

Behavioral and Psychological Changes in Demyelinating Conditions

Part 2

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Krissy Dilger: [00:00:00] Hello everyone and welcome to the SRNA's Ask the Expert Podcast Series. Today's podcast is entitled, "Behavioral and Psychological Changes in Demyelinating Conditions, Part Two." My name is Krissy Dilger, and I will be co-moderating this podcast along with Peter Fontanez.

Peter Fontanez: [00:00:20] Hello Krissy, thank you for the introduction. Now, my name is Peter Fontanez. I am a father of a child who has both ADEM with optic neuritis and MOG antibody disease. I am also with The MOG Project as one of the board members, as well as SRNA. I'm one of the leaders for the SRNA support groups from Florida.

Krissy Dilger: [00:00:40] Thank you, Peter. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. This podcast is being recorded and will be made available on the SRNA website and for download. During the call, if you have any additional questions, you can send a message through the chat option available with Zoom. Our 2021 Ask the Expert Podcast Series is sponsored in part by Alexion, Genentech, and Horizon Pharmaceuticals.

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[00:02:12] Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. We apply scientific expertise and courage to bring clinical, meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

[00:02:35] For today's podcast, we are pleased to be joined by Dr. Cindy Wang, Dr. Alison Wilkinson-Smith, and Denise Maddox, RN.

[00:02:46] Dr. Cynthia Wang received her medical degree from University of Texas Southwestern Medical Center in Dallas, Texas, and completed a pediatrics and pediatric neurology residency at Mott Children's Hospital, University of Michigan Health System in Ann Arbor, Michigan. Dr. Wang completed her James T. Lubin fellowship under the mentorship of Dr. Benjamin Greenburg at the University of Texas Southwestern and Children's Health. Her research study was a prospective, longitudinal study on acute disseminated

encephalomyelitis (ADEM) to identify the clinical characteristics, treatment methods, and follow-up interventions that are associated with better and worse patient-centered outcomes.

[00:03:31] Dr. Wilkinson-Smith is a pediatric neuropsychologist at Children's Medical Center, Dallas and an Associate Professor of Psychiatry at University of Texas Southwestern Medical Center. She is board certified in Clinical Neuropsychology (ABPP), has a subspecialty certification in Pediatric Neuropsychology and is certified in Therapeutic Assessment of children. She is the co-director of the Pediatric Functional Neurological Disorders Clinic at Children's Health. She's actively involved in assessment of youth with functional neurological disorders, as well as research and clinical training. Her interests also include pediatric autoimmune encephalitis and the assessment of children with complex mental health and psychosocial needs.

[00:04:18] She has a PhD in School Psychology from the University of Texas at Austin. She completed her internship at the University of Oklahoma Health Consortium and a two-year post-doctoral fellowship in pediatric neuropsychology at the University of Minnesota Medical Center.

[00:04:38] Denise Maddox is a registered nurse with the UT Southwestern Multidisciplinary Demyelinating Disorders CONQUER team and Children's Health Encephalitis Clinic. She serves as the primary coordinator of pediatric patient care across the disciplines within the Children's Health institution and outside resources for patients and their families, including education, management of therapies, coordination of care outside of the clinic, school needs, and provides transition of care education for teens and their parents. Denise's nursing experience includes roles in the NICU, neurosurgery, and since 2014, with the Demyelinating Disorders Clinic in Dallas. Denise also earned her MSCN, or Multiple Sclerosis Certified Nurse, designation in 2020.

[00:05:29] Welcome and thank you all for joining us today.

Dr. Cindy Wang: [00:05:32] Thank you. We're all kind of, so yeah I think we...

Dr. Alison Wilkinson-Smith: [00:05:37] I speak on behalf of all of us, thank you for inviting us. It's great to talk about this topic that I think all of us are interested in and are really pertinent to our patients.

Denise Maddox, RN, BSN, MSCN: [00:05:47] We're all really happy to be here.

