Dr. Mariam Hanna

Hello, I'm Dr. Mariam Hanna and this is The Allergist, a show that separates myth from medicine, ciphering allergies and understanding the immune system.

Before you know it, they're off to high school and then suddenly university, post-secondary education, and beyond. It happens in the blink of an eye. My eldest is actually off to high school next year. When did that happen?

As allergists, we see this happen with our patients, too. One minute, they're sitting in clinic with a parent answering every single question and not letting the child speak, and the next, they're preparing to navigate their healthcare independently.

So, I've always had a bit of a mantra during asthma follow-up visits: medication adherence is a shared responsibility between the parent and the patient. A 13-year-old shouldn't be expected to manage everything alone, and even a 16-year-old who insists they've got it all under control often still benefits from a parent who gently reminds, observes, and yes, occasionally nags them.

I've even joked with families that until their child is 30 years of age or until they are someone else's responsibility and can take over the nagging, it's still their job to keep an eye on things, because we all know how often a teenager can walk up the stairs to their medication and then this vortex happens in their mind, and somehow they forget what they were doing by the time they get there.

But that raises an important question: at some point, responsibility does have to shift. Parents do have to step back, adolescents have to step forward, as scary as that sounds right now for me. And eventually, patients move from pediatric to adult healthcare systems. How do we make that transition successful, and what happens when we don't?

That's exactly what we're going to be discussing today. We're talking about one of the most important and often overlooked aspects of healthcare, but in allergy and immunology practice, the transition from pediatric to adult care.

And we have a wonderful returning guest for today. Today's guest is Dr. William Anderson, associate professor of pediatrics at Children's Hospital Colorado and the University of Colorado School of Medicine. He serves as clinical medical director for allergy and immunology and directs both the hospital-wide IMPACT Transition Program and the asthma-focused ASCENT Transition Program. His clinical and research interests include severe asthma, healthcare transitions, and the use of technology to improve patient care.

We're going to dig into all of that today. Dr. Anderson, thanks so much for taking time to join us, and welcome back to the podcast.

Dr. Bill Anderson

Thank you so much. I'm so happy to be back, and thank you for the invitation.

Dr. Mariam Hanna

Let's talk about why this is a critical component of healthcare in allergy and immunology specifically.

Dr. Bill Anderson

I think that we're really uniquely set up to be experts in pediatric-to-adult transition. We are one of the few specialties that can treat both adults and kids based on our training.

We have patients that have diseases that start early in life and continue on, and these are chronic conditions that are not going to magically go away when a patient turns 18 or 21. So, for these reasons, I think that allergists-immunologists should be the experts in pediatric-to-adult transition, but oftentimes we fail to do that.

It could be because we're also busy. It could be because we are in an adult practice or pediatric practice and we're siloed into our specific view. Or we're in a practice where we will see people their whole lives, but then we don't take the time to actually think about what's different in addressing care as a pediatric model versus an adult model.

So clearly, it is critical that we take the time to really invest in this time of transition for our adolescent and young adult patients.

Dr. Mariam Hanna

What are the consequences if we do a poor job of it? What happens to the patient?

Dr. Bill Anderson

So we know that adolescence and young adulthood is one of the most perilous times for our patients with atopic conditions.

So, for example, we know that adolescents and young adults have a higher potential mortality risk with asthma than our younger patients. We know that our patients with food allergy become a little bit more adventurous, and they might start trying new things.

For these reasons, we know that adolescence and young adulthood is a time where you're going to be more likely to lose disease control, you're more likely to be hospitalized for your illness, you're more likely to have gaps in care where you're not following up on a routine basis, and you're more likely to have emergency department visits for your illness.

So clearly, there is an increase in mortality and morbidity during this time period. And so the idea of working to have a formal transition program or empower patients to manage their own care is so that we reduce these potential pitfalls as much as possible.

Dr. Mariam Hanna

Okay. And when does this transition concept occur? I remember way back when we learned about the frontal lobe continuing to develop up until—and it's actually not the magical age of 18, right? We continue to learn these executive functioning skills. So when should we start thinking about transition in patients in general?

Dr. Bill Anderson

So earlier is better. Some guidelines will say starting as early as 12 years of age with thinking about pediatric-to-adult transition. In our practice, we usually start around 14 years of age.

