

Infant Tracheostomy and Vent Care

In this episode, we will hear from Addie Begley, a neonatal nurse practitioner at Children's Mercy. She will be leading a discussion focusing on the Infant Tracheostomy and Home Ventilator Program, and the services the clinic offers for its patients.



Featured Speaker:

Addie Begley, RN, MSN, NNP-BC

Addie Begley, RN, MSN, NNP-BC graduated BSN from Pittsburg State University 2000

Graduated MSN from Vanderbilt University Neonatal Nurse Practitioner Program 2008

Children's Mercy Infant Tracheostomy and Home Ventilator Program since 2012

Currently working towards my Acute Care Pediatric Nurse Practitioner at UMKC

I have 3 young adult children, 2 at KU and 1 is a Junior in high school

Very active in animal rescue outside of work.

Transcription:

Trisha Williams: Hi guys. Welcome to the third season of the Advanced Practice Perspectives. I'm Trisha Williams.

Tobie O'Brien: And I'm Toby O'Brien. This is a podcast created by Advanced Practice Providers for Advanced practice providers. Our goal is to provide you with education and inspiration. We will be chatting with pediatric experts on timely key topics and giving you an inside look of the various advanced practice roles at Children's Mercy.

Trisha Williams: We are so glad that you're joining us today. So sit back, tune in, and let's get started. Today we are pleased to have Addie Begley with us. She is a neonatal nurse practitioner that works with the infant Trach in home Vent program in the neonatology department here at Children's Mercy. Welcome to the podcast, Addie.

Addie Begley: Thanks guys.

Trisha Williams: Why won't you go ahead and start off by telling our listeners a little bit about yourself.

Addie Begley: Sure. Like you said, I'm a neonatal nurse practitioner, so my history before coming to Children's Mercy was working in NICUs. And then I got this incredible opportunity to interview for this program here at Children's Mercy, seeing kids with tracheostomies and ventilators on the outpatient side, which is really different than working in the NICU. So I've been here for 10 years at Children's Mercy and the program has changed and grown a lot, but it's pretty amazing, I think.

Tobie O'Brien: Well, we are so excited that you are here to tell everyone all about it. So, tell us about really what is the infant Trach and Home Vent program and like, who is it for and, which patients typically are in this program?

Addie Begley: Yeah, it's kind of a mouthful. The Infant Tracheostomy and Home Ventilator Program, this program was started I think about 18 years ago by Dr. Linda Gratney and was actually started for kids in the NICU who had severe lung disease due to prematurity, who were gonna need ventilators for a long time so that they could go home, be with their families, and make developmental progress at home while they wean the ventilator, to get them off and then eventually get their trachs out.

So, the program evolved even before I got here to not just kids with chronic lung disease, but any kiddo who needed a trach and a ventilator, going home that were at that point in time, less than three or four years old. We now take care of any kiddo who goes home with a trach, even if they don't have a ventilator or a trach and a ventilator if they are two years or under. So things have changed a little, but we do manage any of those kiddos who are less than two years old when they go home initially with their tracheostomy, with or without a ventilator.

The reason our program exists is because they just recognize that those kids who have tracheostomies, whether or not they have a ventilator, they have a lot of needs. They have a lot of equipment needs private duty nursing in the home with a lot of orders that come across. When they get sick, they can get really sick pretty quickly. And so, our team provides twenty four seven on-call coverage for these families to be able to reach us at any point in time that they need to be able to get some direction on things that we can do to try and keep them from having to be admitted.

If they happen to get a cold or some other kind of respiratory infection or even gastroenteritis, there's now a pediatric tracheotomy in home ventilator program here at Children's Mercy, which has been amazing because we've been able to transition some of our kids that we typically would've held onto for a lot longer than we initially wanted to. So we try to transition kids to

that program when they're three or four years old, to help manage them better from a pediatric perspective instead of neonatology perspective, if that makes sense.

Trisha Williams: Right. So are you guys, like, is the infant tracheostomy and home ventilator program, is it a medical home per se, like a primary care, or do they still have a medical home and then this is just in conjunction with their care?

Addie Begley: We actually are a medical home for the kids who live locally. We don't have any kind of set guidelines, , as to what local is. It's mostly if the family is willing to drive here for their primary care needs, we will be their primary care providers as well. Families who live several hours away. We definitely encourage to have a separate primary care provider, but for local kids. And then, like I said, families who are willing to drive here for their primary care needs. We do and are able to be that medical home.

