



# Talking With Your Child About a Difficult Diagnosis

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**Rebecca Whitney:** [00:00:00] Welcome to the SRNA Ask the Expert podcast series, a special edition in collaboration with Centers for Disease Control and Prevention, Division of Viral Diseases, or CDC. SRNA, or Siegel Rare Neuroimmune Association, is a nonprofit focused on support, education, and research of rare neuroimmune disorders.

[00:00:23] You can learn more about us on our website at [wearesrna.org](http://wearesrna.org). My name is Rebecca Whitney, Associate Director of Pediatric Programs with SRNA. For this podcast, pediatric neuropsychologist, Dr. Lana Harder, joined me to discuss speaking with your child or teen about their rare neuroimmune disorder diagnosis, making sure they're included in their own medical decisions, and recognizing difficult questions or circumstances that may arise after a diagnosis of AFM and the other rare neuroimmune disorders.

[00:01:00] Dr. Harder completed her doctoral training at the University of Texas in Austin and completed her predoctoral internship at the Kennedy Krieger Institute and Johns Hopkins School of Medicine in Baltimore, Maryland. She completed her postdoctoral fellowship in pediatric neuropsychology at Texas Children's Hospital and Baylor College of Medicine in Houston, Texas. Since 2008, Dr. Harder has served as a clinical neuropsychologist at Children's Health in Dallas and as Associate Professor of Psychiatry and Associate Professor of Neurology and Neurotherapeutics at the University of Texas Southwestern Medical Center.

[00:01:39] She is board certified in clinical neuropsychology with subspecialty board certification in pediatric neuropsychology. She specializes in the neuropsychological evaluation of pediatric patients from infancy to young adults with disorders of the central nervous system. Dr. Harder serves as the co-director of the Children's Pediatric Demyelinating Diseases Clinic.

[00:02:02] Her research interests include cognitive and psychosocial outcomes for pediatric multiple sclerosis, transverse myelitis, including acute flaccid myelitis, acute disseminated encephalomyelitis, clinically isolated syndrome, and neuromyelitis optica spectrum disorder. Thank you, Dr. Harder, so much for joining me today for the podcast. We're here to talk about talking with your child after a rare neuroimmune disorder diagnosis. And these rare neuroimmune disorder diagnoses of ADEM, AFM, MOG antibody disease, neuromyelitis optica, optic neuritis, or TM can be very challenging from not only the diagnostic perspective and treatments, but also from the mental health perspective.

[00:02:55] It's often a time marked by confusion, fear, and can be an incredibly traumatic experience for the child or the individual diagnosed, as well as for their parents and caregivers. So, although we don't have enough time to address all of the possible aspects of how these disorders and different stages after a diagnosis may impact a child or their parent, caregiver, or even their siblings, when our hope is to better understand discussing these diagnoses and possible ways in which we can help ease some of that anxiety, fear, and empower children and families to be their best advocates for themselves.



[00:03:33] When a child is facing one of these diagnoses, there are generally many tests and a myriad of medical professionals that they may see. As a parent or caregiver, how do we discuss these tests with the child? How does this change with the age of the child? Can we start with those questions?

**Dr. Lana Harder:** [00:03:51] Sure. Sure. Yes. And thank you so much for having me. As you know, this is a topic near and dear to my heart and something that I have learned so much about from our community. The patients and families I've had the privilege to serve at Children's Health, as well as the community with SRNA.

[00:04:07] So, I am so excited to be here to talk about these things. You know, as it relates to all of the tests and appointments, those things, I think so much does depend on the age of the child that we're talking about. You know, that would really shape the way that we would discuss these things with them.

[00:04:28] Also understanding, and I would say, importantly, their developmental level, which may not be the same as their age level. So, that would give us our first step, as far as thinking about what to talk about. I do think in general, it's important to keep, you know, an open and honest stance as we share with kids, what's going on. I think it's so important for any of us to understand what's happening, what to expect.

[00:04:54] That may take a little legwork from parents to get that information ahead of time in order to prepare their child. But I think a couple of things I would mention off the bat is avoiding information overload, keeping things simple, you know, telling them what they need to know to be prepared.

[00:05:12] And then, you know, really monitoring the child for their responses and reactions upon hearing about this. Do they seem afraid, sad, you know, what are the feelings? And then reflecting those back and validating those for the child, I think are all really important aspects to that communication. Some examples might be if a child is going in, you know, to, to have a blood draw, which is not fun for anyone. Right? But thinking about, you know, ways to describe this to a younger child. Or, you know, you could get more sophisticated, if the child is older or a teen. But, you know, saying, "we're going in to do this so the doctors can learn more about you and the best ways to help you." And I think those are just some general thoughts that I have and thinking about how to talk about those tests.