Krissy Dilger: [00:05:50] Awesome. So just to get started... and this is the second part of a podcast that we did in August of last year, of 2020. And so, we just received a lot of questions, so we wanted to get a chance to answer those and have a part two to this discussion. So, we really appreciate your time. So, to get started, what is the odd fatigue and malaise that pops up from time to time and makes you feel so 'blah'? Is this part of nerve damage?

Denise Maddox, RN, BSN, MSCN: [00:06:22] Thanks Krissy. So, this is Denise. And the answer is yes to that second part, if you have a demyelinating disease. But really any chronic disease that you have, you can have a return of old symptoms, you know, especially if you're, if you get sick or there's a lot of stress going on in your life or in the summertime, it can be very heat related. And so those symptoms come back.

[00:06:47] And usually we say, when one of those triggers, which is the stress or the illness or the heat, goes away, the symptom tends to get better when it's intermittent. If it's ongoing symptom, that's something different. But when it's intermittent, then it usually will get better once that trigger goes away,

Dr. Cindy Wang: [00:07:07] Yeah, and I agree. I mean, these are some of the most challenging questions that, that Denise thankfully helps with our patients. But yeah, I think a lot of people will kind of compare their function to the way things were like before, you know, maybe one of these demyelinating or autoimmune conditions.

[00:07:25] And I think there is a sort of a learning process of sort of what, what the new normal or what, you know, how your body has recalibrated to some of the, the damage or inflammation, the results of the inflammation. So, yeah, I think inherent in this question is that if it's kind of mild, it's fluctuating, it's not, you know, steadily getting worse, you're not having any brand-new symptoms that you've never had before. I think more likely than not, it's more your body just kind of dealing with kind of the ups and downs.

[00:07:56] You know, everybody has a bad day, they didn't get enough sleep, or they skipped a meal. Yeah. And I think the more somebody can kind of just check in and kind of figure out any patterns to when those, those, you know, times of fatigue or malaise, you know, not feeling well, if there is a pattern to that, and then focus on the things to avoid, triggers, I think that's usually the most effective.

Peter Fontanez: [00:08:16] Okay. Next question. Could encephalomyelitis be a cause of the patient's fatigue and/or the treatments, treatment, for example, like CellCept?

Dr. Cindy Wang: [00:08:25] Yeah, and I think this kind of ties with the last question, which it, it, it, you know, you kind of have to put on your detective hat and kind of think about like, you know, when you started the medication, like, did you not have fatigue as to the degree that you did when, once you started it. CellCept is, you know, an immunosuppressive medicine and one that I wouldn't necessarily think would lead to significant fatigue. But commonly, our patients are on other things that are either muscle relaxants or they've worked at like kind of suppressing neuropathic pain signals, which do cause fatigue and sleepiness, things like Gabapentin or Baclofen.

[00:09:01] So we definitely get a lot of questions about that. And in those cases, it could be the medicine and it may be something a person has to work with their doctor and also just kind of, again, to kind of check in with their body and take notes. You know, is there a pattern to when those symptoms happened?

[00:09:15] But yeah, and a lot of times it can be a combination of things. So, it's hard to answer this question in general, but yeah, a lot of times it's just, you know, seeing, seeing how things evolve over time, does it depend on the dose. And you can work with your doctor and maybe either increasing or lowering the dose of the medicine you think could be causing side effects to help sort out that question.

Krissy Dilger: [00:09:39] Great. Thank you. Our next question is, are behavioral and psychological changes into my in demyelinating diseases obvious in acute or early stages, or do they become more obvious over time?

Dr. Cindy Wang: [00:09:52] Yeah, no, I think this is a really good question. And it sometimes really depends on, you know, the questions we ask as doctors and, you know, acute stages of the illness, whether that's transverse myelitis, optic neuritis, or ADEM. Particularly with things like ADEM where the brain is involved, oftentimes a patient, a child or adult could be really sick. And, you know, in the hospital, we're not really worried so much that, you know, they're, they're doing their homework or they're doing tests. We're not asking those questions about more of a kind of cognitive function. It's more about like, you know, are we, are we thinking they're getting better, are they interactive, can they breathe on their own? Are they having seizures?