Trisha Williams: Could you shed a little bit of light on some of the diagnoses that these kiddos would have? You talked about chronic lung disease, I'm assuming you mean like bronchopulmonary dysplasia? What are some other, diagnoses that these kids could have that would make them eligible for this program?

Addie Begley: Pretty much anything that a kiddo could need long-term vent support for. So you're right, bronchopulmonary dysplasia, that was kind of what. Is initially set up for, , but any kind of neurologic disorder. We actually have several kids with central congenital hypoventilation syndrome that we follow. We have kids who have genetic disorders that affect ability to breathe on their own cardiac problems. Kids with heart issues that cause compression on the airways. So they need some extra peep, , to keep those airways open until those cardiac defects are fixed. We see those kids as well.

And then our tracheostomy only kiddos could be pierroban or treater Collins or subglottic stenosis. So anything that's causing an obstruction in the airway that we need to bypass for them to have a safe airway for going home.

Tobie O'Brien: Okay. Really interesting. So, one question I have, Addie, is I know that we have the specialty care clinic is the infant tracheostomy and home event program, part of the specialty care clinic?

Addie Begley: Yeah, that gets kind of confusing, so the umbrella term is neonatal follow up clinic, , where any of our patients from neonatal intensive care units across the city are followed up. And we're part of that clinic, so if they have a tracheostomy and or a ventilator, they're gonna see the infant trach and home vent program. If they go home with a nasal cannula or. Needs from being preterm. They're gonna be followed in special care clinic. And then we also have another program called the Neon Clinic, and they follow those kids with congenital diaphragmatic hernias and also kids who have been cooled for hypoxic injury. So all three of those clinics together make up the neonatal follow-up.

Tobie O'Brien: I would love for you to tell us, so Trisha and I, as you know work in ENT so we have a little bit more insight into trachs. Although I would say we have a whole dedicated team as well that focus on trachs, as well. But we would love to get some information, out about trach and tracheostomies and, , home vents, kind of like a trach and vent 101 for advanced practice. Could you help us with that?

Addie Begley: Yeah, absolutely. I will say, a plug for our amazing team that we have here that you mentioned, , there are tracheostomy educators and then certain nurse practitioners and physicians that kind of manage those tracheostomies on the outpatient side, and they're all such amazing resources. I think something to remember with tracheostomy dependent children and especially infants, is that they have very small airways and that tracheostomy tube is taking up a large portion of their airway. If they're having any trouble breathing at and you don't really know what to do. I would say just do a tracheostomy change , or have the parents do a tracheostomy change , have an RT do a tracheostomy change.

Because the likelihood is that there's something obstructing that trache tube, which has been causing them to have difficulty breathing. I have families change the trach tubes at home, even if kids are just having a little bit of mild distress, because sometimes those trach tubes can get clogged with mucus and it makes an even smaller little tiny airway that they have to try and breathe through. And if we can get a clean trach tube in there, , it can really open that up for them and relieve that distress. I can't remember what nurse practitioner it was. Kristy McGowan, who one time told me, if in doubt, changed out.

So that's kind of what I go for with tracheostomy care, especially in like emergent situations. If you have any question or any doubt that tracheostomy tube is patent, go ahead and just change it out. There should be a spare one there. It opens their airway up and allows them to breathe easier. I think the other thing to remember is, these parents and families do so much training and education with our amazing trach team before they go home. They can probably tell you more about what their child responds to than any medical provider ever could.

So I think that listening to these families and asking them, what helps their children when they're having trouble breathing or when they're not wanting to have their trach changed and they're fighting it and you're having a trouble getting the trach tube in. Just listening to the families and asking them what helps, I think is incredibly important. Something that I wanted to get out there is that you can find the settings for the home ventilators in the electronic chart so you don't have to go searching very hard. If you just look under respiratory, there's like a little tab that's actually home ventilator and tracheostomy settings, that will give you the most recent trach vent settings for that.

