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Together At The Table: Kids Need to Feel Good Recorded May 13, 2020

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- [Fawn] Welcome back to our series on responsive feeding. This is part two Together at the Table. Kids Need to Feel Good. Karen and Stephanie, take it away.

- Thanks Fawn, we're really excited to be back.

- Hey, Karen, how are you?

- Doing great, I am so glad we get another opportunity to talk about responsive feeding today.

- Me too, so today we're gonna talk about being together at the table and why kids need to feel good at mealtimes. And before we go through. Before we get into the topic, we want to share the learning outcomes with you. After this course, participants will be able to describe how a child may develop an aversion to certain foods and explain how these aversions may be avoided during developmental experiences. Describe at least three common signs and symptoms which may indicate a child has a food allergy. Described the purpose of a feeding tube and at least two reasons why a child may need a feeding tube. So let's get started.

So we thought we would start off by talking about and reminding you of the idea that mealtimes should feel good. So we talked in the first portion of this series about how feeding develops in the context of relationships, and how families and parents are able to use feeding strategies to build those strong relationships that are based on trust. When parents are responsive at the table and use responsive feeding practices, we know that children are able to experience predictability and consistency and learn to feel safe at the table and is set up for success at every level. So when parents and children both feel good at the table, they're also able to notice those small victories are small indicators of progress that they can then celebrate. And Karen and I talk all the

time about how celebration at mealtimes is so important. If you think back to our discussion about the emotional impact of having a child who might be struggling to eat, we talked about how stressful that can feel for parents and caregivers, how it can cause parents and caregivers to experience a lot of grief, that things aren't going as expected. It can cause them to maybe think they're not such a great parent. And celebration is really the antithesis of that. So when we feel good at the table, when parents feel good at the table, and children feel good at the table, we're more easily able to notice those small moments and celebrate together.

- So we wanted to frame our discussion today with this quote by Marsha Dunn Klein. "Eating is built on a foundation of positive developmentally appropriate experiences." We think that this is so important to remember because when we look at kids who are typically Developing and learning to eat. They're having all of these small experiences that help them learn underlying skills. And we know that oftentimes parents are just really excited to watch kids develop these skills, they're taking pictures, they're celebrating, and they're just having a really good time together. And when kids struggle to eat, this part of the feeding relationship is lost.

So one of the things that we can do is therapists and supporting families is help build this foundation of positive developmentally appropriate experiences, right? I love what Stephanie said about being able to celebrate all of the progress because we're helping parents identify those really good things that are happening and the feeding relationship. Parents can begin to see the success and some of that pressure and stress kind of evaporates. You know, the last thing I wanna say is that we know that when kids are having fun when kids are engaging They're making associations between that skill they're working on, and just enjoying it. And that is so important and fostering internal motivation and development, especially as we're thinking about food and mealtimes.

So a child learns to eat, when their medical issues are managed when they're not in pain when they're not refluxing when they realize they have to, they have control of things and they can make choices in safe ways that are appropriate for them developmentally, kids learn to eat when there's a loving caregiver there to be a mealtime partner and kind of help them figure out how to orient the utensil in their hand and make things work for them without them getting frustrated or upset. And then we know that when kids have loving mealtime partners with them, they also are set up in a place to maybe even have fun and learn about some of the social parts of mealtimes. This is really different than when kids aren't eating well, right and some of the things that a child learns not to eat response to include physical discomfort. So we can think about physical discomfort broadly, we can think about it in terms of pain, it might be related to a gastrointestinal issue. It might be related to an anatomical issue. It might be related to an allergy, right? A lot of kids with food allergies, learn that every time I eat, my body doesn't feel good. And so they put that association together, and they learn that they don't want to eat because they don't feel good. We also know that relationships are so important in eating and that if your relationship doesn't feel comfortable, if trust isn't there, a child can feel emotional discomfort. And that lack of trust can really influence a child's ability maybe to take some risks or to try something that they're looking for that support from their parent or caregiver that they need to engage.

The next few points, you know, we really wanna draw your attention to and highlight with a couple of examples. This idea of a lack of control is so important because when kids don't have control, oftentimes they're not going to learn to eat. I think about this concept in relation to maybe what I would consider an aversion, right? for example, when I think about kids with feeding tubes, or kids specifically with NG tubes, oftentimes those kids have received an NG tube by being held down. a caregiver or nurse or doctor has taken the tube and threaded it up through the child's nose and down through their throat. And oftentimes, this is a little bit of a traumatic or stressful

experience. And the child receiving that NG tube, doesn't have control, right? So then when we think about later experiences, perhaps after a child is done having an NG tube and maybe they're you know, someone wants to help them bring a straw to their mouth, or to begin self feeding. Sometimes those kids can be really cautious and even look resistant, in part because they are remembering maybe even at a subconscious level that when something comes toward them, it's scary, and kids don't have control. So when we help kids to participate, and we give them some independence and supportive, developmentally appropriate way, it can help them to feel better and to engage in a near time. We also know that kids need to feel safe in order to eat. And you know, one of the examples Stephanie that comes to my mind is this idea of aspiration. Because we know that if a child has liquid or food in their mouth, and they realize again, probably at like a subconscious physiological level, that they're gonna choke on that food or that liquid, they might choose not to swallow, right? They might choose to refuse a bottle to spit the food out. And that can be really frustrating for parents. But we know that kids are behaving in that way because they're protecting themselves because they feel unsafe.

