. And that this is something that God gave him and that it's special about him. And he needs to do something with this challenge in his life that he's really called upon and given responsibility to do something special because he has this disorder.

LACY: Beautiful word, responsibility.I like that avenue. I'm definitely going to write that down.

JULIE: And I think it gets really hard when they get older and they start asking questions like, why do I have PKU, why doesn't David have PKU? And we've just said, like, God gave this to you for a special reason. We don't know why, but it's for a reason. And you'll figure it out one day. And we do know that David's a gene carrier. So we said to him, like, we're really honest about the science, like, well, mommy, daddy and David are gene carriers and you have two genes. And then he'll be like, well, why did I get two, and you know you have to go into the whole explanation again. But we have noticed that he can handle much more than we want to protect him from.

LACY: My husband, Darryl, would not want to tell Aspen that something happened, that he'd say it was too spicy. You know and I'm like, it's time we stop lying to her. She can't have it because it's too much protein, because what happens when she's five and thinks she can handle the spice? You know, it's just, unfortunately, I think we need to start head on with it. So she will tell me things like too much protein. Do I think she gets it completely? No, but we're, we're getting there.

JULIE: Yeah, I'd also like to add that Johnny is a very compassionate kid and I'm a social worker, so we talk a lot about social justice and helping people that are less fortunate than us. But he really feels it. And when I say like, well, sometimes people are mean to somebody because they're different. He gets that because he's different.

LACY: Right.

JULIE: And I'm really, really proud of how he really feels these things and, and is inclusive of other kids and kind to other kids. And I think he just has so much more compassion because of PKU.

LACY: I'm sure our kids are always going to, you know, see things in a little bit of a different perspective because they live that perspective.

JULIE: Right.

LACY: And who wouldn't want that attribute in a child.

MUSIC

KATE: Despite these chronic illnesses, the parents we've heard from today find hope in the ways their children talk about the future. Here again are Cole and Sarah Sullivan again.

COLE: When we talk about the kids' future or the kids talk about their future, they don't really ever bring up HCU.

SARAH: Yeah, but they don't talk about HCU like it might limit them in doing something or anything. I mean, Colbie wants to be a vet and she talks about that and she loves animals. And Cayle would like to be an NFL player. Um you know, like he talks about that kind of thing. I mean, but they don't ever think that it's going to limit them from going to college or from doing anything. And we agree it shouldn't limit them from doing any of the things that they want to do.

COLE: What gives me hope is Colbie has a friend that knows her, Colbie's, diet inside and out, and she is always looking out for Colbie. Like I want to have Colbie over to do this but she needs the certain stuff, but she knows the diet. And that's what gives me hope is because I certainly and you certainly haven't talked to her about the diet. So it's something that gives me hope moving forward is that they are navigating life with their friends.

MUSIC

COLBIE: My name is Colbie and I'm 11-years-olds, I'm in fifth grade, I have a rabbit named Black Lightning and I have HCU.

CAYLE: My name is Cayle, I'm 9-years-old, I'm in fourth grade, favorite color's blue and I have HCU.

COLBIE: I explain it to people by telling them I have a different diet and I can't have, like, any animal products, like meat, eggs, animal fat. And then I tell him what I also can have, like I can have vegetables, fruits, some homemade cakes my mom makes and some salads, french fries.

CAYLE: I personally don't eat salad. But I love French fries.

MUSIC

KATE: Thank you so much to Julie Buldoc DeFilippo, Lacy Shafer, the Sullivan family, and the Coleman family for sharing their stories with us. Nutricia is here to support families like yours and theirs. We're proud to provide a wide array of metabolic formulas for inherited metabolic disorders. And our Nutricia Connect platform provides resources like this podcast, reimbursement support for our metabolic formulas, and additional support like low protein recipes. Join us at NutriciaMetabolics.com.

KATE: We hope you'll check out our other podcast episodes to hear more first-person stories from people living with rare metabolic disorders. Find them on NutriciaMetabolics.com or your favorite podcast platform.

KATE: Caring for Rare: Stories of Rare Metabolic Disorders is brought to you by Nutricia North America. It was produced by Alletta Cooper, Ulrike Reichert, and me, Kate Miley. Thank you so much for listening and be well.