[00:10:29] So, I think inherent in this is that sometimes, you know, we're not focused on what symptoms a family and a child may experience over time. Only after they've returned to sort of, you know, kind of back to their normal routine. So I think that's part of it.

[00:10:42] And then, especially in children, and maybe Dr. Wilkinson-Smith can speak to this, is that, you know, it's a moving target. A person that's four years old is, you know, has a different list of developmental

things that they should be doing versus somebody who's older. And, and usually school gets more and more challenging over time, so it's possible in, in kids who get ADEM very young that, you know, we, we don't, we haven't put them in a position where we can really evaluate more of the subtle cognitive kind of sequelae or the consequences of their illness.

[00:11:15] So yeah, I think, because, you know, we're, we're curious about these and we're trying to ask these questions, including, you know, projects we have here at Children's and Southwestern, we hope to, to find information about this. But many of the studies show that there are deficits with, you know, processing speed, attention, executive functioning. But yeah, you wouldn't know that because, you know, usually during the acute setting, things are more focused on just getting you through the, the most severe phase of the illness.

Dr. Alison Wilkinson-Smith: [00:11:43] There's sort of a concept that we talk about in neuropsychology that's called growing into your deficit. And it basically means that, like Dr. Wang said, we're sort of expecting different things from different kids, from kids at different ages, right. So, if you take attention, for example, a four-year-old is not necessarily expected to have a super long attention span.

[00:12:05] And there's also a wide variety of what we might consider normal in terms of attention span for a four-year-old. And then you compare that to a 14-year-old. You know, they are, the, the expectation is that a fourteen-year-old can pay attention for longer and that they're better at it than a four-year-old. So somebody who has some sort of, something happened to their brain at four that affects their attention, you might not notice it until they get a little bit older and the expectations change.

Peter Fontanez: [00:12:30] Thank you for that. On that note, what is the full spectrum of behavioral and psychological changes associated demyelinating diseases?

Dr. Cindy Wang: [00:12:39] Yeah, and I think we'll all maybe try to approach that. And so it's a very lofty question. You know, if we had all the time and research funds to devote to this, I think, you know, we'd all be excited to try to tackle this question. But I think first, it starts with kind of knowing everybody who's had ADEM has had a different ADEM. I've never seen, you know, two kids with exact same brain lesions or the exact same symptoms.

[00:13:03] So I think it first has to do with, if there was inflammation, where did it occur in the brain? And that might get, help us understand if, you know, it may have affected centers that have to do with memory, with movement, with emotion, and so forth. And then the brain, you know, as, as much as we'd like to understand it more simply, is a very complex organism, or organ rather.

[00:13:27] So there are things that even if you damage parts of the network or parts of the cables, you, you can disrupt, you know, the function as a whole. So, you know, I can speak broadly and say, it's pretty common that we see deficits in attention, short-term memory, sometimes, you know, using, using visual information, integrating it to what we're doing, you know, like motor skills, mood, and behavior are also pretty commonly affected.

[00:13:56] But yeah, I mean, I think we can see the whole gamut of things. And sometimes it relates to where, you know, that where the inflammation happened in the brain, sometimes it relates to just the process of, you know, having a medical diagnosis and having lost time, you know, in the hospital and getting back in school. So, I'll pause there because I know it's really a big question and I'm sure other, my colleagues have their thoughts, too.

Dr. Alison Wilkinson-Smith: [00:14:20] I mean the short answer is all of them. Potentially, just about anything in terms of behavioral and psychological changes.

Krissy Dilger: [00:14:31] Yeah. I think that's a good point. There's a broad spectrum and you can't really pinpoint any one issue. This next question came in from a parent. With behavioral issues, can some children with demyelinating conditions, show signs or symptoms similar to autism, but without the consistency? For example, right before, during, or after an inflammatory attack. Some parents have noted that their child has been misdiagnosed with autism right before an attack, or just have had treatments or techniques that are similar to working with children who have autism. So how does a parent or a medical professional separate the two diagnoses for the correct diagnosis?