- So I'm glad you said that Sorry to interrupt. But I know that because you and I talked so much about those words and the weight of those words, refusal resistance control. And I think that one of our biggest goals throughout this entire series is to help parents understand what kids are communicating and why. And to help parents understand that control is not such a bad thing in the process of learning to eat. And we're gonna talk a lot more about that when we talk about working with families and the next part, but I'm glad that you highlighted that here.

- Yeah, that's a great point. Because, you know, when we talk about not having control, I think that some sometimes has a little bit negative connotation, but when we talking about kids being independent, that's usually a positive thing that we're looking for as therapists. So what an interesting point. But you know, we know

that when we think about what an experience might feel like from a child's perspective, it really helps guide our intervention as parents and caregivers and therapists. And I think it really causes us to pause and to think about the way that we're guiding families and supporting kids. And it really helps us to remember that pleasure and connection are such important parts of meal times and eating experiences, even with young kids.

- So for the next portion of our talk, we'd like to introduce you to a term that's been proposed that was published in a paper in 2019 by Pervy Goday and his colleagues with the support of the feeding matters organization. They published what they proposed as a unifying diagnostic term and the reason that they did so is because in our fields, feeding challenges are described in so many different ways, and often they're described in a discipline specific way. And so what the author's strove to do by publishing this paper is present a unifying diagnostic term in an effort to promote collaborative care across domains and across disciplines. So they use the International Classification of functioning disability and health framework to create this term. And they really also highlight the importance of understanding the interplay between domains that result in disability which results in an impact on participation in daily and family and community life. So I'm gonna read this to you. Impaired pediatric feeding disorder is impaired oral intake that is not age appropriate and is associated with medical nutritional feeding skill and or psychosocial dysfunction. And again, I wanna highlight for you that the author's really are hoping that with the use of this terminology with consistent use of this terminology across disciplines, we can collaborate perhaps in a more comprehensive way, and understand how each of these specific areas impacts the others.

So with all the different terminology that we've now discussed is used to describe children with feeding challenges. We want to share with you one paper that reported the prevalence of feeding challenges to be between 33 and 80% in children with developmental disorders. And at the time, the author also noticed that the incidence is

increasing. So we acknowledge that as you look through the literature for some of these prevalence figures, you're going to find a wide range. And the reason for that is because of the varied populations that each of the authors have looked at, but I think the takeaway important message here is that the children that we are working with who come to us with a variety of conditions and diagnoses are at much higher risk. For having feeding challenges, and we know that for these infants and children, every bite of food can be painful, scary or impossible, and potentially impeding nutrition development, growth and overall well being.

So the impact really is just so widespread. So what we're gonna do next is we're just gonna highlight for you some of the conditions and diagnoses that may occur, or that may have been pediatric feeding disorder as a component of, we're not gonna go into the technical aspects of each, but we want to share this list. So if that you are working with children with these issues, you really can be on the lookout for feeding challenges. The first point on our list is prematurity. And we discussed this in part one, how preterm infants have immature neurological systems, immature feeding skill development, immature respiratory systems, and they really need that time to mature and grow so that they're able to coordinate all those bodily systems for the task of feeding, we also know that children who are born preterm have a much higher risk of having a feeding challenge. Children with cardiopulmonary disease may have challenges with feeding related to endurance or their ability to participate for the duration of a feeding in order to take in adequate nutrition to support growth.

Feeding is really a workout for little babies and for young children. And so for our kids with cardiopulmonary disease, we need to be watching for their ability to maintain that endurance. Children with chromosomal abnormalities and syndromes such as Down syndrome may have characteristics associated with those diagnoses that impact things like their muscle tone, or their motor planning, or even their structure the structures of their oral mechanism that may cause them to have difficulties

coordinating and Carrying out feeding tasks in a way that's most efficient. Neuromuscular and neuro motor disorders, so things like cerebral palsy, spinal muscular atrophy, those are considered conditions that have as characteristics as primary characteristics, differences in muscle function and neurological control. And what we know about eating, coordinating, sucking, swallowing and breathing involves many different muscles and fine tuned coordination and timing.

So we know that children with neuromotor, or neuromuscular disorders are absolutely at risk for those things being, you know, having challenges in those areas, oral and or pharyngeal dysphagia. So we acknowledged that this is a diagnosis that can stand alone. Or this is a diagnosis that a child might have, again associated with these other conditions. And really, what that means is that there's a disruption in some way, in either the oral phase, the oral pharyngeal phase, the pharyngeal phase of the swallow or the esophageal phase, I should include that in this in this bullet point as well. And then food allergies or intolerances. So you've heard us bring that up in the past. And what we want to say about food allergies, and intolerances is that again, if a child doesn't feel good, when they're eating a particular food they start they may start to build that association between not feeling good and mealtimes and that not feeling good physically in response to difficulty tolerating a specific food, then can impact those other domains that were listed in that pediatric feeding disorder definition. Gastrointestinal disorders are another group of issues that we come across quite frequently in our work.