**Rebecca Whitney:** [00:06:05] Okay, thank you so much. And you, you mentioned a bit about not necessarily getting into too much detail. How do you know when, especially for some of these tests or some of the treatments, they can be incredibly invasive. Thinking of things like plasma exchange. If, if that's something that's to be used, how do you explain something that is going to be painful?

[00:06:30] How do you advocate for that and prep them for that experience so that it's not as traumatic as it could potentially be?

**Dr. Lana Harder:** [00:06:41] Yes. I think that's a great question, and I can tell you at Children's, and I think as healthcare providers, we are very aware of, and it's important to us for everyone involved to understand what's happening.

[00:06:55] You know, what we're going to do, what the plan is, how long is it going to take? When will we be finished? All of those important questions. So, I think that as parents and caregivers, we can make sure that that information is available even by calling the care team ahead of time to get detailed information about what to expect.

[00:07:13] A lot of times clinics will provide that or hospitals provide that ahead of time. And then in the moment, it's a great modeling of advocacy that the parent can do that eventually the child will, will be



responsible for as they age, very likely is asking questions and saying, you know, if you would just let me know step-by-step what's happening.

[00:07:35] There are things that we have in the way of tools to alleviate pain, of course. I think, again, going back to needle procedures and there's a, a cream we can use to numb the skin. And that is usually available to patients, but sometimes it's important that parents ask for that or they need to ask for that.

[00:07:54] So, that would be something to be aware of. Other things would be tools to distract the child, to watch an enjoyable like video or a movie or something during the procedure, something to take their mind off of it. Distraction is a powerful tool for any of us going through something difficult since the mind can only focus on one thing at a time.

[00:08:16] And then I think having something to look forward to when this is over. So, what are we going to do right after this? Or what can we look forward to? If that's some type of treat or activity, I think can kind of help power through that situation. So, those are some of the tools we've used in pediatric settings when facing a difficult or challenging procedure.

**Rebecca Whitney:** [00:08:39] Okay. And how do we as parents ensure that the child themselves, regardless of their age, or, you know, taking into consideration what is age appropriate, how do we ensure that they're involved in asking their questions, making sure that their, their specific concerns are addressed? If they, you know, might be fearful of asking those questions or if they're older and think that, well, maybe that's not a good question. How do we as parents make sure that they and their specific questions - because they're likely going to be different than what we as parents think of - how do we make sure that they're being answered and addressed by the physicians?

**Dr. Lana Harder:** [00:09:21] Yeah. So, making sure they're part of that conversation. And I do think this becomes increasingly important with age, but it's really important, you know, from the beginning too. A few things, prior to the procedure or doctor's visit, talking to your child about what's going to happen, what questions they might be able to share with you right then and there. And you can say, "you can tell me your questions and I can ask those of the, the doctor, or we can have you practice asking. We can write down the questions ahead of time." Some kids aren't going to have any questions that they can come up with in that moment. Maybe the questions come later during the visit or after the visit.

[00:10:02] So, I think it's a, an opportunity to check in to collect those questions from the child and then even encourage them in the moment to ask the questions directly. I noticed that pediatric providers are pretty good, pretty skilled at addressing the child directly in developmentally appropriate language and trying to elicit that information from them.

[00:10:26] So, I think it's, it's hard because sometimes visits can feel rushed or there's a lot going on. But I think kind of slowing things down as a parent to say, you know, "I'd like to see if, if Johnny has any questions before we proceed." Or telling your child ahead of time, "if you think of something, just, you can lean over and tell me, and I can kind of serve as the advocate." But increasingly over time, encouraging them to use their own voice I think is really critical.

**Rebecca Whitney:** [00:10:55] Okay. And do we have any knowledge through research or clinical experience that if by allowing that child to have a say in their medical care from the beginning or even while they're younger, if it's helpful to them as they continue to grow up with having to continue treatments that might be related to their diagnosis or ongoing therapies?



[00:11:17] Is there anything that, that we can look to for additional answers there as, as encouragement to continue as parents to make sure that child's voice is heard?

**Dr. Lana Harder:** [00:11:27] Yes. Thank you for this question. I think it's so critical to think about this idea of transition to adulthood and transition to adult care. That's what I think of as I hear your question. We know that for our patients with these rare conditions that many of them are going to be managing this for long-term and beyond the teen years. So, absolutely. We believe that by engaging with providers in their visits, that they are getting a lot out of this that is setting them up to be more independent in the management of a complex medical problem.

[00:12:02] And I can give you an example of some research data we have from our clinic. And what we looked at across our... it was a group of teens that were undergoing transition of care planning, which we began at age 13 or 14. So, we start that process then, and I want to emphasize the word 'process.' This doesn't happen when someone turns 18. We start, you know, as they're becoming teenagers and work with them on a whole host of things to prepare them.

[00:12:32] And this relates to refilling prescriptions, making your own doctor's appointments, knowledge of your specific disorder, understanding symptoms, understanding when to call for help, if that's your primary care physician, your neurologist, or even for emergency care. So, it's very involved and it spans a number of years in our clinic.