But you bring up a great point, Mariam, that it's all about this idea that it's not going to happen overnight, this is a process, and just because they've met certain age criteria does not mean they've met the development criteria or have sufficiently developed the skills to take over their own care.

So starting early is a great opportunity then to have anywhere between 8 to 10 years to then start thinking, all right, how am I going to start having you learn the skills that you need to care for yourself as an adult?

Dr. Mariam Hanna

So I'm going to walk into the room with the 12-year-old, and we're going to say, "Okay, we're getting ready for your adult transition." What actual steps am I going to take in that room to help this process start or move along?

Dr. Bill Anderson

Yeah, so at those first early onset ages at 12 to 14, it's more just outlining that this is the expectation that you're going to be moving to an adult model of care or an adult provider, depending on what your individual clinical practice looks like.

It sounds very intuitive, but you would be shocked how much that does not necessarily come through for patients. I have patients all the time that are like, "Well, I just thought I'd be here forever." Well, yes, I am board certified to see you forever, but at Children's Colorado, we have a cutoff where we try to get patients to the adult side. So letting them know that this is the expectation and our goal that we're going to be working toward.

Very commonly, some practices might have an actual policy where this outlines what that will look like. So, for example, what is the ideal age that we might try to transition you to adult care? What are some of the metrics that we're going to use to follow that moving forward to see that you're ready to transition? And some of the responsibilities, including medico-legal, that might change around 18 years of age.

Dr. Mariam Hanna

I've often hushed the parent for the first 30 seconds and said, "No, no, I was really asking the patient to update me as to how life has been since we last connected." So what do you suggest here?

Dr. Bill Anderson

There is nothing wrong with doing that, I would like to emphasize. That's really an important part of it.

But I think that having at those early visits at 12 to 14, doing exactly what you're doing in terms of asking the child directly the questions and seeing how well they can respond to that.

Then starting at maybe age 15 or 16, having more prolonged time with the parent out of the room when you're asking questions and say, "Hey, I want you to tell me about your care, I'm going to bring mom or dad or your caregiver back in and we're just going to double-check that everything we talked about today seems correct." And then starting at 18, obviously, having the parent out of the room.

But that is just the history component of it. You also want to have them understand what their medications actually are and why we have them. You want to think about starting to reinforce action plans, whether that's a food allergy action plan, an anaphylaxis action plan, or an asthma action plan.

And then, as you get closer and closer to 18, that's when you might start thinking about things like, do you know how to pick up your medications from the pharmacy? Do you know what to do if you had to call someone in case of emergency?

So I think that the communication component is one very critical aspect of it, but you also need to be thinking about these skills that they're going to be developing and give them a little bit of a homework assignment, if you will, between this visit and the next visit to see if they can maybe take on those tasks.

Dr. Mariam Hanna

Okay. Tell me about the formal programs that exist within your hospital. I'm actually not familiar whether most hospitals have this or most programs have this so formalized. What is this formal program doing?

Dr. Bill Anderson

Yeah, so I will say we're very fortunate at Children's Hospital Colorado to have this program, and we are more than happy to partner with any other hospitals, institutions, and clinics that may be listening to this right now that are looking to establish their own programs.

So my work in this space initially started with an asthma-specific transition program. We call it ASCENT, much like everything in Colorado, it has to have some kind of mountain acronym associated with it.

Dr. Mariam Hanna

Obviously.

Dr. Bill Anderson

But ASCENT stands for Asthma Self-Care Education and Transition. And we specifically work with our patients with asthma who are seen either in the allergy and immunology clinic or in the pulmonology clinic.

We ensure that these are patients that have established care, so you're not coming in for your very first visit at 14 and we're talking about sending you to adult care, but having a process where you're identified, we develop this policy that lets you know about the expectations, and then we track your readiness to transition over time, which we can certainly talk about how we do that.

We have a nurse care coordinator that meets one-on-one with these patients either during visits or outside of visits, if it is one of those more chaotic visits, and we have this series of communication that goes on emphasizing these principles that we've discussed during this time of transition.

We then help to specifically identify adult providers in their area who will take their insurance, who feel comfortable for their care, and then help set up those appointments and navigate and make sure that they attend. So that's our asthma-specific program.