An example of that might be eosinophilic gastroenteritis, constipation, we really wanna highlight for you that as we're thinking about the gastrointestinal system and what can maybe go wrong or be disrupted, we wanna think about that system from the mouth all the way to the bottom. So that when we are working with children, we're collaborating with other professionals to figure out you know, where in that sequence are, might this child be experiencing discomfort, structural abnormalities. So this is

things like cleft palate, laryngomalacia tracheal, esophageal fistula, changes in a child structure and anatomy that may cause them to aspirate or may cause them difficulties with protecting their airway. These are things that we might refer to an ENT for a little bit of help and diagnostic support. As we figure out what might be different in this child's anatomy, developmental experiences or lack thereof. This is such an important point in our discussion, because we've talked about as we've explained, responsive feeding and offering developmentally appropriate experiences, how important those things are to the development of the feeding relationship in a child's learning. And we want to acknowledge that many of the families that we work with have different levels of resources. There may be environmental challenges, right, this family might not have a home or might not have a designated space in their home to share meal times. They may not have the financial resources to access the variety of foods that might be the best sort of next steps for their children.

So we wanna be thinking about what that child's developmental experiences have been, and how the parent may be managing their resources as they strive to provide their child with those experiences. Sensory Processing difficulties are absolutely a significant factor in learning to eat. We know that some of our children experience sensory stimuli at mealtimes differently. They may be overresponsive or underresponsive to all of the different sensory components of that experience. And if they are experiencing things from a sensory perspective that is not pleasurable, that can absolutely cause them to have a disruption in the process of learning to eat. And lastly, I think these last three points sort of go together, you know, mental health challenges, we talked about how parents feel more stressed as a result of having a child who maybe struggles to eat. We also know that parents who have been through traumatic experiences perhaps in their personal history, or have been through traumatic experiences with their child may have altered behavioral patterns and stress responses that makes sense based on everything that they've been through, and that as providers, we can help recognize how that might impact the process of learning to

eat. We also know that anxiety is a possibility in terms of the responses that we might see from parents and children at the table, and that's something that absolutely can get in the way of in the way of the process as well.

- So during these next couple slides, we wanna talk about the intervention process. And it's therapists who are going in and meeting families for the first time, we're always identifying those strengths, those things that are going well. And also those areas of need. Those things that we recognize are hard for parents and kids. And when we recognize what's hard, we always are thinking about, okay, how can we help a child feel good and resolve the underlying medical issues that might be contributing to that difficulty? So for example, we might have questions about a medication a child is taking, maybe, you know, some children are on medication for reflux, and we know that that medication needs to be calibrated to a certain dosage for it really to work.

So you know, we might ask Ask with a parent's permission to have a phone call maybe with the parent, you know, and the child's pediatrician and to say, Hey, you know, we're worried about this child's reflux. What do you think about this medication? Do you think it's working? Do you think the dose is the right amount? And what we do when we have those exchanges is that we really advocate for parents and kids that we're working with, we're able to bring different parts of the team together in ways that promote collaboration and good communication. And then we're really able to address a child's physiological and maybe even medical well being. The second thing that we're doing while we're helping a child to feel good and advocating for them, is we're doing therapy, right. We're using the strategies that we have as therapists. We're giving parents feedback and helping them to use responsive feeding practices. And you know what I think about the second box here I just think about those sort of like normal therapist activities that we do as professionals. So it's really not enough to only do one or the other, we have to be working on both things concurrently.

- Absolutely and I love how you described the potential impact of us as therapists helping parents to get some of those answers, of course, if they want our help and support in that process, because it serves to build trust between the provider and the caregiver as well. And it helps parents answer those questions that they so often begin with when we meet them, those questions of why is this happening, but also empowers them to have some things that they can perhaps implement that feel good as they're going through the process of answering that, that big question of why?

- Yeah, so we always wanna know what feels good. So some of the questions that I asked myself are what's comfortable now? You know, what's working for this child? Maybe work for A child who has a G tube, for example, who maybe isn't quite eating food or eating quantities of food, we might recognize that they're really good at bringing their hands to their mouth. They're really good at mouthing teetherers. They're really good at letting their parents help them have oral experiences. So we're always thinking about where is a child experiencing comfort? Where is a child experiencing success? And how can we start with those positive experiences and build on them. In ways that are safe in ways that feel really, really good for kids, but also really good for parents? Because we know that when parents see a child's response change in a way that's helping them grow and learn different things, that parent can just really celebrate the process of therapy and feel like their child is making good progress. So this is just such a, just a fun process to be a part of.

