

Transitioning From Pediatric to Adult Care A Conversation

You can view this presentation at: youtu.be/mtA9XBNYog4

[00:00:00] **Roberta Pesce:** Hi, everyone. We have reached, I believe, the last session from track three of today. We will be hearing from Dr. Cristina Sadowsky, from Kennedy Krieger Institute, and Cody Unser, from the Cody Unser First Step Foundation more about how to transition from pediatric to adult care. When a child is diagnosed with a rare neuroimmune disorder and he, she, or they near the age of adulthood, you must begin learning how to handle your own care, and this is a very important conversation so we're happy to be having this talk today.

[00:00:44] Unfortunately, Dr. Sadowsky and Cody Unser weren't able to join us live at the moment, they had other commitments, but again we do encourage you to still ask the questions in the Q and A even though we won't be having a Q and A at the end of this talk. They might pop in through the chat and be able to address some of your questions or we will send them over and I'm sure they'd be happy to answer them. Also please remind you that there is a closed-caption feature available on the right-hand side. Yeah. And if you have any additional questions, SRNA staff is here to help you at any time. So, enjoy the talk, and over to Dr. Sadowsky and Cody Unser for this conversation.

[00:01:28] **Cody Unser:** Hello, everybody! I am so excited to be here with all of you and with Cristina Sadowsky, this is a very important topic to talk about transitioning from being kind of a younger sort of patient, transitioning into adulthood and so I'm so excited to be here with all of you at the RNDS. So yes, my name is Cody Unser and I, briefly for those of you that don't know my story, I became paralyzed when I was 12 years old due to transverse myelitis. So, my whole entire world completely changed. I then with the help of my mom, Shelley, we started the Cody Unser First Step Foundation, so for the last 22 years we've been really trying to push the awareness about transverse myelitis, advocating for people with disabilities, and trying to improve the quality of life of people with disabilities using our scuba diving program, so, yeah, so it's been a wild, crazy ride and this topic, again is very important. So, with that, Cristina!

[00:02:32] **Dr. Cristina Sadowsky:** Yes, hi, everybody. I'm sorry I am only virtually present with you today, but I know that Cody would be able to answer all the questions in the Q and A session that is following this recording. My name is Cristina Sadowsky, and I am a psychiatrist. I am a spinal cord injury medicine specialist, and I am an Associate Professor of Physical Medicine and Rehabilitation. I work at Kennedy Krieger Institute

in Baltimore, Maryland, and I do my academic work at Johns Hopkins hospital also in Baltimore, Maryland! And I've known Cody for the past, hmm, how many years? I shouldn't say how many years but a lot of them.

[00:03:19] **Cody Unser:** It's over a decade, but I think what's important here is that you did see me I think around when I was 14, 15, so still kind of being a teenager, paralyzed, scared, trying to figure out the world, so yeah, it's been a while.

[00:03:36] **Dr. Cristina Sadowsky:** Yeah. So, I've been really blessed to be part of your team, and hopefully we made it a transition team?

[00:03:48] **Cody Unser:** Yes.

[00:03:49] **Dr. Cristina Sadowsky:** Can you elaborate a little bit more on your transition, from pediatric to adult spinal cord injury disease, paralysis, and everything that comes with it?

[00:04:04] **Cody Unser:** Yeah. So, I guess for me, I mean I was 12 years old when I become paralyzed, and right from the get-go what I understood was that this is my journey. This happened to me and when, I remember distinctively that I was laying in the hospital room, still, this was like maybe 2 weeks after I became paralyzed, laying in the hospital bed and looked out into the window and saw that the doctors were talking to my parents, but I wasn't in the conversation.

[00:04:41] So I was very self-aware at that moment that I needed to encompass and be involved because this is, it's my experience. It's happening to me. Even at a young age I understood how important my perspective was, so I told my parents, no more talking to doctors without me. I have to be involved. And once that started happening, I think being so young and being paralyzed, you do definitely have people doing things for you. Like my mom, my mom definitely cathed me before I did.