[00:12:54] What we found in our research is when we looked at how ready a teen was to transition to an adult provider - so we call that their 'readiness' - we found that readiness had a strong association with the knowledge that the teen had of their disorder. So, the more they knew about their condition, the better prepared or the more ready they were to make that transition.

[00:13:18] And I thought that was very validating to, to see in the data. And it tells us that by having them engaged in those visits is so very important, because at each and every visit, there's an opportunity to learn more about their condition and how to manage it.

**Rebecca Whitney:** [00:13:34] Excellent. Thank you so much. If a parent is noticing that a child's not involved, they're not asking questions because they're not necessarily not aware or able to do so, but they're just simply allowing the parent to take the lead on that. Should they be encouraged to ask those questions?

[00:13:56] Should a parent speak up and ask them and try to, to get more questions out of their child to get them to be more participatory in their, in their decisions?

**Dr. Lana Harder:** [00:14:07] I would say, definitely we want to encourage that. And what you point out is a great point that, I think as kids grow up, especially when they're younger, they rely more on the voice of their parent in, in any situation.

[00:14:23] So, the idea with the transition preparation and planning, as we're gradually handing the reins to the child to start to be responsible for those interactions. And so, one way that we do that is having the medical provider in the room addressing that child or teen directly and eliciting responses and questions from them.

[00:14:46] We even kick parents out of the room at a certain point at doctor's visits so we can have that one-on-one time. And that's very intentional and to model what it's like when you are the only voice in the room, and you're there as an advocate for yourself to get the information you need and to give the information that the physician needs about your specific medical care.



[00:15:07] So, I think that there are some kind of process things. So, encouraging the physician to speak directly one-on-one with a teen, or turning to your teen in the room at, at the clinic and saying, "what questions do you have?" Maybe talking about that beforehand so in case, so they don't feel completely put on the spot.

[00:15:27] I will mention one other thing. I notice when we walk into clinic rooms, a very common scene is for the child or the teen to be on an electronic device, listening to music or playing, you know, and that's totally fine because they're waiting for a while between each provider. So, we understand that they're entertaining themselves.

[00:15:47] But what we want to see is once the provider's in the room, that we put up all distractions aside and really have them try to tune in. I believe that our kids are listening. I think their siblings, if they're present, are also listening. Even if they don't let us know that, I think that they are taking in a lot of information, even if it seems a little bit more passive.

[00:16:08] But what we see typically with age is that our teens become better able to speak up for themselves, to ask those questions and engage in, in giving answers. So, I think it's hard for parents, but gradually having parents not provide the answers and, or at least let the teen speak first before maybe they chime in with supplemental information. That's just one, one kind of behavioral change a parent could make to let their teen speak up for themselves.

**Rebecca Whitney:** [00:16:39] Okay. Thank you. And I think you mentioned in your clinic, you typically start the transition process at about 13, 14 years of age. And my next question was going to be, is there a, a more appropriate age at when a child should kind of take that lead in those questions? And for those who may be newly diagnosed and they're already an older teen, is, does that change the process? Does that add some urgency to making sure that they are very much aware of what is, is going on? More details? I know from personal experience with a child who had medical concerns as an older teen, as soon as that child hit 18, I no longer had access. I had absolutely no say. So, just curious about that aspect of it.

**Dr. Lana Harder:** [00:17:39] Yeah. Sure. So, as far as the age, I think since it is a process. We, you know, start that process by 13 or 14. What we're really expecting, realistically, as, as they get to, I'm going to say 15, 16, and older, we really want them to start being the main voice that we're hearing in the room.

[00:18:02] Of course we want parents to be involved. Parent and caregiver involvement is absolutely critical, and there's a lot of information parents can provide that we have to have in that setting. But as you point out, at 18, things really change. And then we're looking to the adult patient now to say, "do we have your permission to talk to your parents as part of this visit?"

[00:18:25] And so things really change overnight. The transition process is, is much more gradual, and that's why we start early. So, I don't think there's a magic age for that. But as we look at our teens, quote, unquote, 'graduating' from our clinic, you know, we're really expecting this by the time they reach 17, 18.

[00:18:46] We are very mindful of the patient who comes to us at that age, at 16, 17, 18. We don't have as much time to practice and work with them on that. But we, we do use the time that we have and still go through the same information with them. So, we meet them where they are and set the expectations and the timeline that we have available.

**Rebecca Whitney:** [00:19:08] Okay. Thank you. Facing one of these diagnoses, it can mean that there may be a, a certain level of, of disability, whether it's short or long-term, associated with it for the child. How does a parent begin to answer questions, those difficult questions from their child that we simply may not have an answer to yet?