So I'm gonna talk about this next slide is a means to kind of let you know where we're going with this talk. For the rest of the talk, we are gonna explore a number of different conditions that might influence why a child is saying yes, I want to eat, or no thanks. I'm not so interested right now. So we're gonna go through a number of different medical issues. And then we're gonna transition to talking about sensory and emotional factors that might contribute to a child's willingness to eat. So first medical, we know that kids need to feel good both physiologically and medically. So when

we're thinking physiologically and medically, we're thinking about things like feeding tube management. We're thinking about things like making sure a child has a diagnosed allergies, right? We're thinking about collaboration and working with all those different medical specialists that can really inform our practice is therapists. We wanna know who the appropriate referrals are, and who are those professionals that could be on our team. But I think it's also helpful just for you, as a professional to know who are those people in your area that are really good. You know, who's the local pulmonologist who's the local gi doc that you wanna have their contact information, you know, on your phone or in your computer so that you can send your clients over to work with those people. You know, when you need a good gi doc. It's also so important for us to communicate with parents about why we might be making referrals, and why we're asking them all of these questions about things that may or may not seem like they're really relating to feeding. I think sometimes parents think that we're just really nosy and you might be really nosy, for good reason, because we're trying to understand the backstory, right? We're trying to understand all of those things that might be contribute contributing to a child, maybe difficulty eating and When we think broadly and we get a full medical history, we can really make informed decisions and support parents and kids.

- In our next section working with families, I just wanna point out we're going to dive deeper into parent education and how to support parents in the process. So this is the list of specific medical conditions that we're gonna go through in the next portion of the talk. We're gonna start by discussing suck, swallow, breathe in coordination, move into food allergies and intolerances. Talk about tethered oral tissues. Talk about motility concerns and wrap up that portion with a feeding tube discussion. So when we think about suck, swallow breathe in coordination we first as practitioners need to know what's normal. What's typical. We know that most infants as they begin to feed from the breast or bottle feed us a pattern of one suck, one swallow and one breath. And if that one to one to one feeding ratio, maybe altered at some points during the feeding,

but generally should remain consistent if those underlying conditions or systems that support feeding have not been disrupted, and that that child repeats that sucks, swallow breeds suck, swallow breathes suck, swallow cycle over and over and over again in long sucking burst. So they have the endurance to repeat that and sustain their respiratory comfort throughout the feeding while protecting their airway. So when we think about suck, swallow, breathe in coordination, you know, we often wonder, Well, how do I know how do I know that something is going wrong in this process? We have parents that expressed to us I know something's wrong, but I'm not quite sure what it is. And I know I've heard lots of therapists you know, mentioned in the past, you know, how do I know what's normal? How do I know you know when things are going wrong and one of the biggest pieces of it advice that I give them is that if you have family members who perhaps have had an infant or friends who have had children spend some time feeding those babies, because the more experience you have observing when things are going well, the better you will be at knowing when things are disrupted.

So signs and symptoms in preterm infants have stuck swallow breeds disorder, disorganization includes some of the things we discussed in part one, based on the work of Katherine Shaker, you might see changes in the state of alertness, changes in postural control or movement patterns, you might see changes in cardio respiratory behavior, and all of those things that are challenges that newborn infants often have can result in what she refers to as uncoupling of swallowing and breathing. We also wanna highlight for you that silent aspiration is more common than you might think, in children. So I think as therapists we may have learned in our in our coursework in our graduate coursework or post graduate coursework that we're supposed to be looking for things like coughing, gagging during feeding. But what we know from the research is that silent aspiration, which is the entry of a fluid bolus or food bolus below the true vocal folds, in the absence of a clear cough is the predominant pattern in children who aspirate. So we'd love to refer you to this study that we have highlighted in the second

bullet point where the researchers looked retrospectively at almost 1300 and 12 studies of children under the age of 18, and found that 31% of those who aspirated did so silently, so without a cough, and under six months, that percentage was even higher. We know that in a specific patient populations, for example, patients with laryngomalacia, who have recurrent respiratory chews, we also see a large percentage of those patients demonstrating silent aspiration. And the reason why we care about this so much is because when a child feels unsafe as Karen highlighted earlier, they may begin to move away from the feeding activity, because they've learned that it just doesn't feel good. I've heard from several different lecturers and authors, the idea that that breathing always wins. And that's certainly the case in children who aspirate and we may not know what's going on.

So with this knowledge, we know that we just need to ask maybe some more questions and refer on to some additional diagnostic testing. Food allergies and intolerances is the next condition that we wanted to highlight for you. So in this study by Ruchi Gupta and her colleagues, she found they found in a sample of 38,408 children. This was a study that was completed in the United States that approximately 8% of those children had food allergies, and of that group 2.4% had multiple food allergies. So she also highlighted the most prevalent allergens as being peanuts, milk, shellfish, and tree nuts in this sample, but what we know and what she and her colleagues also shared in this paper, is as we think about the most common allergens, we also need to be considering the region of the world where a family lives, and what maybe is characteristic of those regional diets. When we're thinking about what those allergens might be. We know that allergies may be immune mediated or non immune mediated, and that immune mediated reactions can also be subdivided into IgE responses or non IgE responses.