Trisha Williams: Very helpful information. I think that as advanced practice providers, there's a possibility, you know, in the pediatric world that we could, take care of a patient with a tracheostomy and a home ventilator regardless of the subspecialty that you work in. If you're in the ED or you're in, in ENT or Gen Surge, there's always a possibility that these kiddos are gonna need our expertise. And I feel like the patients with these types of things can be very intimidating to somebody that doesn't know. So it's very helpful for you to tell us, lean on the parents. The parents know what's going on. They are critical part of the healthcare team. We don't have to be the expert in their tracheostomy and their home ventilator management.

So lean on the parents to guide us with what needs to happen. And so that's really great that you put that out there. Kind of walk us through some clinical safety tips. You had mentioned, you know, when in doubt change it out. I have heard and have seen our tracheostomy go bags that our family has what are some things that advanced practice providers in our community need to know about for our tracheostomy patients? Like what equipment do they have and what could they do to help?

Addie Begley: The tracheostomy go bags are something that every family should have with them anytime they leave the house with their child with a tracheostomy. We actually provide those bags and they're these red large backpack looking things. But I do have some families that switch over to some other kind of bag after they go home, just based on family preference. But what goes in those bags is everything you would possibly need to change a trach in an emergency situation. So there should be another tracheostomy tube of the same size.

There should be a smaller size tracheostomy. So the next step down, so say these kiddos have a 4.0 inner diameter trach in, normally there should be a 3.5 inner diameter trach in that bag. And that is in case you can't replace that 4.0 for some reason, you would then place the 3.5 so that they would have an airway, and be able to either breathe or be bagged through that airway. There should be the obturator to help with those tracheostomy changes in that bag. There should be lubrication to help with the trach change, trach ties to hold the trach in place.

And then there should also be an emergency resuscitation bag. So all of our kids go home with self-inflating resuscitation bags, and parents are trained how to use that in case of an emergency. Another thing that families should never ever leave their home without is a suction machine. since these kiddos obviously need some help clearing those secretions out of their tracheostomies, so they should always have at least those two pieces of equipment with them. We Also encourage families to always travel with a pulse ox oximeter and with oxygen just in case.

Trisha Williams: That's a lot of equipment, but very necessary.

Addie Begley: That's a lot of equipment. . I'm trying to think.

Trisha Williams: A lot of equipment, but very necessary. So I think that it is important.

Tobie O'Brien: No wonder you need a nurse, , like a home health nurse. You just need somebody else to like carry the stuff, right? I mean, all joking aside, but like, that's a lot of stuff to carry.

Addie Begley: It is, , we do provide them with a modified stroller. This is kind of a cool thing that a lot of people don't know, but our carpenters here at the hospital will actually take a twin double stroller and they take one of the seats off and they modify it with some shelves to be able to put all of that equipment on the stroller for the family. And then we provide that to them at discharge. So that works for the little ones until they get a little bit bigger. But it's really nice for the families to be able to.

Trisha Williams: I love that. Well, and I feel like it's so important to get these kiddos home with their family out into their community. And so you had talked previously, for the trach clinic being their medical home, and. is it a multidisciplinary team? So you're working with PT and OT and you know, how are you helping these kids meet their developmental milestones and helping them into that nature? Is it a multidisciplinary team that kind of approaches these kiddos?

Addie Begley: So we are a multidisciplinary team and clinic in the sense that, , we have a pulmonologist who comes to clinic once

a month. We have a gastroenterologist who comes to clinic once a month, and then we have our ear, nose, and throat physicians who come twice a month. We don't have OT or PT in our clinic, but we're right next door to ot, PT clinic, which is really nice. So sometimes I'm sure they love us because we'll pop over there and be like, Hey, can you come look at this kid real quick, or can we get your opinion on this real fast? All of our patients also have early intervention program in the home.

So either Kansas Infant Toddler Services, or Missouri First Steps to provide OT and PT to help them continue to make that developmental progress. We do find it's amazing the developmental progress that a child tends to make after they go home. Parents have them down on the floor. They're playing with them on play mats, they're helping them to sit. Doing therapies with them like three or four or five times a day, and the difference that we see in these kids over just a period of a few months is amazing.

Tobie O'Brien: I agree and I'm curious, you mentioned that you had a career in neonatology before you even came to Children's Mercy, so I don't know how long you have been a neonatal nurse practitioner, but I am curious if you can speak to what life kind of used to be like for those babies that had been either born premie with those diagnosis that you had mentioned requiring, a tracheostomy and ventilator dependency versus like what life was like then versus now knowing that they can go home and have these other options for assisting in their development? Like, have you been able to see the progression in your career?