[00:19:31] If a child has lost their ability to, to walk, the mobility in their lower extremities has been impacted and they ask will they run again? Or will they have the ability to play baseball on their, on their team as they did before? Where do we start as parents with those kinds of questions?

**Dr. Lana Harder:** [00:19:53] Yes, a really difficult question without any easy answers. I would say, first of all, it is perfectly fine to say, "I don't know." And to focus on, you know, the here and now and kind of immediate future for, so what are we doing to shape the future? If that is in terms of rehab, so this would also depend on where the child is in their medical trajectory.

[00:20:21] Are we in the acute phase? Are we post-acute? If so, how far out? And what do we know from our doctors and our rehab team as far as the expectations go? And I think engaging those teens in these discussions can be a really great thing and to, to partner with them, to have the conversations.

[00:20:40] So, I think, again, it's okay not to know exactly what that answer is, but to focus on what are we doing now to make gains and improvements? What are we doing to adapt, right? What are the things we can do to adapt? And how can we be involved? You know, now we're in the future with activities that can be adapted for, for the child or the teen that we're talking about.

[00:21:08] I think that it's really important to embrace different concepts along the way, disability being one of those. I think disability becomes part of that identity formation, and it's so critical to know what age the child is when they had the event and as they go through rehabilitation and as they adapt to life in whatever situation they're in.

[00:21:32] So I'll give a shout out to our colleague, Dr. Anjali Forber-Pratt, who does research in this area who is studying exactly this topic of how does disability tie into a person's forming of their own identity. And I think that's really important. And also plugging our kids into communities where they can, you know, be with others who have disabilities and explore what that means and, and develop and foster those relationships.

[00:22:01] I think our Camp, our Family Camp through SRNA is one great way to do that. Adaptive sports being another way. So, so much of the answer to that question depends on that individual child and where they are within this journey.

**Rebecca Whitney:** [00:22:16] Yes. Thank you. Thank you so much. How about addressing what the future may or may not hold when it comes to different aspects of managing symptoms or concerns that are a result of their diagnosis. So, perhaps understanding possible surgeries. For acute flaccid myelitis, there may be the possibility of nerve transfer, nerve decompression surgeries.

[00:22:45] Thinking of like transverse myelitis and some of the others where spasticity is an issue, a Baclofen pump. Or in many of them, if there's muscle weakness and scoliosis sets in, having to go through those kinds of surgeries. How, how do you talk about those far enough in advance without inciting fear or anxiety about that future, but also giving a sense of some preparedness for those possibilities? When do you bring it up? Do you bring it up?

**Dr. Lana Harder:** [00:23:21] Right. Also an excellent question without clear, easy answers. And I should emphasize throughout this conversation, there is never going to be a one size fits all to, you know, any scenario, and we know that. I think this goes back a little bit to the idea of avoiding information overload when we were talking about preparing for different procedures.



[00:23:45] So, as parents, as caregivers, medical providers, it's our job to anticipate the future and anticipate sometimes just this exhaustive list of scenarios, possible surgeries, possible procedures that might be needed. And we need to be informed, and we need to know what's a few steps down the road.

[00:24:07] I don't know that that's always going to be the most productive or helpful for, for our kids who are... maybe if they're in the acute phase or even post-acute. So, that information overload could actually be counterproductive. And I think you mentioned, how do we not worry them unnecessarily, I guess. But also, how do we keep them from being surprised if something comes up down the road.

[00:24:30] And I think this is where kind of that reassurance from the, the parents the, the care team of, we're going to go down this road with you every step of the way. Things may emerge. A problem may come up. You may notice spasticity increases. We've got tools for that, and we're going to tell you what those are and we're going to pick the best one for you so we can address that.

[00:24:54] There are any number of scenarios that could come up, but we're going to take each one of those and it's about pacing, right? Addressing things as they come up and being honest. I'm not suggesting that we hide anything from anyone, but that we may not need to lay out everything all at once. But I do think pacing to have the conversations, especially as we see that there may be a realistic need to pursue a certain treatment, surgery, whatever the case may be.

**Rebecca Whitney:** [00:25:26] Okay. Thank you. And obviously, emotions for both the child, individual diagnosed and in the parent or caregiver may run the gamut during a critical time of initial acute diagnosis or when you're facing a hospitalization that's treating something related to the diagnosis. Are, are all of these emotions okay? Are they normal? Is there a typical pattern that you see with these kinds of diagnoses, or is it normal for it to be a very rollercoaster type of situation?

**Dr. Lana Harder:** [00:26:08] Right. Yeah. And there's no playbook for any of this, right? I think the variability is probably the norm, right? And, and that our patients and families are kind of riding through this in all kinds of different ways, depending on their own life experience, their own coping strategies and what exactly is going on at any given point in, in the process.

[00:26:32] So, it's where do you catch them in that snapshot in time? And what does that look like for them? So, that's not the most satisfying answer because we can't really say that there's one expected thing. But I think the term that's been used is rollercoaster, I think that's absolutely right and something that we see, understandably.