So IgE immediate reactions typically occur right away. So those are things like anaphylaxis, or oral allergy symptoms where you may start to feel itching and burning

upon eating a food. Non IgE mediated reactions are delayed and typically take up to 48 hours to develop but they still involve the immune system. An example of that would be a diagnosis of FPIES. We know that non immune mediated reactions primarily are what we think about is food intolerances, they're a bit harder to diagnose and diagnosis of those conditions are typically based on a combination of reproducible clinical signs and symptoms. It's consistent with a food allergy that occurs upon exposure to a food, and that when we remove the food, those symptoms tend to disappear or go away. So we encourage you to read more about the different forms of food allergies and intolerances so that you can grow your knowledge base. But some of the symptoms that you might notice in the children that you work with, are of course feeding aversion or reluctance to participate in eating experiences. Slow slower than expected eating, vomiting, a child who vomits a child should never vomit, and if a child is vomiting, we wanna be asking questions about maybe information in the GI tract that might cause impactions as we might see in kids with eosinophils esophagitis that would result in vomiting, reflux.

So Karen and I definitely work with a lot of children who are on reflux medications. And when we meet those kids and start to ask some of the questions, to dig a little deeper, we want to know, you know, what might be causing this reflux and really make sure that parents understand that reflux is a symptom. And a food allergy might be the underlying cause, slower than typical growth. So we also work with a lot of families that come to us with a primary concern of slow growth or weight gain. And food allergies may be the condition that's impacting that child's ability not only to consume enough volume to support growth, but also to consume a very diet balanced, you know, with balanced nutrients. The last point I wanna highlight about food allergies is that if you are working with a child has a topic dermatitis or a rash? A skin response? that that is something that should prompt you to be asking questions about that child's diet about the family history of allergies. Because what we know is that children between the ages of zero and two, this is just one study 29% of children who have food allergies also

have a topic dermatitis. So there's a very real connection there and link. Referrals might be to an allergist gastroenterologist or registered dietitian, and we wanna make sure that we communicate to you that as feeding therapists, we are not the professionals that are making recommendations for changing a child's diet. We need our colleagues for whom that is within their scope of practice, to help us understand what the appropriate next steps might be. And that testing for food allergies is going to be dependent on a child's age and the symptoms that are presenting.

So the next topic we want to share with you some information about is tethered oral tissues. The term tethered oral tissues was coined by a pediatric dentist in the Chicago area by the name of Kevin Boyd. And it's another name for those terms you might have heard, such as tongue tie or lip tie. But essentially what that means is that the freedom or bands have tissues connecting the lip, to the central part of the maxillary gums, the tongue to the floor of the mouth, and then at different points on the top and the bottom, the cheeks to the gums, maybe shortened, thickened, or just tight. And the reason why we care about this and why we're looking for this in our oral mechanism exams is because we know that tethered oral tissues have the potential to limit range of motion of oral structures.

So if we think about the complexity of the process of coordinating sucking and swallowing or coordinating Chewing as a child learns to manage different foods, we need to understand that tethered oral tissues may have an impact on that child's efficiency and motor planning. We also know that if we look through the body of literature that the literature base is still growing, there are a lot of different opinions in this area of practice. And there really isn't any conclusive evidence based support for any one protocol for assessment. So there are a lot of practitioners out there who have published assessment protocols. And I think at this point in sort of the development of the evidence, we encourage you to use resources like the American Speech Language, hearing associations practice portal, if you're a speech language pathologist to access,

the compilation of what's out there and then also integrate that with your own clinical experience and what you may have learned from mentors. We also know that assessment of functions of the child's oral structures is critical.

So as we notice structures, we don't want to make the assumption that just because something might look shortened or look tethered or look tight, that the child is having difficulties with function. So as the feeding therapist, we are going to assess the mobility of the tongue, the lips and the cheeks during all of the different eating experiences that this child may be engaging and based on his or her developmental level, and that we are communicating what we have noticed based on our clinical expertise, with perhaps a pediatric dentist or an ear, nose and throat doctor that we have referred to in order to make a comprehensive team based decision. The reason that we care about tethered oral tissues is because as you might have concluded, based on what I've said so far is that a child who has difficulty managing different food, textures or consistencies, may not feel safe during a feeding experience. May learn that he or she can't manage that maybe piece of chicken that's being offered and may begin to avoid specific textures or consistencies. So we want to highlight the need for appropriate referral and for critical assessment of the body of research that exists now.

- So we're gonna shift gears and we're going to talk about motility issues. Now, motility is a term used to describe the contraction of the muscles that power the gastrointestinal tract. So as you see here, each of these different boxes have some of the important parts of the intestinal tract including the esophagus, the stomach, the small intestine, the large intestine, otherwise known as the colon, and then the pelvic floor. So we know that in gastro intestinal motility disorders, the contractions that happen in your GI system are abnormal, so they're either too slow So for example, constipation or they're too fast, you see that in conditions like diarrhea. We also just wanna highlight that children with motility disorders can also experience really bad pain. So one of the things that we wanna highlight for you is that motility issues can be

hard to diagnose. Oftentimes a child medical team starts looking at motility issues when they've explored some of those other more common feeding difficulties. And a child hasn't responded to either you know, pharmaceutical intervention or feeding therapy.