Dr. Cindy Wang: [00:15:17] Yeah. And autism also is, you know, a wide spectrum of conditions, and there are many different ways that autism can present. So it's also a bit of a broad, but I mean, a lot of times autism, there are deficits in language and communication, there may be repetitive behaviors or stereotype movements. Yeah, it's possible that encephalitis could lead to changes in the brain that produce symptoms that can resemble autism.

[00:15:45] I think that the most helpful thing for me is trying to get more history on the timeline of how symptoms emerged and evolved. With autism, we think of it as more something, you know, that, that starts slowly, or it could be, you know, present earlier in life. Whereas a lot of these demyelinating conditions, they, they start over weeks to days.

[00:16:05] So if a person, a parent notices that their child has a, a fairly abrupt regression of skills, whether that's speech or behavior, then I think that's definitely something worth talking to their doctor about. And then, yeah, I think, hopefully, the medical community's knowledgeable enough about autoimmune encephalitis that would enter their thought process. But, you know, these are still relatively new diagnoses and conditions.

[00:16:32] So I think, you know, if something doesn't sit right with the parent and this doesn't seem like what they've read about autism, then, you know, always getting a second opinion could be helpful. And it's good that there are organizations like, you know, SRNA and Anti-MOG Projects to help guide families that are in that position.

Peter Fontanez: [00:16:51] Thank you for that. What are some treatments, therapies, or ways to help manage psychological problems? More so in children who do not know how to control their behavior.

Dr. Alison Wilkinson-Smith: [00:17:01] So this is another question that's, that's pretty broad. And you know, when it comes down to formulating a treatment plan for an individual patient, there are a lot of things that we would consider, including like the age of the patient and what type of symptoms are we talking about and what kind of environment they're in. But, sort of broadly, you can think about three different categories of interventions.

[00:17:25] So there's medication. And often, when we're talking about psychological problems, we're talking about psychiatric medications. There's things where you're working directly with the child, and you're trying to, for example, teach them some skills - coping skills, behavioral management, teaching them, you know, awareness and self-advocacy, all of those things.

[00:17:48] And then there's the environment. So, for most kids, we're doing some combination of those three. You know, I think it's pretty rare that you would only recommend one. You know, there are some kids who maybe can manage things through learning some skills and being in the right environment and don't need medication.

[00:18:06] There are some kids with, who, with skills and medication, can be in all kinds of environments and you don't have to worry about that as much. I think it's really very individualized. And it also might depend on the kid's age. So, you get, again, a four-year-old or even, you know, maybe a five- or six-year-old, it's going to be really hard for them to learn some skills, say, by working with a therapist and then go on their own and apply them in their everyday life.

[00:18:32] That's just expecting a lot of a really young child. And so, for those kids, for younger kids, we really need to work with the environment. And often that means working with families, right? So teaching parents to basically become their child's therapist in the moment in their everyday life. Right? So, your kid is learning a coping skill, like for example, deep breathing techniques, right?

[00:18:57] It's one. A five-year-old is not necessarily going to remember on their own to take deep breaths. At least at first, when they're just learning these skills, they're not going to know, 'Oh, I'm getting upset. I should take some deep breaths.' And that might be something we could expect a 16-year-old to do.

[00:19:13] But a really young child is going to need support from their parents or their teachers, or whoever's around them. You know, they're also going to need, you know, different kinds of things in their environment that might just sort of take into account the fact that they struggle with things that their peers don't.

[00:19:29] You know, so they might need, the school accommodations are something that we deal with all the time. For example, a kid who's, you know, maybe has some sensory sensitivities, they might need to take them to a quiet room by themselves so that they're not, you know, exposed to all the various noises of other kids in a classroom, rustling papers, clearing their throat, tapping their pencils, those sorts of things.

[00:19:52] So, you know, again, we, we really try to, as much as we can, develop a tailored treatment plan that takes into account that individual child and their family and their environment. But sort of broadly, I think we, we're always thinking about those three classifications, right? How can we help this individual child develop skills?