[00:26:53] There's so much going on. And there's the acute phase when there's just so many things happening just to manage the hospitalization and all of the things that are going on. And really it, there's not even a time where psychologically, it often wouldn't even be appropriate to be able to process these things and accept them in a way that you could process them.

[00:27:18] So, people have compared this to, you know, stages of grief where there's kind of that shock at the beginning and moving through all the way toward increasing hope and having some acceptance around all of the changes that have taken place. So, it's complicated. I know that when we're in our clinic, our goal is to meet that family and that patient exactly where they are, and sometimes those are different places.

[00:27:47] Children can really amaze us with their resilience, and so can parents for that matter. But there are just a lot of things that, that are going on and going into all of this. And it also depends on that, you know, the child's age and developmental stage, and who they were before all of this.



[00:28:05] They're still the same person, but maybe before they, they could have had anxiety or depression or none of that at all. So, it's just, it's so unique. It's as unique as each of the individual patients. So, it's, it's hard to speak to that. I can definitely speak to some of the trends that we see as far as when emotional problems do surface and of what the nature of those looks like.

[00:28:33] And so for our patients, with these, these rare conditions, we tend to see more often than not that these are internalizing type symptoms. So, that might look like symptoms of depression, symptoms of anxiety. These may or may not reach a clinical threshold where we would call it an anxiety disorder or a depressive disorder.

[00:28:56] But we do often see that there is a kind of elevation of these symptoms that can kind of come up throughout, could come up here and there and not over any clear trajectory. So, we are always screening for that, looking out for those things. I think in some of our younger kids, we may see more behavioral disturbance.

[00:29:18] So, more symptoms of aggression, kind of acting out, maybe more hyperactivity depending on the situation. So, those are all things we have on our radar as we evaluate our children in clinic.

**Rebecca Whitney:** [00:29:33] Thank you. And as you're processing whether you're in the midst of the acute setting when you're first discovering this diagnosis, or even down the road, how much of your own emotion as the parent or caregiver is... is it okay to allow your, your child, the one who you're supporting to see? It, does it help them to see that you're human, you're scared, you have those anxieties? Or does it, does it hurt them? Does it put that upon their shoulders as well? So, that's something personally that I've often struggled with. So, I'm just curious how, where should we draw the line for our kids?

**Dr. Lana Harder:** [00:30:21] Yeah. Yeah. Also not an easy question and that, this doesn't have a, a clear or definite answer because, you know, you can go back to the variables we've said before that are important here. As you mentioned, as the parent, the caregiver, you're supporting that child. We have said throughout this conversation, it's important to be honest. We want to be authentic with our family members when we're going through something. You know, I think a little bit about that information overload.

[00:30:53] We want to find a balance there. I think it's very reasonable to articulate and name the emotions that you're feeling, and in that way, letting them kind of see, you know, if you're reflecting back their feelings, that I can see that you're afraid, or I can see that you're sad. And, you know, mom and dad feel that way too, or, just kind of naming it, reflecting it back, and validating those feelings that they're having.

[00:31:21] I think all really incredibly important to do. You mentioned something about putting it on their shoulders. And so, I think it's always good to just be mindful of how you, you know your child and their management of the situation and kind of using your judgment around how much or how little to say in that moment. I think parents are the experts on their kids. They know them better than anyone else. And so, being able to kind of judge in those moments, what is, is helpful to say or what we might save to have in a later conversation.

**Rebecca Whitney:** [00:31:58] Thank you. So, for some of these disorders, there may be ongoing immunosuppression treatments or medications that may be recommended to prevent additional attacks or worsening of symptoms.

[00:32:10] For most of the disorders, physical therapy has been shown to be of assistance in recovery and restoration of function. And for AFM and TM, sometimes surgical interventions are a part of the recovery process or options that may otherwise offer restored function. We talked about it a little bit earlier, but how



does a parent or caregiver ensure that the child continues to have a voice in those options that may exist for their disorder?

[00:32:38] Like the, the nerve transfers or the Baclofen pump or a limb lengthening surgery. And what happens if the parent and child disagree about the necessity or even the desire to, quote unquote, 'fix' an issue that, that one may identify?

**Dr. Lana Harder:** [00:32:58] Yeah, this is a big one and this is really important to consider, I think. Well, first of all, this notion of fixing a problem or identifying and addressing a problem, I think it's really important to understand what that means to each person involved in the conversation.

[00:33:15] So, for the child or adolescent themselves who has the condition and who is looking at this intervention, for the parents, what it means to them. There will surely be disagreements, difference of perspectives over time. It's important to respect the child's autonomy here. This is their body that we're talking about.