And then I co-direct a hospital-wide program called the IMPACT program, or Improving Pediatric to Adult Care Transition program. And the idea there is that we want to standardize transition efforts across the institution.

For many of you who may be listening that are in an academic medical center, you know your patients will see many different specialties, and how often have you been in the situation where you're like, "All right, I'm really looking to get you to adult care at 21," and they're like, "Well, my gastroenterologist said I can be here until I'm 26," and my neurologist said I can be here till I'm 30." Well, that leads to a lot of really mixed messaging.

And so how can we have a uniform standard that we all work toward, and how can we make sure that we're optimizing communications between specialties so that no one's left unexpectedly in this position where they're trying to explain to their child why you feel transitions are appropriate but another person feels that it's not?

Dr. Mariam Hanna

So much to unpack here. Okay, go first into the asthma one, and you said your nurses work with patients. Let's unravel that a little bit more, what do they do?

Dr. Bill Anderson

I think that one thing that's really important to recognize about pediatric-to-adult transition is that this does not have to be an exclusive task where you as the medical doctor or advanced practice provider have to be the one doing all this work.

There's actually really great literature out there about the role of nursing and empowering them to lead this kind of work. There's also information out there about the role of social work, care coordination, even your medical assistants, if they're properly educated, they can help with some of this role. So it's not necessarily one person is responsible for it all.

So whenever we're working with our patients, we use a tool called TRAQ, or Transition Readiness Assessment Questionnaire. There are many different transition readiness assessment questionnaires that exist, several of which have been validated. The reason we picked the TRAQ is because it's the one that's most commonly used in literature and probably has the most research done on it.

But what it will do is it will ask patients individual questions about their disease and their disease management. So, for example, it's broken into a few domains including managing medications, appointment keeping, talking with your provider, understanding health insurance, and understanding your underlying disease.

And then the patient fills out the questionnaire, and in this particular tool, they either say, "I don't know how to do this," "I don't know how to do this but I want to learn," "I am learning how to do this," "I have started doing this," or "I have always done this and I know how to master it."

So based on those responses, we then will focus on particular areas that we want to address. So once again, I know this is a process. We're not going to address every one of these at every single visit. But say you come in at 16 and you score really low on knowing what your medications do, that might be our area of focus for today on how we're going to provide that education for you.

I always say, though, you need to trust but verify these questionnaires. So true story: I had a patient that filled this out, and it was like knowing how to refill your medications, and they were 17. I was like, "Wow, that's pretty impressive for a 17-year-old to be refilling their own medications." And so I said, "Tell me how you do it," and he said, "Well, when I'm out of my medicines, I go to my mom, and then my mom calls the pharmacy and she fills the medicines."

Dr. Mariam Hanna

Technically yes, he did find a way to fill his medicines, but that's not going to be the long-term solution here.

Dr. Bill Anderson

It's going to be a short-term bridging solution.

Dr. Mariam Hanna

Correct. How many questions is the TRAQ questionnaire, how long does it take to fill out this questionnaire just for those that aren't familiar with it?

Dr. Bill Anderson

Yeah, so the TRAQ is 20 questions. It's a little bit of a longer one. So that is something that in your individual practice when you're looking at these different questionnaires, balancing how much information you're getting versus how much time it takes for the patient to do it.

One thing that we are doing at Children's Hospital Colorado is we're sending it out as part of our pre-visit questionnaire so if you have a MyChart you can do this. The one caveat to all this is you have to ensure the child's actually the one filling it out because how far too often does the parent do all these pre-questionnaires and so once again that's where the trust but verify comes into play.

And so if you're able to do it before your visit, that helps to save a lot of time for the provider, and we actually have a little flow sheet that it auto-populates into so that you can take a quick look to say, all right, these are going to be like maybe the one or two domains I'm going to touch on today.

Dr. Mariam Hanna

And you're verifying with the patient, you're not verifying with the parent. Because sometimes they give me discrepant, okay, with the patient.

Dr. Bill Anderson

Correct. And I actually think that when you get discrepant answers, that's one of the best learning opportunities that you have.

Because, like early on in your introduction, you talked about having the child take their medicine and you hear from the parent, "Oh, yes, Timmy knows how to take his medicines and takes them all the time." And Timmy is like, "Zyrtec is an inhaler, correct?" And you're like, "No, no, no, no, no, these are different things."