Addie Begley: Absolutely. I, have been a neonatal nurse practitioner for 16 years now. and I can remember working in the NICU, we would rarely place a tracheostomy, in a preterm kiddo because we didn't know what to do with them after that. So a lot of times if you had a child who got a tracheostomy who needed vent support, they were either going to live in the hospital or if you were lucky enough to live in a state where there was a long-term care facility, they might go there.

Now I feel like we tend to place tracheostomies even a little bit earlier than we did when I first started in this program because we've seen such good outcomes and we have seen such amazing developmental progress for these families that we've found. It's so much better to get the trach placed, get them stable on their ventilator, and get them home with their families as early as we can. We obviously aren't doing that before they would be like term gestation.

So if they're born at 24 weeks, we're not gonna place a trach at 32, we would wait until they were 40 weeks to see if we could get them off the ventilator. And certainly we give it a very good try to get them off the ventilator. But if we are really feeling like this is a kiddo who's gonna need this vent for six months or more, it is just so much better to get the trade placed and get them out the door as quickly as we can.

Trisha Williams: Medical advancements are amazing and I love that they're allowing our kids to go home with their families. That's where everybody thrives the most adults included when their family is all home together, so I love that. Some things I just kind of wanna reiterate for our advanced practice providers adding to the community, like it's important to remember to utilize the family for part of the medical team and for the knowledge and then look for their emergency equipment. Correct?

That's what I'm hearing you say. Look for that medical go bag, look for those extra trachs, their suction, their oxygen, and. Utilize the family to help you. They've been extensively trained. That's kind of what I'm taking away , from this discussion with you in regards to how to care for our kiddos out in the community.

Addie Begley: Yeah, you're exactly right. , it can be pretty intimidating. I am sure because I was terrified when I first started in this clinic. But just knowing that they have an artificial airway that can be changed out is actually a bit of a reassurance, and knowing how well these parents are trained should also be a reassurance. They should be able to do a trach change without anybody's assistance. One parent can even do them by themselves a lot of times. That's not what we want to happen on a routine basis, but in an emergency, a family could even change out a trach with just one person. So just yes, remembering that the family knows how to intervene if there's any kind of emergency.

Tobie O'Brien: Wonderful. It's so nice knowing that we have the infant program and the pediatric program and it's just dedicated to these kids is wonderful that we have that. So, we really appreciate you chatting with us today, Addie. We really enjoyed your insight and just kind of hearing about, , what is involved with infant tracheostomy and ventilation program. We like to end each episode where we ask our guests the same question, like we've asked all of the guests so far this season, this same question. So we wanna know in what way do you love to encourage your colleagues.

Addie Begley: I love teaching and I love when people ask questions about the kids that we take care of and share knowledge. And I think that that's so important across the different subspecialties that we all work in. I love, love to learn from the different subspecialty, advanced practice providers, and I love to help with information and provide that whenever I can. So I think my encouragement would be to just always ask. Most of us, I feel like are probably in that boat where we would love to share our

knowledge and give people a little bit more comfort in caring for different systems.

Trisha Williams: Knowledge is the key. I love that. And I love sharing and I love receiving. So thank you so much for sharing your knowledge with us today, Addie. We loved having you on the podcast.

Addie Begley: Thank you both. I really enjoyed it.

Trisha Williams: You're so welcome, and listeners, thank you for tuning in today. If you have a topic that you would like to hear about or you are interested in being a guest on our podcast, you can email us at tdO'Brien@cmh.edu or twilliam@scmh.edu (**mailto:<script type='text/javascript'><!-- var prefix = 'ma' + 'il' + 'to'; var path = 'hr' + 'ef' + '='; var addy94432 = 'twilliam' + '@'; addy94432 = addy94432 + 'scmh' + '.' + 'edu'; document.write('<a ' + path + '\" + prefix + ':' + addy94432 + '\>'); document.write(addy94432); document.write('<\a>'); //-->\n </script><script type='text/javascript'><!-- document.write(''); //--></script>This email address is being protected from spambots. You need JavaScript enabled to view it. <script type='text/javascript'><!-- document.write('</!'); document.write('span>'); //--></script>.)twilliam@scmh.edu (mailto:twilliam@scmh.edu)**). Once again, thanks so much for listening to the Advanced Practice Perspectives Podcast.

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