So symptoms of a motility issue might include vomiting, constipation, gassiness, abdominal pain, nausea, limited or inconsistent volume intake or reflux. We think it's so important to really understand you know, what's going on when a child is exhibiting the symptoms. So we don't just want to identify the symptoms are always asking, collaborating and trying to figure out how can we really help that child's gi system to function well, it can be so important to have a GI doctor that you have a good relationship with that you can collaborate with and really ask these questions. Oftentimes, his feeding therapists were the people that know kids and families so well because we spend so much time with the kids and families that we work with. And so we can use the observations that we gained from our time together to really help a GI doctor understand what functionally are physiologically for a child. Right? We want you to know that motility issues can occur in isolation, so just sort of by themselves, or with other gi neurological or neuromotor conditions, things like eosinophilic gastroenteritis or cerebral palsy.

And then the last thing we want you to know is that if a child is experiencing a motility issue, they might do further diagnostic testing. Oftentimes, different physicians will use manometry, which is diagnostic testing that's looking at the pressure and a child's gastrointestinal tract, or a gastric emptying study to determine how fast food and fluid is moving through a child's GI tract. And a transition to talking about feeding tubes. Why might the child need a feeding tube? Well, there's a lot of reasons. Some kids end up with feeding tubes because the child's medical team needed a way to provide that child with nutrition either during or after a medical procedure. feeding tubes are those lifelines that enable children to receive Nutrition. Well, a child's medical team is

working on other things, to help them to be stable or to grow well. A lot of times kids end up with feeding tubes because they're not growing well, there's some reason that their body can't receive nutrition and their growth isn't quite normal. We know that growth is so important, especially in young children to brain development, and just other developmental processes and gains a child is making.

So a feeding tube can be such a gift to a family and helping that child grow well or other medical issues resolved. We know that a child might receive a feeding tube because there's a structural abnormality that's making it impossible for that child to eat. So for example, something like an esophageal atresia, that's when your esophagus isn't connected. Both parts aren't connected. So a child might need to receive nutrition from G tubes straight into their stomach. We also know that other kids need feeding tubes because they have an inflammatory, metabolic, or gastrointestinal disorder that makes it hard for their body to metabolize food and grow well. And then the last thing is, and probably the most common reason that you all know why kids get feeding tubes is because they might be aspirating, right? The liquid that's going into their mouth is going into their lungs, and it's making it unsafe for them to eat with their mouth. So we're gonna highlight two different kinds of feeding tubes. If you're a feeding therapist, or you've worked with kids with tubes before, you know there are lots of kinds of tubes, but for our purposes today, we're just gonna highlight these two.

As you see this little guy in the picture has a nasal gastric tube or an NG tube. And when you look at the schematic on the left hand side, you see that that blue line is the NG tube, which goes up through a person's nose, down their throat, into their esophagus and into their stomach, right? And so an NG tube is great because it's not a permanent thing. But it can also be really, the insertion of an NG tube can be really hard and sometimes even traumatic. So there's a number of different issues that we wanna consider as we're talking about NG tubes. NG tubes are really meant to be used for the short term right? Some different groups of professionals think that NG tube

should be used for no longer than two weeks. Other groups of folks think NG tube should be used no longer than six weeks. However, we know that in practice the use of these two varies widely and different parts of the country tends to adopt different standards on about how they're using NG tubes.

So we just really want you to know as a professional that, you know, NG tubes can be really useful for the short term, but aren't always a long term solution. We wanna encourage you to think about the long term impacts of an NG tube. And we also want to encourage you to collaborate with different team members usually feeding therapists are not the people to decide if a child is going to get a feeding tube, and then how it's going to be used. There's usually lots of professionals who are a part of those discussions. So just know that you know, NG tubes can be used well, but probably not for the long term. The one exception to that rule is children who have a history of cardiac issues. Kids with heart conditions sometimes have NG tubes that are used for a longer amount of time. In part because having a surgery to have an insertion of a G tube might be too risky for those kids. So just something to think about. N

ext we're gonna talk about G tubes. This little girl has a G tube as you can see here. The port that actually goes through her skin into her belly is called a button and we're gonna talk about buttons in a minute. You see that there's a little piece of gauze that's helping that button to sit against her skin without rubbing. And then affixed to the button is that piece of tubing which is called an extension. So kids do need a surgery to have a G tube inserted right. And the way that I kind of like to think about g tubes is they're just like pierced earrings. A surgeon goes in and makes an incision from the outside of a child's stomach in through the their, you know, stomach wall into actually the stomach. And that's where the button goes through. So if you flip to the next slide, you can see that a picture of what that might look like.

Okay, so these are the buttons that are on that top part is the part that sits outside of a child's stomach, right? That's the port where you put the tube in with the food. And on that inside, you see that little balloon. So if we go back to our Pierce earring analogy, the balloon is like the back of an earring. I think it's really important to just explain this because a button should sit comfortably. It shouldn't be too tight, and it shouldn't come out either. I always make a point to explain this to families of kids that I'm working with that has these buttons. Because oftentimes families are afraid to put a child on their belly during developmental activities. So think about things like tummy time, or maybe kids who are learning to push up onto their arms and crawl. Parents are working that these buttons are gonna fall out. But really, when they're fitted well and the balloon is inflated, we don't need to worry about these buttons coming out. There are two buttons that you see in practice.

