

Transitioning – Taking Charge of Your Health as a Young Adult

Cory Nourie interviewed by Petra Harvey

Petra Harvey: *Welcome! My name is Petra Harvey and I am a Health Educator at the Osteogenesis Imperfecta Foundation. One of the primary activities of the OI Foundation is to provide timely, accurate and medically verified information to medical professionals and constituents alike. We are using this series of podcasts to provide information on a variety of topics related to the diagnosis, treatment and life of people with OI. Each monthly podcast will feature an OI medical expert or professional. Today, our podcast features Cory Nourie, a Patient Transition Social work Coordinator at Nemours Al DuPont Hospital in Wilmington, DE. Cory has spoken at the last two OIF National Conferences; in the youth forum, teen center, and a separate breakout session. Thank you so much for joining us today, Cory.*

Cory Nourie: Thanks for having me, Petra.

Alright we're going to go ahead and get started with our first question. Can you tell us a little bit about your role at A.I. DuPont?

Sure- so I am the transition social work coordinator at the children's hospital and what that means is our patients started as very small children, from birth on, and as they're getting older and older, we need to shift the focus to start thinking about how they're going to manage their own healthcare in the adult world when they eventually transfer to an adult oriented system. So my role as the social work coordinator is to help address all the nonmedical aspects of transition. What I usually say is what someone does the 363 days a year that they aren't visiting their pediatrician. So thinking about long-term what they're doing for career, education, legal matters, and insurance. Also things about your quality of life, I get to focus on that as well as connect young adults to their healthcare providers and make sure they have healthcare providers who know about OI or whatever the special healthcare needs may be and they have access to the information they need to be successful.

That's very interesting – so we use the word “transition” a lot when we're talking about moving from the pediatric healthcare setting to the adult setting. What are we really talking about?

I think what we're really doing is thinking about a shift just in the way people receive care. In pediatrics, typically the experience is that the child is the patient and the parents are the ones who are really talking to the providers, to the doctors, the social workers, the nurses. The parents are making the decisions on behalf of their child. Transition is really a shift in the focus to say “hey, this young adult or this child is eventually going to be an adult.” So they need to start to accept more responsibility, get more involved in their healthcare, understand how to talk their providers, questions their providers when necessary, to advocate for themselves. Our idea of transition is to really prepare people over a long period of time to be able to be good consumers of adult healthcare and to be able to have great adult lives. It's not just finding a new doctor one day, from a pediatrician to let's say an internist. It's really about the process of developing skills and taking on responsibility and having some hiccups along the way- that's all part of transition. The goal is that over a period of time people are gaining skills so

that way they can go be successful adults. A lot of that revolves around having the parents let go a little of the reigns of control as well.

That's great, thank you. As young people with OI transition into adulthood, there's so many things that they need to take on related to their healthcare. Can you talk about that for a few minutes?

So, again, thinking about the way the focus is typically with young children is that the providers are talking to the parent or the caregiver who brings them in. One of the responsibilities I tell young adults to take on is something as basic as checking themselves into their doctors' appointments, to their clinic appointments. Usually, people are in the routine of walking up to the counter with a parent and the check in person talks to the parent and says "who is here?" and the parents answer the questions. One of the responsibilities is that young adults can say "hey, hold on a second, ask ME the questions" or tell the parent to wait in the waiting area. They know their names, they know their address, and they can confirm all of that information. They know what doctor they are there to see and the time. Those are all things that, again, shift of responsibility to say "hey, this is me, I am my own consumer and I'm the one that's going to be leading this from now on." Other areas are young adults getting comfortable actually answering questions in clinic appointments – this can happen from an early age on. If you have a child who is 5, and the doctor asks the parents "what's wrong with Bobby today?" Bobby can tell you what's wrong at 5- if his belly hurts, or his head hurts, or his arm doesn't feel good. So, encouraging that young child young child to actually be the one who is directing their care and being involved in the decision making is a really powerful thing that in the long run will really help in transition. Additionally, we want young adults to know their personal health history and also their family medical history. We always joke around with the teens I work with that when they were little it didn't really matter about "old people issues" because they were still so young, but as they start to make that move into the adult healthcare system, those "old people issues" actually become much more relevant. If you have a family history of having high blood pressure, the doctors may start screening you differently than someone who doesn't have a family history of blood pressure issues. Encourage that young adult to know their family history. There are lots of great tools available out there through the CDC and online to help people really capture that information. Sometimes it's hard to really capture it and keep it all in your brain, so I'm a big proponent of using any tools or strategies like apps for cell phones to help keep track of the information that you may not have all the time available to you, but when you need it you really need it. I know the OI Foundation does some great things with putting together tools to help young adults keep track of that so I would definitely look at those resources as well.

