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### Supporting Patients Transitioning to Adult Care

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## Supporting Patients Transitioning to Adult Care

In this episode, transition program manager Stephanie Pratt leads a discussion focusing on ways to support patients as they transition from pediatric to adult care.



Featured Speaker:

**Stephanie Pratt, LMSW**

Stephanie Pratt, LMSW is a Transition Program Manager.

Transcription:

Supporting Patients Transitioning to Adult Care

Rob Steele, MD (Host): Welcome to Pediatrics in Practice: A CME podcast. I'm your host, Dr. Rob Steele, Executive Vice President and Chief Strategy and Innovation Officer at Children's Mercy, Kansas City. Before we introduce our guest, I wanted to remind you to claim your CME credits after listening to today's episode, and you can do so by visiting [cmkc.link/cmepodcast](https://cmkc.link/cmepodcast), and then click the Claim CME button.

Today, we are joined by Stephanie Pratt to discuss pediatric patients transitioning to adult care. Stephanie Pratt is a licensed master's level social worker who is passionate about working to improve coordination of care for youth with special healthcare needs. In her role as Transition Program Manager, she is responsible for communicating the scope of the transition to adulthood program at Children's Mercy and supporting the execution of consistent transition measures in each division. Stephanie has experienced transition professionally in the adult and pediatric hospital settings.

She also personally understands the transition and its importance as a mother to a 10-year-old with cerebral palsy and a tracheostomy. Stephanie received her master's degree in Social Work from Loyola Chicago and is a member of several professional organizations, including the National Got Transition Learning Collaborative, the Healthcare Transition Research Consortium, and the Kansas Department of Health IDD Health Equity Coalition. Stephanie, welcome to the podcast.

Stephanie Pratt, LMSW: Thank you. I'm happy to be here.

Host: I have to ask, because as I've done podcasts, it's amazing the number of guests that we have that do a lot of traveling. You have done a fair amount yourself, with your favorite being Whistler, Canada, which of course is a great skiing area. Did you go there to ski? Did you go in the summer?

Stephanie Pratt, LMSW: We went in the summer and it was gorgeous. We just had so much fun exploring the mountain. And my son uses a wheelchair so it's extremely accessible, because they had the Paralympics there when Vancouver hosted the Olympics. So, he could do all the activities. We went ziplining, we went hiking, and it was just lovely.

Host: Yeah, awesome. I haven't made it out there myself. It sounds like I need to put that on my bucket list.

Stephanie Pratt, LMSW: Yeah, absolutely. We want to go back in the winter and do skiing.

Host: Very good. Okay. Well, let's get right on into it. You know, the importance of transitioning those pediatric patients to adult care, that is a conundrum for not just healthcare systems, children's hospitals, but the primary care pediatrician too, particularly for those children with chronic disease. So, can you give our listeners a sense of when do those conversations begin? At what point do you really start talking about that transition from pediatric to adult care?

Stephanie Pratt, LMSW: So, we want to start talking about that between the ages of 12 and 15 years old for young adults. And you have to think about it. A lot of those topics, providers are already talking to them about. What are your medications? What do you do in the case of an emergency? Do you know your medical history and condition? But just starting to talk about it in regarding to healthcare transition of not just "here are the meds you're taking," but why are you taking them? How often are you taking them? Are you able to take them on your own or do you need your caregiver to do that? And if you think of any 16-year-old you know, whether it's your child, your neighbor, they're not ready to go out on their own and manage all of these things. And they might not have healthcare needs, but when you add medical complexity, you add a previous transplant, you add epilepsy, diabetes, it just gets so much more important to make sure we're adequately preparing young adults and we're not trying to do it all at once. So, that slow transition, slow progression is what's really important.

Host: Yeah, I would imagine there's, you know, a fair amount of anxiety with both the family and the patients. They get really comfortable with their care team, have often been with them for years and whatnot. And so, to think that they're going to now move on to some other care team, I assume that's part of the reason why you start those conversations fairly early.

Stephanie Pratt, LMSW: Absolutely. And one of the other things, the more complex a young adult is with medical complexity, the more challenging, traumatic this can be. Because if you're thinking about it, just think of your own practice 20 years ago, if you have a 20-year-old, 20 years ago, patients sometimes weren't surviving some of these diagnoses. Parents kind of grieved, "Okay, is my child even going to make it past this certain age?" They never even thought they were going to have to transition. And so, some of these providers, they feel that they literally saved their child, and they gave them their child and their childhood, and then to think to have to leave that safety net is really, really challenging. And so, we're not just preparing young adults. We're preparing caregivers to step back, allow their young adult to do it and entrust their care to a new provider. And that's just all really overwhelming and something that we really have to walk them through.