[00:33:36] And so, I think one of the most important tools and steps to take would be to engage the, the care team, the physician, the people who are expert on these interventions, to really sit and take the time to provide information to the parents along with the teen. I think it's so important for everybody to be in the room together hearing the same information and weighing those pros and cons of risks and benefits to come to a decision, whatever that might be.

[00:34:08] And it may be that there's not always agreement there. But I think going through the steps to, to get the information needed to make an informed decision is, is really, you know, the best that we can all do when looking at these, these questions.

**Rebecca Whitney:** [00:34:26] Okay. Thank you. I know it can be a very difficult one, especially as one may be developing their disability identity, and making sure that they are comfortable and confident in who they are as a person.

**Dr. Lana Harder:** [00:34:46] Yes, absolutely.

**Rebecca Whitney:** [00:34:49] Anxiety and depression. We mentioned them briefly before, but they're both mental health issues that can impact someone at any age and exist outside of a rare disorder diagnosis. So, what information or research exists about these two concerns in particular for children or teens facing specifically one of the rare neuroimmune disorders?

**Dr. Lana Harder:** [00:35:14] Yeah. So, the, the most information we have in these CNS demyelinating disorders would be in our pediatric multiple sclerosis literature. And so, we know that, at least we would say about a third of those kids will struggle with some type of, typically an internalizing condition like related to anxiety, adjustment, depression. When we look at that data for our kids with these rare conditions we've been discussing today, we, we can see that there is probably a slightly higher risk for these things compared to what we might see in a general population.

[00:35:56] And again, those symptoms tend to be around anxiety or depression. So, those are the ones we're really on alert for, really looking for. Symptoms that we might suggest that, you know, parents keep an eye out for. Along the lines of depression, of course, would be if there was increased sadness, changes in sleep or appetite, and that can go either way - too much sleep or too little sleep, overeating, under eating, either of those.



[00:36:28] Often these things can manifest as more irritability in children. So, seeing them, you know, be more irritable or have reactions that are maybe disproportionate to the situation that could be assigned there, too. With anxiety, excessive worrying of course and things of that nature. There are many different types of anxiety disorders.

[00:36:52] And as I said earlier, it may be that some symptoms are present. It may not reach a clinical threshold. What does that mean? Well, does it interfere with daily life and their ability to function and do what they need to do each day? Does it interfere with relationships, whether that be family relationships or other social ones? So, these are the kinds of things to look out for.

**Rebecca Whitney:** [00:37:15] Okay. And, do the possibility of either of these, anxiety or depression, does the, the chance of it happening change for a child or individual who's been diagnosed with a recurrent disorder versus a one-time inflammatory event?

**Dr. Lana Harder:** [00:37:35] Yeah, that's a great question. I don't know that we have the clearest answer from the literature, but what it makes me think of is some of the, the data we do have in MS, and this has typically been done in adult population. So, multiple sclerosis being a brain-based disorder with inflammation that is recurrent. We can see that that inflammation in the brain can actually underlie depression symptoms.

[00:38:00] So, from a biological perspective, the risk goes up based on the inflammation. So, if we were to translate that to the conditions we're talking about, potentially there could be something there that, to my knowledge, that research hasn't been done explicitly, but it makes me wonder as a clinician and a researcher if, if that same risk wouldn't be present for our kids with recurrent disorders.

**Rebecca Whitney:** [00:38:26] Okay. And so, it kind of leads to the next question. For those who who've experienced like an encephalitis or lesions in the brain, versus those who may have only had lesions or inflammation in the gray or white matter of the spinal cord. Is there differences there for those?

**Dr. Lana Harder:** [00:38:44] So, theoretically, that brain-based involvement, it could create a higher risk. Kind of like we're talking about with a disorder like MS. That being said, when we've looked at our data on transverse myelitis, which is, you know, restricted to the spinal cord, we have seen elevations and depressive symptoms in about a third of those patients.

[00:39:06] So, it's, it's hard to say for sure. I think that would be an excellent research study, or an excellent place to investigate.

**Rebecca Whitney:** [00:39:15] Okay, thank you. And how long after a diagnosis can these potential concerns present themselves? Is it a matter of, you know, it's within weeks of, of learning of a diagnosis? Or is it something that can come about months or even years after the diagnosis?

**Dr. Lana Harder:** [00:39:35] Yeah, I'll answer this in two different ways. From a research perspective, I don't think we know the answer to that question. From a clinical perspective, working with patients over the last, you know, 12 years and being in a clinic that long following patients that long, I've been able to really watch them through development and see changes over time.

[00:39:55] I would say I don't see a hard and fast rule, or a trend, for that matter. I can see these things pop up at different times. And, as you pointed out earlier, with or without one of these medical conditions, any of us could experience an anxiety disorder or depression. So, it's hard sometimes to tease those things apart to know, would this person be experiencing depression five years later at age 16, if they hadn't had this medical



event? It's just very hard to tease that apart. But the good news is that we, as clinicians, are on the lookout for all of these things and have really effective research-based tools to address them.