Another area that young adults can take on responsibility is around medication adherence and taking their medication. That would also mean being the ones who does it themselves without having to be reminded. It's not uncommon for me to work with a teenager where the parents are still putting out their medicine for them every morning on the kitchen counter. Or, sometimes the mom will say "Can you just tell her that she really needs to take her medicine? It's her body and it's really important." So then I get to say "right, it's her body so she needs to understand that." We start to talk about taking responsibility and what are some tools or strategies that you could use to remind yourself to take the medication. Again, utilizing apps- there are so many apps out there or even setting your cell phone to have the alarm go off 4 times a day for your medicine, any of those are ways that you could be more

involved. Same thing with refilling prescriptions, it's not uncommon for someone to go away to college and when it's time for them to get a prescription refilled, their like "oh boy, what do I do now?" because their parents have always been the one to do it for them. Working on those skills before someone goes away to college and also similarly, someone's going to college to think about things in advance and navigating the system and what kind of accommodations and accessible features they might need in their dorm or in the dining hall. We have a lot of times when young adults have gone away and gotten established and felt like they were ready to be successful and the next morning they wake up to take their first shower and their shower chair doesn't fit in the stall in their dorm and their parents are already gone. So we just always try to think in advance about ways you can get more involved and troubleshoot for those areas. Also, if somebody had any kind of major medical equipment or supplies, for them to be the one who starts to refill those things or order them or talk to their company that has their bypass and talk about their settings, or If they need new tubes. All those things that parents have kind of done for the young adult over the years, we want them to start to get more involved in. In a perfect setting, it's done with those parents or those caregivers still there as a safety net to help catch somebody. I usually use the expression "you eat an elephant one bite at a time." The idea of transition with it being a process is that these are all skills that you're building on slowly, one after another, not that we expect everybody overnight to now be able to miraculously be in charge of everything and know all of their information. By working together over the years, to say ok, the parents sit back a little bit to say, "I'm not going to answer all of the questions, I'm going to let you answer the questions." Just to work on those skills, so that way overtime, the adult is able to be as independent as they can possibly be.

That's very helpful. I know you've spoken at the National Conference at the Teen Center and in the Youth Forum. Those ages are usually from 13 to upper 20s. What ages do you typically work with on an everyday basis?

We're unique in that we actually have an age limit here at Nemours, which is the 21st birthday. So, typically I would like to take to somebody by around the age of 16. That's kind of late in the game, except hopefully their current everyday providers have started having these conversations earlier on. Continuity of care conversations should really happen at 5, 6, 7, to say "ok what are you doing? How much responsibility are you taking?" By the time they meet me at 16, I can really focus on 5 years from now, here's what you need to be connected to, and do you know about vocational rehab? With that being said, there are many times I get a call about somebody who's turning 21 tomorrow or someone who turned 23 yesterday. It doesn't matter, people may feel like they're late in the game in transitioning, but it's always better to start sometime. Even if someone is in their 40s, there's still ways to develop those skills.

That's really good information. What, in your opinion, constitutes a successful transition?

That's a tricky question. I think the definition of successful transition to me is that we have people who are educated consumers of healthcare. Working with your team. Sometimes, honestly, the team doesn't change between the pediatric system and the adult system. If someone's not bound by an age rule the way we are, there may be someone who is 40 and still seeing their pediatric specialist. That's fine,