One is a Mic-Key button and one is a Mini button. And different physicians use different buttons. The one thing to note about the difference between the two is that one of them is longer than Mic-key is like a longer piece of equipment, and the many is shorter and fatter. So some physicians like to use many buttons and little kids because the balloons tend to take up less length in a child's stomach, and sometimes they just fit better, but they're both okay. And you see both of them in clinical practice. So this diagram is just to give you an idea with where a G tube is positioned in relation to a child's body. We really like g tubes. I'm sorry, we really like buttons to be positioned at the bottom quarter of a child's stomach. And the reason for that is because when fluid or blended food goes through the button into the child's stomach, we want the child stomach to fill from the bottom up. That's important because so many kids who end up with a G tube struggle with reflux or vomiting. And when the food starts from the bottom and fills up, we're doing our best to prevent that vomiting or reflux from occurring.

So just a couple basic things you should know about feeding tubes. Some kids receive their food using a pump. A formula pump can be used with either an NG tube or a G tube. oftentimes there's formula or breast milk that's going into a pump. The really good thing about a pump is that for kids who struggle with volume, or need to have that food delivered at a consistent rate, so there isn't a lot of stretch on their stomach. A pump is that tool that allows kids to have those just right feeding experiences. When kids get to be a little bit more medically stable and are able to tolerate a larger volume, and especially a larger volume in a shorter amount of time, a child might be ready to transition to what we call bolus feeding. And bolus feeding just means that a child's tube feeding is happening and bigger chunks, right. So they're getting more volume in a shorter amount of time. There's a break and then they're getting another tube meal where there's more volume in a shorter amount of time.

So this little girl is receiving bolus feeding with blended formula so a combination of different blended fruits and vegetables and proteins that her dietitian helped, you know, come up with a blend. So she's receiving that homemade blend in her and her grandma are putting together through a syringe and it's going into the extension through the button into her belly. Some of the things that we wanna highlight about bolus feeding is that bolus feeding can really mimic typical eating. This is so important as we're thinking about helping kids get off of feeding tubes. I also really love this picture of the little girl being tube fed with her grandma, because you can see that they're doing it together. And they really have that relationship in place. So we can think about responsive feeding and relationship based feeding even when kids have NG tubes and G tubes.

So feeding tubes are just a bridge to oral eating, right? We talked about in that last slide how when a child is being bolus fed that schedule of food being pushed through the tube can really begin to mimic a typical meal time where a child has a tummy meal and then a break and then maybe a tummy snack and then a break and then tell me

lunch and then a break. Just like a child might have a breakfast and then a snack And then a lunch and then a snack and then a dinner. Also, a lot of different things can go through a child's feeding tube. That's why one of the reasons why it's so important to be working with a dietitian, or maybe even a child's pediatrician or a Gi Gi doctor, and figuring out what is the best thing to go in that child's tube. Some parents choose to put breast milk through a tube, especially with little kids. Other people choose to use formula or as kids get older, they'll make a homemade blend. And then it's always so important for water to go through that feeding tube to make sure that a child is being hydrated. Of course when they're at the right developmental age and stage as therapists supporting kids and parents with feeding tubes. We're always thinking about how can we take this procedure of a tube feeding and make it feel more like a meal time.

So some of the very practical ways we can do that is use language that just seems more like typical mealtime language right? Little bit earlier I talked about you know, maybe instead of saying we're having a feed, or we're having a tube feeding, you know, we're having a tummy lunch, we're gonna have a tummy snack. We're gonna have, you know, a tube snack. There's all different words that you could use to just kind of help parents and kids realize, Oh, yeah, the food is going into their belly. It's just like having an oral meal except their mouth is involved. And then again, a child's schedule of tube feeding can really help tube feedings begin to feel like meals right? If a child is fed all day through a drip that isn't typical of, you know, a normal child's eating pattern for the most part, but when kids are medically stable and are physiologically stable, we can help them have a meal time to feeding schedule. That's gonna kind of feel like a typical oral eating schedule for a child in that developmental age and stage.

So we always wanna help kids participate in meals as much as they can. Even if they're being tube fed, so even if they're not eating by mouth, we might give them a

meal time job, we might have them sit at the table, they might get to pass out forks, they might get to help other people, you know, put food on other people's plates. And we know that when kids participate in these daily mealtime routines, they learn what a mealtime looks like they learned smells and tastes and textures. And it can just be such an important part of First of all, helping kids learn meal times, which is really important and helping them get off with tubes. And then second of all, it can just feel really good for the whole family to be together at the table together.

So the idea of a tube transition is a really hotly contested issue and there's lots of people's with lots of thoughts about it. Oftentimes, people use the term, the term tube, wean, you're helping a child get off of their feeding tube. I really like the term tube transition because we understand that a child eating process is a journey. And so it's okay to be fed with a feeding tube. And it's okay to learn to eat by mouth. And as we're going from one method of nutrition to a different method of nutrition, it's a transition. It's a journey that we're taking together. We know that in order to be thinking about helping a child get off of their feeding tube, they need to be medically stable, right, which means that they need to be growing well, they need to be comfortable. That underlying medical and physiological issue about why they got the feeding tube needs to be resolved. We also know that kids need to be able to tolerate a volume of food in their belly. Because if a child can't tolerate a volume of food, you know, it's not gonna be sustainable for them to eat and grow well. They need to be good at having enough attention to sit at a table and to make it through a meal time in a developmentally appropriate way of course. And then we You know, we also just really need to make sure that our family is ready to participate in a transition.