**Rebecca Whitney:** [00:40:35] Okay. Thank you. And another question that has come up is can one of these diagnoses, AFM, TM, NMO, et cetera, can they impact learning or cognition? And does that make a difference if it's one that is generally restricted to inflammation or lesions in the brain versus just in the spinal cord?

**Dr. Lana Harder:** [00:40:59] Yes. So, the short answer to that, and when we look across all of these different clinical groups and all of the research that we have, is that there is an increased risk for learning difficulties, but I quickly then want to emphasize these do not affect everyone the same way.

[00:41:18] And in fact, many, often most, of the patients won't have those problems. So, we want to keep all of this in perspective, but know that there seems to be an increased risk for kids with demyelinating disorders as a whole, as it relates to learning and cognition.

[00:41:36] And one of the things that seems to pop out every time we look at this data is the ability around certain aspects of memory, which is all part of learning, right? So, if we ask someone to learn information across, say, five trials, where we give them that information five times, the weakest area inevitably, when we look at the pattern of performance, is that trial one, that very first trial. So, that initial learning is many times below what we would expect for someone that person's age to be able to learn and retain.

[00:42:15] The other has to do with what we call our mental scratch pad or working memory. So, that also tends to be an area where there's a little bit more difficulty. And attention is also related to all of this. So, attention is the gateway to memory. And so, if we have a compromise there, we're going to struggle to remember information being given to us. So, those are some of the areas where I see more difficulty.

[00:42:44] And I'll mention one more thing that some may or may not put into a cognition category, but it certainly relates to school performance, and that has to do with fine motor skills, which can be impacted in different ways and in a whole range of severity. So, just the act of writing things down, taking notes, or, you know, typing notes for a class. And so, we have to really be mindful of how the fine motor components can play into that learning experience and participation in a classroom.

**Rebecca Whitney:** [00:43:17] Okay, thank you. These are very important pieces of information to know when learning of these diagnoses. Are there signs or anything for learning concerns that parents should be aware of? Should we be putting in place educational plans, accommodations with schools and teachers from the get-go? Also, when would a parent caregiver start talking about seeking assistance from a neuropsychologist or a licensed therapist to help address these concerns? Do we do that from the very beginning or as we go along?

**Dr. Lana Harder:** [00:43:56] Yeah. So, I appreciate all of these questions. I will say, in Dallas and our outpatient clinics, so, this is post-acute phase, but we might be pretty newly diagnosed, pretty newly stepping down from inpatient, we take a pretty proactive approach where all of our patients will see me, as the neuropsychologist, to do a screening evaluation.

[00:44:19] So, we want to look for all these things we've been talking about, inclusive of cognitive issues, learning issues, as well as those emotional symptoms we talked about. So, we're looking kind of across the board. To see, are there any signs of any difficulty, even from the very beginning? So, I tend to take that approach of just being proactive and wanting to look at this for everyone. That's not always feasible and different clinics have things set up in different ways.



[00:44:47] I would mention one thing, if someone is kind of in that post acute phase on steroids, we would wait for a period for steroids to leave the system before doing any formal testing. Simply because we know steroids can impact things like memory and even emotional state.

[00:45:05] So, we just want to have all that cleared out before we move down the road on a more standardized assessment because we don't want to have to explain, if we saw changes or problems, that oh, this could be related to steroids. So, I'll just mention that piece of it.

[00:45:20] Signs and things to look for. We certainly want to know about school performance. We can see grades change or there's difficulty participating. I mean, going back to the point of engaging the patient in the whole process, I ask them, what's hard about school, where do you struggle in it? And if I have trouble eliciting that information, I'll start to get into real specifics, do you ever run out of time when you're taking a test? Do you ever have trouble getting everything down as your teacher is lecturing? You know, there are ways to get at that information.

[00:45:54] So, we want to understand and not make assumptions about how a condition affects someone. We want to understand for that particular individual, how does this show up for you, say, in a classroom? So, looking for school related difficulties, changes as it relates to engaging socially or with family members, or even around the house if, you know, they're asked to do a couple of things, two or three step thing, and they are unable to complete that without a reminder.

[00:46:23] So, I would emphasize relative change. If previously they were able to do one thing, but now they're having more trouble and it seems to stem from a cognitive place of they're not able to pay attention to me long enough to hear it, they can't remember what I'm asking them to do. Those would be examples.

[00:46:40] So, I would say, if those things start to come up, what we would call like functional difficulties in daily life, that would be a time to possibly seek a referral for some testing assessment with a neuropsychologist.

**Rebecca Whitney:** [00:46:55] Okay. Thank you. And, if these symptoms and these changes occur years out from a diagnosis, how important is it to consider their rare neuroimmune diagnosis that they may have had in years prior, when they're seeking assistance from a neuropsychologist or a therapist? How would an individual go about seeking that information and making sure it is part of it? And should they make sure it is part of addressing whatever concerns they've realized?