Host: Yeah. So, maybe as an aside, but actually I think it's part and parcel of this conversation is, to your point, there are a number of those children that didn't make it past the childhood age, which means that those adult providers often, I mean, they just weren't trained and didn't take care of those patients. And now, they're coming into their practice. Do you find finding those providers that are able to take those patients a challenge?

Stephanie Pratt, LMSW: Absolutely. It's just, one, they aren't aware of the diagnosis because they didn't learn about it in school, because they weren't doing a pediatric kind of joining degree, or our pediatric providers really took on that knowledge. They created the surgery, they perfected the surgeries, and it just didn't translate over to the adult world. One of those examples is our Colorectal Surgery clinic. We have a really robust colorectal surgery clinic, and we have a very limited number of adult providers who can take on that care. Providers that aren't aware of the procedures that they've had. How do you manage it? What are the DME orders that they need? And so, on our end, it requires a lot of education and outreach with our adult provider partners to make sure that they're comfortable and adequately equipped to take care of these patients.

Host: Great. So, that's actually a really good segue into sort of the assessment. So, walk us through the assessments that are needed in order to make that transition.

Stephanie Pratt, LMSW: So, we do an annual transition readiness assessment for our young adults ages 15 and older that have been deemed to need to transition their care to an adult provider. We have some kids that are seen, you know, in Ortho for a short course of treatment, a short course of cardiology treatment that we don't think will need to transition that care, so they don't do this.

But if we feel that they're going to need to transition to a provider that cares for adults. They complete an annual transition readiness assessment. And we also know that one size doesn't fit all for this. So, we have three different groups of assessments that we use. We have three surveys based on the anticipated independence of the young adult. We have one for our young adults that are going to be independent at the time of transition. These are our kids going off to college, going into a new job, moving out of their mom and dad's house. And this survey is directed to the young adult, to be completed by the young adult, and it grows as they get older. So, we have one set of questions for 12 to 14, one set for 15 to 18, and one set for 18 and older. When we get to that 18 and older survey, we're asking questions about sexual health. Do you know your medical history? How do you care for yourself? And the questions just kind of grow as they get older.

The next group of surveys that we have are for our young adults who will need some support at the time of transition. So, those patients that may be able to go into a group home setting or will need kind of that ongoing support from their caregiver. Maybe they're appropriate for just supported decision-making. This survey has simpler questions to still be completed by the youth with support of their caregiver. And those questions don't change. So, they're very direct, very forward in a way that the young adult can learn to answer them.

Host: Is that the point where you add in sort of goals for them to attain as they're going through?

Stephanie Pratt, LMSW: Yes. So for those first two groups of patients, they have what we call our standard transition goals. So at the end of their survey, they select a goal that they want to work on for the year. We've decided, we've done a lot of research with our parent advisory councils, our teen advisory councils, transition stakeholders, and really the feedback was teens want to choose what they want to learn. We wanted to allow them to have that perspective to say, "I want to know about my medications," "I want to know how to create a three-sentence summary," "I want to know how to learn my medical history." So, they pick a goal at the end of their readiness assessment that they want to learn, work on for the next year. And then, we provide education on that goal. Those first two groups pick from what we call our standard transition goals, so that's really kind of concrete. access to the patient portal medical history and condition. Alcohol, drugs, and tobacco, and how does that affect my medications if I was to partake in anything in that area? What are my medications? How do I create a three-sentence summary? So really, how does the teen learn to take on, absorb that information, and learn those things?

The last group of surveys that we use that we've really just redone. So in April, we launched our transition readiness assessments for our young adults who will need full care guardianship. Because we really view those as we're not necessarily preparing that young adult who's going to need guardianship to assume their own care, obviously, because they're going to need a guardian. But our job is to prepare the caregiver who is going to become that guardian, to transition that young adult's care into the adult world, to make sure that they're adequately prepared to access complex medical care in the adult healthcare system. So, those surveys really focus on assessing caregiver readiness. And then, we've expanded those transition goal options to include residential care planning, school transition planning, waivers, Medicaid, social security, just to kind of encompass the entire picture that those transition patients encounter.

Host: Great. So, I'm going to assume that as you're going through this transition, there's not this period of time where you just go, "Okay. great. You know, you're gone," you know, "Off you go." So, talk about, you know, so now they've now been introduced to their adult provider, they're starting, what is the overlap and walk us through the actual transition, that part where you actually move that forward.

Stephanie Pratt, LMSW: Yeah, absolutely. So, our goal for the organization is to transition between the ages of 18 and 22. And it looks different for our patients that follow at Children's Mercy for both primary care and specialty care, and those that follow for just specialty care. So once we've kind of identified a provider that we want to transition for, so I'm going to use our Beacon Clinic just as an example. They've talked about, they've done the readiness assessments, they've done the goals, they had the education. And now, it's time to really talk about where are we going, what are we doing?