You know, one of the analogies I oftentimes share with parents is, you know, when a child is tube fed, the parent is the one who is in charge of nutrition. And it's kind of like giving, you know, control over to the child. It's like giving a child the family's car keys and saying, we've been driving you your whole life, and now you're in charge. And that

transition of, you know, letting up parent be in control to letting the child be in control can be really, really hard for parents. So we just need to make sure that families are ready to take part in this process. We can do lots of things to help families get ready. We can include mental health professionals. We can do a lot of counseling on our end, we can work with teams to make sure that you know parents and caregivers feel supported and ready to go through this process with your kids.

- I love that you describe that as a process because I think Sometimes that to Wayne terminology leads to an outcome of either it was successful or it failed. And if we're really truly thinking about this as a journey sort of takes away the high stakes in that way. So for the last portion of the talk, today, we're gonna talk about feeling good emotionally. We're gonna talk a little bit more about sensory regulation and build on what we've already shared with you. We're gonna talk about emotional regulation and talk about how both parents and kids can feel good emotionally at the table. And we're also gonna talk a little bit about anxiety. So we know that mealtimes are full of sensory experiences and the words of Marsha client eating is sensory. A child is synthesizing sensory input at a meal time, including things like the smell of their food, the taste, what they're seeing in their environment, and right in front of them, and the texture that they're feeling through their sense of touch. We also know that there are other important sensory systems that we may not be thinking about and that we use therapists need to remember that a child is managing internal sensations, which is referred to as Interoception. That child's ability to feel and respond to his or her internal sensations, perhaps as it relates to hunger and satiety. We also know that the sense of proprioception is so important, so a sense of where child's body and maybe oral structures are in space. And that sense of proprioception is so critical for a child to be able to really sense where food is in his or her mouth, maybe how large a piece is, how to grade they're biting and chewing, and when that food is ready to be swallowed. Lastly, we know that vestibular input is really important to some of our kids. This

makes me think about those kids who have trouble staying at the table and yeah, just they're always wiggling and jumping up and running around.

- I love the wiggly kids,

- The wiggly kids, but I find that once parents understand their child's sensory needs and have some strategies to help their child's body feel better. That child feeling better at the table usually results in a more peaceful and calm mealtime that feels good for everyone. Feeling good emotionally. So we know that when kids have been through tough experiences, when they sense they're in danger, they have stress responses that are mediated by the vagal nerve. Those stress responses might include a fight or flight response, or even a shutdown. So this makes me think of those babies that fall asleep as soon as the feeding begins and aren't able to participate fully. We know that stress responses and a perception of danger that triggers a fight or flight response also has an impact on our gut function and that our vagal nerve is also responsible for regulating digestion, and that when we are stressed and when we sense that we are in danger, our digestion slows. So we need to be asking these questions if we're working with a child who may have, who may seem to never be hungry or may take a couple bites and seem to be satisfied. All of these stress responses are gonna get in the way of a child's ability to participate in mealtimes. But if we can help parents to understand and help children to manage those stress responses and set them up to succeed, they're really going to be in that place where they're ready to learn that we talked about at the beginning of the section.

We know that parents emotional states also impact how children feel and that parents who have been through hard things, not only with their children, but also in their own personal histories, maybe in their childhood, come to the table with different sort of emotional states and abilities to tune into their children and truly maintain that responsive pattern of feeding. So we want to make sure that as Karen said, we are

using our Mental Health colleagues when we need them and understanding the impact that feeding challenges have on not just maternal mental health, but also the mental health of all of the caregivers that are maybe feeding this child. When a child feels good at the table emotionally when a parent feels good emotionally at the table. Those two sort of states serve to reinforce and continue to establish those strong trusting relationships. A child who feels good physically and emotionally is better able to communicate their cues and their experiences clearly to that parent. And a parent who's feeling good is able to better understand their child's communication and truly make contingent responses at the table. That continuous reciprocity builds over the long term, to strengthen relationships, to strengthen attachment, and ultimately really allows children and parents To experience that predictability at the table that is so, so important. We know that when everyone's feeling good parents particularly can use some of those co regulation strategies that we highlighted in the first part of the talk that really can help children maintain a good emotional state at the table.

- So thanks so much for journeying through this talk with us today. As we're coming to a close, we just wanna highlight the fact that trust is essential. We want kids to be able to trust their own bodies. We want kids to be able to trust food and meal times and be able to have really good experiences. And then we also want kids to be able to trust your caregivers. We know it's just so important for that loving relationship to be part of mealtimes. And I'm sure that's something that you guys are coming to understand and you've heard us say it so many times today. So during that our next conversation we're gonna be talking about the role of parents. And we're also going to be talking more about just feeding intervention. So we look forward to having you join us then. Thanks so much.

- Thanks for joining us.

- [Fawn Carson] Thank you so much. Looking forward to the next section, thank you.