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Clinical Pearls in Transition: Supporting Patients and Families Into Adulthood

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Dr. Gu:
This is CE on ReachMD, I'm Dr. Payal Gu, and here with me today is Dr. Jennifer Martelle Tu. For many families, the transition into adulthood is one of the most difficult parts of Rett syndrome care. In this episode, we'll share practical insights to help clinicians better support patients and caregivers through that process.

What do you think is the most important when it comes to preparing for the transition?

Dr. Tu:
So this is a really important topic for families. We know that our patients live into adulthood, and we have to prepare for that, because the care in pediatric is very different than the care in adulthood.

So one of the things I focus on in our clinic is really starting early. We want to make sure that with our families, we're setting expectations. We're being very clear about what that transition is going to look like, and we want to make sure it's a gradual transition, not something that's abrupt. And that's best, not just for the patient, but for families who have to deal with these transitions. So there's a lot of anticipatory guidance that goes into this, but really it's just starting early and setting clear expectations.

We know that as a patient ages, they may carry the same comorbidities through their life. They may always have epilepsy; they may always have scoliosis. But sometimes transitioning into the adult world, the team that takes care of those conditions can change, and so it's important that we identify what their needs are specifically and then who are the care teams that are going to be taking care of them in the future so that when we start that process, we can educate families about that transition. We can do the counseling early, and we can set up these individual plans depending on the specific patient needs.

And we know that in addition to the medical care, we have to think about in-home care, because about 70% of our patients end up living at home through their adult life. And so there can be challenges that the families face because they age out of the school system, or they have loss of physical therapy or occupational therapy, depending on the state services. And so it's really important that we try and address those challenges and help families prepare for those transitions early.

So one of the next sort of steps in this conversation is looking at some of the key legal and clinical considerations. So what are things that you feel like clinicians should be aware of during this phase?

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Dr. Gu:
So guardianship is a really important and difficult conversation that has to be made. That means understanding who is capable of making the decisions on behalf of the patient. Is the patient involved and able to voice and provide some of their own sense of what they would like to happen in their care? Those are really tricky questions, but also very important to have in advance and along the way, as you had also mentioned, preparing for those things.

In regards to decision-making, consent becomes a challenge as well. Given the wide variety of clinical presentation that we see in Rett syndrome, there are some with milder phenotypes who maybe lack some of the capacity for abstract thinking but have the capacity to answer basic questions. But then there are others who may not be able to really declare their capacity or their wishes in a verbal nature, and that's often more common.

So there's a lot of variability in both what we see as how patients present themselves and the severity of their Rett syndrome, but also the legal implications and variability that there can be by state.

The International Rett Syndrome Foundation is an exceptional resource that families have available to them online where they can find a lot of legal documentation and outlines of how someone should approach transition for their child. These tools can be really helpful to families and also to the clinicians that are helping them to move along in this process.

So how can we best support caregivers during this transition?

Dr. Tu:
It's a really important question. So I think there's a few things to point out, because this is a very stressful time for families, because there's a lot of, like you mentioned, legal implications about can they actually consent to things, can they actually have capacity to make decisions? And so really what we want to make sure we're doing is providing families the framework for these transitions. We're making sure that we help them navigate the system and go through all the paperwork that's necessary.

There's logistical support that needs to happen, and so this is another important time where it's important to bring in our social work team. It's going to vary state by state and sometimes even county by county, so it's important that you have someone who's an expert in this area that can really answer family's questions and help them identify how they navigate, what paperwork needs to be done. How do I actually satisfy the legal requirements that are necessary for this adult transition?

So we know as Rett providers that these are the things that are expected and these are the transitions that families have, but what do we do for our adult care systems who are less familiar with Rett syndrome? How do you advocate for these patients within that framework?

Dr. Gu:
Yeah, that's a great point. It's really important to educate the providers.

It's really important for physicians to avoid the one-size-fits-all approach as well as the caregiver to recognize that oftentimes as physicians there are nuances to what specialists you need to see and recognizing that the complexity is helpful and important to document for your own notes and notetaking, but also for the providers so that you're on the same page.

Thanks so much for a great discussion. Our time is up. Thank you all for listening.

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