And so we need to take the time really then to emphasize, all right, this is the gap, why is there a gap, and how can you, mom and dad, help empower your child? There's great literature out there that while we as the healthcare team can provide this education, having the parents model the education and emphasize it at home is what really leads to them being most successful in these outcomes.

Dr. Mariam Hanna

Fantastic. Now, this is an issue with the entire healthcare system so I don't know if you can answer this for everybody, but you also talked about being on the same page with other specialists in terms of transitions. So this is the other program that you run. How do y'all go about doing that? Because that seems like a big thing to take on.

Dr. Bill Anderson

It is a big thing to take on. Yeah, I've been in that role since 2019, so coming up on seven years, and it's not fixed yet, I'll be in full disclosure, but we're making a heck of a lot more progress than we did seven years ago.

And so there's a couple different ways that we're trying to do this. One is we're trying to leverage our EMR. We have a tool built into our EMR called the Transition Planning Tool, or TPT, where you can see what other people are documenting. So that's one central resource that we're trying to get everyone to go into and at least document that you are having these conversations so that you can see who's all working with this patient.

We also are very fortunate in that we have a central referral hub with a separate nurse care coordinator and social worker and family navigator who can maybe help contact a lot of these specialties if we end up in a corner. We use it for those most complex cases, or maybe where transition has failed.

But it really boils down to finding the best way to improve communication within your healthcare system. And clearly, me talking about improving communication is the key to every aspect of healthcare, so probably not going to be solved during this podcast, but that is the goal of where we're working toward in transition.

Dr. Mariam Hanna

You can only chip away at big problems so we can chip away at this one, too. Okay, I too was a teen at some point, risk-taking, feeling invincible, and all these fun things that I don't feel anymore. But anyways, how do you deal with that portion of the teen? Not all teens are ready to fully take on responsibility.

Dr. Bill Anderson

I think that in terms of the risk-taking behavior that you brought up, it's almost a little bit of scenario playing with them to say like, what would you do in this scenario? And some people have thought it through and they've recognized, okay, I would call X, Y, and Z for help, I have my epinephrine with me, I have my rescue inhaler, whatever it may be.

But other ones, this is like the first time that their brain is really having to go through this exercise. And so taking the time to recognize, first off, risk-taking behavior will occur, even no

matter how many times you try to emphasize not to do stuff, it's going to happen. So you have to prepare for that worst-case scenario in that time.

Sometimes, to your point of the brain development, we're sometimes against a clock, unfortunately. We have patients that go on from high school to college and they're going, whether or not they're ready from a medical perspective. So, in those cases, I try to see what is the highest priority and how can I potentially emphasize that, with in my mind priority being what's most likely to cause you serious medical harm, but for the patient, we also need to recognize what do you reasonably foresee that you might encounter that you're most worried about and addressing that aspect as well.

So, to your point, it's not easy, it's something that we need to chip away with, but I think it's being very realistic that these situations are going to occur and trying to find the best way to plan for them in advance.

Dr. Mariam Hanna

Okay, and digital health is actually another area where you have lots of interest. Can digital health tools be used to help with this or what's the literature like on this area?

Dr. Bill Anderson

Like everything with technology, I'm not going to say it's going to fix it all and that's the answer, because it's not the case. But it's another tool in our arsenal that we can be using to help engage these patients more.

A lot of these patients, they don't want to pick up the phone regardless of who it is. Maybe we leverage MyChart where they can message back on their own time. Some of these patients work really well with having feedback provided to them by apps and trackers. That might be a really good opportunity to engage with them.

I think we know also that things are just becoming more and more advanced, like this is going to be the future for them. So the same way that you are developing a skill for them with anything else, you want to make sure they have appropriate medical technology health literacy. And so I think about that as an aspect that we should be exploring more in these adolescents. It's not something that comes up in a lot of these questionnaires because they're a little bit older and maybe that is an area that we need to be exploring more.

Dr. Mariam Hanna

Okay. Biggest barrier that you face in establishing a program for transition programs?