[00:05:23] There were a lot of people that were always touching me and so, I think that's one thing to take note of is the fact that when you're a kid you have other people around you that are controlling and dictating and figuring out the medical side stuff and you're kind of involved but not really making decisions. So, I will say, though, that after I, and I definitely, I mean when I met you at Kennedy Krieger, and I had been trying to create a health care team, that is so crucial, but my mom had more to do with that than I did.

[00:06:06] And I will say that after when I was 18, I went off to college. So, before I was 18, my mom ordered my catheters. My mom got my medication. Everything was done for me. And then when I went off to college and lived in a dorm room it was now suddenly, now it's my responsibility. It was a big kind of, and I think every person goes through this transition. Whether they're paralyzed or not, right?

[00:06:38] We go from being a kid into adulthood and yeah, to oh my gosh I have bills to pay. I need to change my oil in my car. You go through those things, but I think for those of us with paralysis, that's even heightened because we're dealing with a paralyzed body. It's extremely, way more of a responsibility less than other people experience. So, when I went off to college it was oh wow this is, I am now having to order my catheters. I am now having to call my doctors and order my medications but, in that respect, too, it's also very empowering.

[00:07:15] And I kind of developed more of an identity once I was able to kind of control my care. So that was kind of my transition. It was more mental, emotional than anything. But again, it's taking control of your life because you're the drivers' seat in your car. So, it wasn't easy but it's definitely, it's empowering to be able to kind of take everything and make decisions on your own, no matter how difficult it is.

[00:07:50] **Dr. Cristina Sadowsky:** So, Cody, transitions can be gradual or abrupt.

[00:07:56] **Cody Unser:** Mm-hmm.

[00:07:56] **Dr. Cristina Sadowsky:** And I know we've talked about this. What was your experience with the speed of transition? Was that abrupt dive off the cliff when you went to college? Did you have any preparation before the, traditionally in the medical field we're thinking of transitions as being a combination in between the individual, the family, school, and the health care professionals, the team. Did you have all of those involved in your transition and how did that make you feel and how fast did you go up or down that hill of transition?

[00:08:47] **Cody Unser:** Yeah so, I guess for me the transition was gradual, because I became paralyzed when I was 12. And my mom was really involved with my care. And so, for me, like, it was definitely gradual. It wasn't just abrupt and sudden, "Oh, my gosh, I'm on my own." But I also, I mean I think that, even when I went off to college my mom was still calling because we were running a foundation, my mom was still calling and reminding me throw that catheter away, get a new one.

[00:09:25] So I think family, medical professionals definitely, can be on the outside but now it's me making the decision because I don't want to get a urinary tract infection, I don't, I need to watch my skin carefully. I don't have people as an adult. My sister can check my skin every now and then, but, again like the responsibilities of your medical care become totally, solely on you. And it can be a little scary but having a team in place, I mean, I am so thankful that I've got a great amazing team.

[00:10:05] But not a lot of people know how to do that. Not a lot of people know how to get doctors talking with each other. That becomes really important because the family starts off as sort of your health care team in a sense. And then, when you transition into becoming an adult and able to make the decisions yourself, you then take that health care team and transition it into your medical, the medical professional side. So, I think family and friends still can play a role, but the empowering thing is that it's totally, solely on you.

[00:10:46] **Dr. Cristina Sadowsky:** And you have the advantage of having had a really good team, especially your mom which we all remember with a lot of love.

[00:10:59] **Cody Unser:** Yeah.

[00:11:01] **Dr. Cristina Sadowsky:** From, as a health care provider I think that we can use this notion of portal health care records. It's actually a specific document that can be used to ease that information to the transitioning individual. It contains the name of your physician, the name of your, and address and telephone number, of your pharmacy, it contains the name of your DME provider, the ones that provide you with your catheters and the name of your wheelchair provider, where name and number. So, contact information. So, having this portable health record I think it's something that eases the need to remember or reach out to somebody every time you need that information. Did you develop one, or...