honestly, I still want in that relationship for the responsibility to have shifted to that 40 year old and for that 40 year old to be the one who's navigating and being the self-manager. Even though the doctor may be a pediatrician or a pediatric specialist, that young adult can still be the person who is spoken to as an independent autonomous person and making decisions to the best of their ability. For successful transition, I think people are living the lives that they want to have; they're connected to resources and supports that they need in their community. There are a lot of gaps out there where people don't know that there are services that are available. With a condition like OI, that's why I love coming to conference, because people get a chance to meet other people who have OI and they feel not so alone anymore. I think a lot of times, even someone who has a fairly common condition; it's a relatively isolating experience to have a healthcare need. Sometimes it's really easy to get wrapped up in the idea of "I'm the only one of my kind, there aren't services for people like me, etc." My goal for transition is to help everybody understand that there are services for children, services for adults, you just have to get steered towards those services. In trying to explain how the adult healthcare services system is set up differently than in the children system. People are used to the educational system where they're entitled to services because of an IEP. In the adult world, people aren't entitled to services anymore, it's all based on eligibility. So, if you have someone who has OI and they're applying to voc. Rehab, their vocational rehab counselor may have no idea of what OI is or never met anyone else who has OI. We have to do a good job of preparing people to advocate for themselves to explain their condition and explain this symptomology so that way they go "oh yeah, I get it, I know someone else who has a similar condition and I helped them get accessible equipment for that job or I helped them negotiate with their dorm manager through their college to make sure they had an ADA compliant dorm and everything met their needs." All of those things together make for a successful transition where people are really leading their own way, recognizing that as human beings we all make mistakes. That's part of being a human, right? Part of being an adult is saying "ok, I tried it, it didn't work. Now let's figure out where to go from here" and recognizing that that's all part of everyone's existence and we all need to make sure everybody has a chance to fail in things and to feel hurt and to figure out ok that didn't work what can I do differently next time. Sometimes, for someone that has a special healthcare need, there's a lot of babying that goes on and people thinking "I just need to do it for you." The goal is to empower people to do it themselves or the way that they want to do it, which may not be how other people would naturally choose.

That's great. For people who are not in the Delaware region, what other kind of professionals could they try to contact so people like you that do this type of work if they're not patient transition social work coordinator, what other types of professionals could they reach out to for this type of help?

It really varies around the country. Typically I would say people need to be connected to vocational rehabilitation and that is going to give you a "voc rehab counselor." That's really focused on employment skills and continuing education – everybody should be connected to voc rehab, they pay for college for some people, they pay for modifications to vehicles for some people, they help with job trials and exploration and all those kinds of great things. Great resources for people through voc rehab services. Other professionals to reach out to – you may have some sort of transition coordinator through your school district, it varies across the country. In the adult world, every state has what's called ADRC

(Adult Disability Resource Center) and anyone could call those ADRC's, usually through the Department of Aging or Adults with Physical Disabilities depending on what state you're in. The ADRC has benefit counselors or options counselors who can really talk about "ok tell me what your situation is now and we will help figure out what you're eligible for and how to apply for that service. Or, is there a waiver in your state that's going to give you access to home healthcare that you otherwise haven't had?" Those are kind of the big ones that people typically need to be connected to, as well as potentially (depending on their insurance situation) some sort of case manager or care coordinator just to make sure that everybody is working together and that person is getting the services they need and there aren't gaps, it's very easy for there to be gaps.

That's very true. Thank you so much for sharing this information. As you said earlier, the OI Foundation has information on our website for adults, the "Take Charge of Your Health" package. Cory, do you have any other resources, I know you have the video library.

Yeah, so we have the videos that we made, actually there's a young man with OI in one of the videos around genetic planning and counseling. Other resources, there's 'Got Transition' which is the national clearinghouse of transition information and support around the country. I would say really utilize what the OI Foundation has done because you guys really put a lot of time and energy into them and really good resources that are user friendly, both for adolescents and adults, so I really would encourage people to look at those.

Awesome. Thanks so much for joining us today.

Absolutely, if someone wants to contact me, no matter what state you're in, I am happy to field email questions from people. The email address is cnourie@nemours.org. If I don't know the answer I probably can find someone who does. I'm happy to help people all over the country with questions because transition is a really big issue and a lot of time things come up and you hadn't anticipated that. You don't know what you don't know until you don't know it. If you have any questions, feel free to email me anytime.

Awesome. Thank you so much Cory.

Thank you!

Alright, we'll be back for another podcast next month. Thanks for tuning in.

www.oif.org/MedEd