Dr. Bill Anderson

Honestly, the biggest pain I've had is culture. People don't necessarily want to be thinking about having their patients leave their practice. We get so attached to these kids. Like you see this

child from the time they're six months old when their eczema was flaring and now they're 21 and it's hard to let go. It's hard to let go for the patient, it's hard to let go for the provider.

And this is something that we don't want to end up in this situation where both people feel like they're in the middle of a breakup or their family's being ripped apart. And so really empowering them to recognize this is in the best interest of everyone involved here, so that is probably the biggest hurdle that I've encountered.

Now, let's say you are already, you've crossed that barrier, you're saying, "I'm on board with this bill, you're preaching to the choir," it's then the logistics of one more thing that I have to do during a visit. And I would argue that it's not one more thing that you have to do, it's taking things that you're already doing and being much more conscientious and intentional about doing them.

How many times during a visit do you talk about, "All right, do you have your epinephrine with you? Do you know what to do in case of an emergency?" Well, that is actually all adult transition planning, but you want to make sure that you're actually capturing that the patient is understanding this and directing it to the patient themselves.

Dr. Mariam Hanna

Yeah, I've been chipping away at asthma questions with you, but I struggle with this one with my OIT patients as they hit that transition spot and their adult allergist handover to take them over that threshold as well.

Dr. Bill Anderson

Yeah, I often wonder about that myself, and that's an area that when I see a patient come in that's a teenager—I just had one yesterday, a teenager that's on OIT doing great—and I'm thinking to myself, is this going to continue to go great when he goes off to college and is having a much more chaotic life on a day-to-day basis with many other stressors and challenges that may cause him to react during his OIT or may cause him to miss doses and then all of a sudden he decides to pick it up later? Like what are these going to be long-term outcomes?

So, yes, I am talking a lot about asthma because that's my interest, I know food allergy, among other things, is your interest, but I want to make sure that this is applying to all aspects of it and it's not isolated to just these individual conditions.

Dr. Mariam Hanna

Okay, last one, off the record, but I am totally still recording. Personalities are a little bit different between our pediatricians and our medicine-trained people. Everybody knows what I'm talking about, there's no secret here. How do we prepare our patients for this? I cannot crack a joke or smile during clinic. So how do I prepare them that their providers care for them but there's different dynamics here?

Dr. Bill Anderson

Yeah, so I feel I'm allowed to answer this question because I am Med-Peds trained, so I am board certified in both pediatrics and the adult medicine side. So I am not taking a swipe at anyone.

Dr. Mariam Hanna

Was I taking a swipe?

Dr. Bill Anderson

No, no, no, no, no, you're not taking a swipe. But beyond just saying that it's going to be far less colorful on the walls over at that institution, I think that you need to let them know that just because they may not be as warm and as friendly or maybe—I think sometimes, and this is a criticism of pediatrics, I think we sometimes bend over backwards far too often for some of our patients and our families that lead them to a position where they expect that's the way everybody is going to be, that's not the case.

So understanding that even though the culture is different over there, they care about you just as much, they are just as invested in you as we are. And I like to let them know that I've had the pleasure of working with you for 18, 21 years, but this person's going to have the pleasure of knowing you even twice as long as that.

And really letting them know that it's a change, but not all change is bad, and recognizing that just because their culture is a little different doesn't mean that they care any less and they don't have any less good intentions for you.

Dr. Mariam Hanna

Perfect. That's a good way to end. All right, time to wrap up and ask today's allergist, Dr. William Anderson, for his top three key messages to impart to patients and physicians on today's topic, Transition to Adult Medicine. Dr. Anderson, over to you.

Dr. Bill Anderson

All right, first one, not a shocker, it's a process. So starting early and continuing on until the patient reaches a point where you feel that they have the skills to transition to adult care, trying to do your best to chip away at this at each visit, even if it's just in a small way. That's my first.

My second is that it's not all on you as the medical healthcare provider to do all this work. You can engage your nurses, you can engage your other staff, you can engage the parents to really help work on this.

And the third is try to have a system in place where you are actively documenting their readiness and their progression so that you're able to assess this and provide the education appropriately.

Dr. Mariam Hanna

Perfect. Thank you, Dr. Anderson, for joining us on today's episode of The Allergist.

Dr. Bill Anderson

My pleasure, thank you so much.

Dr. Mariam Hanna

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