[00:12:05] **Cody Unser:** Yeah! I mean, I definitely, I mean, I kind of did it in the form of it was kind of a back-and-forth e-mail between my mom and I. Once I got to college in California, because I was born and raised here in Albuquerque, New Mexico. So once I got to California where I went to college, she kind of, she sent me, and I think all parents do this when they send their kids off to college, change your sheets, do the laundry, kind of give them a housekeeping list.

[00:12:37] **Dr. Cristina Sadowsky:** You have to call them every day.

[00:12:41] **Cody Unser:** Yeah, call me every day. But for me, again, that list was longer than my able-bodied friends because I was independent on my own in my own dorm room and I do, I did have to make sure that my catheters were ordered, where the address was sent to, taking, my medication properly. Just that list kind of extends I think from parents and family members to people with spinal cord injury or paralysis. So yeah. I think that document was more of an e-mail form from my mom, and I think I still even have that.

[00:13:26] But yeah, it's just reminders and kind of learning how to take care of yourself because yeah, with the secondary conditions we do deal with, it's hard to keep up. I sometimes forget to, I need to refill my bladder medication in time before I run out or else, I'm going to have bladder accidents. Little things like that so it's just our list of responsibilities are, I think a lot longer, but in that respect again, like, it's so empowering to be able to make your own decisions about your own body, because you're the one experiencing it. You're the one experiencing the paralysis and all that encompasses it. So that's kind of my sort of experience so far but what about you?

[00:14:22] What's been your, as a physician and a provider, what have you seen from kind of the outside of how people have transitioned?

[00:14:32] **Dr. Cristina Sadowsky:** Well, so I'll start with picking up on what you said, it is so empowering to be able to be in control of your own life and that takes the disability to the ability side, that you are as able as you think of yourself.

[00:14:55] **Cody Unser:** Right.

[00:14:56] **Dr. Cristina Sadowsky:** And there is nobody that can take away your ability except yourself so that would be the philosophical point that just came to me when you're talking about empowerment. I'm big on empowering everybody. From the transitional point of view as a health care professional, I'm also interested in compartmentalizing the transitions into medical care, and we talked about the medical part a lot. But it also, our goal is to transition to the social aspects. Knowing about your insurance. Knowing about resources for self-advocacy. Knowing about resources for entering the workforce.

[00:15:53] **Cody Unser:** Yeah.

[00:15:53] **Dr. Cristina Sadowsky:** And that is also part of transitioning because you're not expected to know about SSI and insurance if you are ...

[00:16:04] **Cody Unser:** Yeah.

[00:16:05] **Dr. Cristina Sadowsky:** ... you know, a regular teen.

[00:16:07] **Cody Unser:** Right.

[00:16:08] **Dr. Cristina Sadowsky:** So, that comes, that's something that the health care team needs to provide to empower, to give to you so then you can take advantage of everything that is available.

[00:16:26] **Cody Unser:** Right.

[00:16:27] **Dr. Cristina Sadowsky:** So, when did you learn about your insurance coverage?

[00:16:31] **Cody Unser:** I think it, I mean it was definitely later. I think it, I mean I was probably right before I went off to college. My mom kind of gave me all my insurance cards, who to call if I have an issue, so yeah. So again, like it's pretty much everybody deals with transitioning from being a child into an adult, but we have to deal with a lot more issues.

[00:17:01] Not only medically, but like you said, socially, like figuring out not only like the outside the medical care stuff, but also like being able to make responsible choices and go out with friends but make sure you have enough catheters while you're going out. Or things like that that kind of because you don't, it can be, going off to college is a whole other experience and some people, with paralysis or other disabilities actually isolate themselves because they find it very challenging just from the accessibility side, but I think, kind of, it's really fun to be able to take control of your life, like I can't say that enough, like making the decisions. And I've made huge mistakes along the way too.

[00:17:56] **Dr. Cristina Sadowsky:** Yes.

[00:17:56] **Cody Unser:** And that's part of growing up, part of being an adult, in general. But for me, some of those mistakes can be very medically detrimental so that's why you have to be so vigilant and have a good health care team, create a list for yourself if you're big on organization and creating lists to help guide your care. Because it is a lot, and it can get overwhelming. You don't have your parents with you, your family, members with you, so it comes down to you.