**Dr. Lana Harder:** [00:47:28] I would say 100%. Absolutely. That is a critical piece of information. When we complete a neuropsychological evaluation on anyone for any reason, with any medical problem, we want to go back to the beginning.

[00:47:42] We want to know about pregnancy, the gestational period, birth, their weight at birth, how they were as an infant. We start at the very, very beginning. So, having a demyelinating event, an inflammatory event on the central nervous system is very relevant, even if it's, you know, five, 10 years later.

[00:48:02] And, from a neuropsychological perspective, we want to know when that happened. Did it happen, when they were an infant? Was it during a certain critical period of development? If that might be, let's say around age three, when they're developing language and it affected the brain, how did that change their development after that point?

[00:48:19] I mean, those are really important pieces of a puzzle. Maybe they experienced it pre-teen or teen years. All of those things are really important for us to understand because that moment in time can affect the trajectory.



[00:48:36] And we talked about identity development earlier. Those are things that help us understand that person in the most complete way that we can, to see where they are present day, to find out what their strengths are, and to leverage those to address any challenges that they're facing at that time. So, I would say that's highly relevant and to always include that information.

**Rebecca Whitney:** [00:48:58] Okay, good to know. Thank you. I know that we're coming to the end of our hour here. And any one of these questions or topics, I feel like we could do a much deeper dive into, completely separate from this podcast. But is there anything else that you want to make sure is addressed? Any advice? Any information that you want to make sure is put out to our community, whether it's for the kids or the individuals who are being diagnosed with these rare disorders? Or for the parents or caregivers, themselves, who are supporting and managing this disorder alongside of their child?

**Dr. Lana Harder:** [00:49:42] Yes. So, I could talk for hours in response to that prompt. I'll try to keep it contained. One thing we haven't talked about as much that I think plays a really big role for our patients has to do with fatigue and sleep. And so, those are things... if we have significant fatigue, that can mimic, you know, a depression, that can show up as mental foginess, we might think they have an attention deficit disorder.

[00:50:14] Getting a handle on understanding fatigue, the role that it's playing, ends up being so critically important for then also understanding coping, mood, adjustment and cognition, and their ability to focus and participate at school. So, that is something that requires careful assessment by their care team. A neuropsychologist is well positioned to do that, to kind of try and disentangle that from all the other things we've talked about today and sort of figure out what is what there.

[00:50:46] The other thing is, if sleep is not where it should be in terms of the quantity and quality, all bets are off. None of us are expected to cope or think clearly if we haven't slept well. And so, I know that seems like a very basic thing, but we know that sleep disturbance can be part of this picture and can be with or without these rare conditions. So, I really want to emphasize those things. I think that we can get a big bang for our buck on intervening when it comes to fatigue and sleep, and often those go hand in hand.

[00:51:19] So, that can just have a powerful effect on the rest of life and quality of life. So, I wanted to say that. And then the other thing I would mention too, for our patients, for our caregivers, for the siblings of our patients, who are a group I have had the privilege to get to know through our camp programming over, gosh, a decade now, I think, there is a community out there and people that can talk to you about this.

[00:51:47] And even though we said every situation is unique, there are overlapping challenges and there's a place to share those stories. I know this is what SRNA is all about. The camp experience, I think, is truly unique in that these are people that can come together, be in the same space, COVID aside, when we get back to in-person.

[00:52:09] And I think that that just has such a powerful effect on our families, on our teens with the conditions, to be able to sit and talk to one another about this. And I'll say one more thing, a big theme of this has been how do we engage our teens in their care and talking to their providers and being, you know, having that voice, being able to become an advocate.

[00:52:31] I was running a teen group at camp, and we decided to bring in a physician, Dr. Kyle, just to Q and A with him. And we were just going to do this for a few minutes at the beginning and then move on to our other activities. We kept Dr. Kyle the entire time. We went over time. They had so many things that they wanted to ask in a relaxed environment where they could talk to a physician, are not in a clinic, and it was just this safe space to be.



[00:52:57] And so I, say all this to say I think our teens do have questions, and I think coming together and hearing the questions that the other ones have, kind of comparing notes, comparing strategies and what works well, that to me is as powerful as anything else when we talk about addressing all of the things that we've talked about today. So, I wanted to mention those things, as well.

**Rebecca Whitney:** [00:53:22] Yes. Well, thank you.

**Dr. Lana Harder:** [00:53:25] I'll stop.

**Rebecca Whitney:** [00:53:25] Thank you so much. I truly appreciate your time and your insight into so much of this. And I look forward to getting back to in-person camp with our families, our kids, and making sure that parents and the kids themselves, the teens, have that support as they may go through these diagnoses. So, thank you again.

**Dr. Lana Harder:** [00:53:49] Thank you for having me.