And so then, we have identified referral processes with our adult hospital partners. So with KU, St. Luke's, University Health, Aza Health. So, we'll make an initial referral to their primary care and then that primary care then reviews the information, reviews the records. We've kind of identified 10 topics of things that we provide at the time of the referral, name, date of birth, insurance, diagnoses, special health care considerations, what equipment are they using, any social concerns, you know, kind of just to give a picture at the time of the referral. And then, they take that information and we have identified staff members to make sure they're getting to the right primary care provider because we kind of view primary care as the best entry point into the adult healthcare system. So, families aren't having to transition 10 different specialties. So, we want to get them set up with the new primary care.

Once they've kind of identified a provider, then our provider at Children's Mercy will do what we've called a warm handoff and talk to that new adult provider. That can either be via email, via phone, or via telehealth appointment or via, you know, a Team's call. But really, the opportunity for the pediatric provider to say this is where we are with this patient, this is their history, and this is what our goals are moving forward. So then, the adult provider can then take that warm handoff and be prepared for when that Children's Mercy patient comes in for the first time.

Host: Very good. And our listeners in Whistler, Canada, the Beacon Clinic is our clinic that has the medically complex children, higher concentration of medically complex children. So, it's a good example on that.

Stephanie Pratt, LMSW: And I will say, you know, we're not perfect at doing this. This is still a growing program, a work in progress, but we really see the need and the opportunities to involve care coordination within this kind of transition to the eventual adult provider so we can provide a single exit for our patients into adult care and a single entry into their system. The idea is that we're not making our families go through hoops. We want to be able to provide a direct path for them. And, you know, that's still something that we're working on. It's our ultimate goal within our program because we really see the need to support these families through this process and know how emotional and how challenging it is.

And then also, we want to have the staff and the ability that after they attend that first appointment to be able to follow up with them. How did it go? Did you like your provider? Did you understand what they were saying? Are you comfortable with the direction of this care? And allowing the family to say "Yes," "No, I don't know yet." You know, and some of our job is also setting expectations for adult care and making sure the families understand the differences between transition between pediatric care and adult care because the pediatric setting doesn't exist in the adult world.

There are a lot of changes and also reminding families that you're not going to have this connection that you have with your pediatric provider at that first visit with the adult provider. So, it takes time to develop that relationship, develop that trust. And so, some of our job at the pediatric side is really setting understanding and expectations for the differences that will occur once you leave the pediatric hospital.

Host: Yeah, that's really great. And Stephanie, for our listeners, particularly ones that are not in the Kansas City metro area, I mean, the program that we have here with you and your team is really remarkable at being able to do that. But many of the pediatricians and others that may be listening don't have those resources and you've had some experience in other areas of healthcare. Do you have some advice for those that don't have the resources that you're going through at this point?

Stephanie Pratt, LMSW: I think that kind of just developing your knowledge and your understanding about transition is so important. When I came into this role, I was so surprised by the numbers of how little that's being done nationally you know, I think as anyone especially that has a family member that's experienced the pediatric setting,

everything's gone so well and you just assume that healthcare transition is going to be that. And for a lot of us, it's not true, you know, a lot of systems, community partners, rural communities or just, you know, even providers within our own organization that just aren't talking about transition, and we're not providing that education.

So, I think the first thing is just develop the knowledge about transition, the why. Why is it important? And I think also thinking for providers in the community is you're doing a lot of this. You're talking to your families, you're preparing them, but realizing that we need to have a structure.

I would also say we do a lot of consultation with other hospitals across the country within our program, with community providers. So, we are available to be a sounding board in what we do, happy to share our resources and kind of the guides that we've created, and I think that there's a big opportunity for us to, as a major children's hospital in Kansas City, to connect more with the community PCP, to make them aware of what resources we have and how we can support their work in their, you know, community practice.

Host: Very good. Stephanie, thank you so much for joining us today. You know, before I let you go, I understand that you're now preparing for a trip down to Hawaii. So, you've got Whistler, Canada and Hawaii. Whistler's your favorite. I got to tell you, Hawaii's going to make a run for your money on that one.

Stephanie Pratt, LMSW: I know. We're excited. My kids are really excited to go. We're going to do kind of the lay on the beach, do luau's and that kind of stuff.

Host: Okay, awesome. Well, safe travels for sure.

Stephanie Pratt, LMSW: Thank you.

Host: As a reminder, claim your CME credit for listening to our show today. Visit [cmkc.link/cmepodcast](https://cmkc.link/cmepodcast) and then click the Claim CME button. This has been another episode of Pediatrics in Practice, a CME podcast. I'm Dr. Rob Steele. See you next time.