[00:18:26] **Dr. Cristina Sadowsky:** So, let me ask you one other thing because you're so big on self-advocacy and you are so good at it, what would you prepare the most in the transition part because there is a transition to self-advocacy to mobility, to mobility, as in getting your own driver's license. So, what would you best prepare? What were you best prepared? On medical self-advocacy, access, and mobility, what did the system, and I'm going to go to the system, not your mother because your mother was a force of nature and I know that every mother is a force of nature...

[00:19:07] **Cody Unser:** Yes.

[00:19:07] **Dr. Cristina Sadowsky:** ...for her own child, but I want to hear the system, because again it's about empowerment, and if the system doesn't give this to you, you have to ask for it.

[00:19:18] **Cody Unser:** Right. Yeah, and that, I mean that is a great point, and very important because I mean, my mom always went with me to my doctors' appointments especially in the beginning. I think this is true for a lot of people when paralysis first happens and rocks everybody's world. You do see a lot of health care professionals to get answers, to get information, resources, and so, my mom kind of went with me everywhere to gain that kind of knowledge but I had her kind of advocating for me because I was still a kid, and asking the doctors questions, speaking for me.

[00:20:02] And I think, along the line, I was, I would always say, "Mom, be quiet," or "it's my turn to talk." Because yeah, self-advocacy is so important especially when you go to a doctor's appointment. No matter what kind of doctor it is, it can be intimidating and overwhelming to not just take what they say on the surface and on face value but because that definitely happens especially in today's health care industry a lot of doctors are not familiar with spinal cord injury and paralysis, so they'll say whatever even if they don't know. And if you don't have that "no, I'm better than this, I'm worth more" kind of attitude, you will just take whatever the doctor says and not question it, not ask for more information. So that is definitely challenging. I still kind

of have challenging moments with that like not speaking up for myself when I know I should and I can but you learn, right? Like it's not, you're not just going to wake up one day and have all the answers of how to care for yourself.

[00:21:21] It's really kind of experiencing it moment by moment and taking your time and giving yourself patience to kind of explore what that means. To take care of yourself, speak up when you're, when that there's something that they can do more. Especially outside the spinal cord injury health care industry. It's challenging and it can be overwhelming, but again that's why there are so many different doctors out there. Always ask for a second opinion.

[00:21:58] I do remember my mom saying that right before going off to college in case I got sick with the flu or a cold, because again some doctors don't know what medications I'm taking and if it can interact with any cold medicine, that kind of stuff. So, it's crazy, but it's definitely, it's about really kind of empowering yourself, and I would give my advice right now for any parent's kind of or family members struggling with how to help their child transition is kind of give them some breathing room.

[00:22:32] Don't expect them to get it right away. We all make mistakes and that's how you learn, that's how we grow, so, definitely give your child some breathing room, be patient with them. They'll figure it out eventually. So yeah.

[00:22:54] **Dr. Cristina Sadowsky:** Yep. Well I wanted to say thank you for teaching me a little bit more and I want to assure you that even if you feel that you're not speaking up for yourself you speak up for a lot of other people from how you present yourself and everything that you do, advocacy-wise, and one of my favorite, and I want to end with one of my favorite sayings, we are not able without each other so thank you for making us all able.

[00:23:26] **Cody Unser:** Yeah. Thank you, Cristina!

[00:23:29] **Dr. Cristina Sadowsky:** Thank you all! See you!

[00:23:32] **Roberta Pesce:** All right, we have reached the end of track three, I believe we're ready for a well-deserved break at this point. We have a 10-minute break right now until 3:10pm Eastern Time. Please grab some water, food, or go to the networking area. You might find someone there. We'll be back at 3:10pm Eastern on the stage so you're going to have to move to the stage area and we'll hear more about adaptation, mobility devices, driving, and home modifications from Sandy Hanebrink from Touch the Future.

[00:24:10] So looking forward to seeing you there after a well-deserved, I believe, break. It's been a lot of information, I feel like. See you soon. Bye, everyone!