[00:20:13] Do they need some medical intervention and how can we optimize their environment?

Krissy Dilger: [00:20:19] Great, thank you. And I think that your answer is really thorough and kind of can segue into our next question. Can acute or preventative treatment help stop or better control behavioral changes in patients with autoimmune encephalitis, ADEM, or MOGAD? And this could be applied to adults as well.

Dr. Cindy Wang: [00:20:42] Yeah, I can start with that one. I'm thinking what the, what the person may be asking is in terms of immune treatments, in terms of like, types of conditions where the immune system can come back and, you know, do more damage and cause relapses, in which case, yeah, we always want to sort out, you know, if there is a sudden or a progressive change in mood or thinking or behavior, then I think it's a job of the doctor who was treating the person to, to think about is this, you know, a new immune attack. And ways of answering that question, may be through getting an MRI of the brain or perhaps looking at the spinal fluid to see markers of inflammation.

[00:21:24] You know, a lot of times we hear stories about people having worse symptoms, but then all of these tests return negative. And then I think it becomes, a question is, you know, is there something about, you know, again, a stressor on the body that isn't actually a new attack of this, you know, autoimmune disorder that could be leading to the symptoms.

[00:21:46] Sometimes things, you know, as simple or mild as a cold or urinary tract infection, or just not getting enough sleep or rest can trigger old symptoms. So yeah, that's, again, something that is a little bit individualized to the person. But yeah, we never, you know, want to, to miss any time where there's new inflammation that could be causing more problems. In cases of ADEM, which is mostly a one-time illness, the likelihood that another attack returns is relatively low. We are learning that children and young adults who have presentations of ADEM and also have MOG antibodies do have a chance of relapsing inflammation. So, in those cases, we'd be a little bit more attuned to new or worsening symptoms.

Peter Fontanez: [00:22:31] Thank you for that. What are the notable differences in initial symptoms and long-term effects of each of the rare neuroimmune disorders from a psychological standpoint?

Dr. Alison Wilkinson-Smith: [00:22:43] Another like pretty tough question to answer just because it's so broad. You know, and I think many of these disorders are going to present very differently, both in terms of acutely and over the long-term. You know, psychologically, you always want to think about, okay, so some of these disorders are going to produce psychological or psychiatric, whatever you want to call them, types of symptoms in the acute phase. And then, no matter what those symptoms are, whether they're psychiatric, psychological, neurological, you know, what, what have you, once you get into a sort of a chronic phase, if you have somebody with chronic symptoms, then you're always going to introduce some of the psychological factors that have to do with, like, coping with a chronic illness.

[00:23:28] Right? So that's, you know, just a long-term stressor that families have to learn how to manage. So. Which is maybe not necessarily as much of an issue in the acute phase. You know, in the acute phase, you're often dealing with things like just helping families come to terms with a major change that's happened over a short amount of time.

[00:23:45] And they need to kind of get their feet under them and get some treatment going and, and get back into their everyday lives before you start thinking about, how do we manage this as a sort of chronic stressor for a family?

[00:23:56] Yeah, I think that's sort of the best, best I can answer, like sort of generally, because each of these disorders is going to present kind of differently.

Krissy Dilger: [00:24:03] Great. Thank you. The next question is, how do conditions that target specific areas, like optic neuritis and transverse myelitis, but not the brain cause behavioral and/or psychological changes?

Dr. Cindy Wang: [00:24:22] Yeah. You know, I think some interesting research has come out of our group, including Dr. Lana Harder, in which, you know, they looked at functioning, neuropsychological functioning in children who had transverse myelitis, and they were surprised to find that, you know, despite it not looking like it affected the brain, there were some clear deficits, and it didn't seem to be related to other things like fatigue. So, I think with all of these inflammatory conditions, we wonder if inflammation does act on parts of the brain that may not just be, you know, visible on the tools that we use. And so that's, you know, that's, that's certainly one possibility.

[00:24:59] The other possibility is there's, you know, a lot of, you know, changes in function and, you know, psychological wellbeing that can come from an illness. There's probably trauma for the child and family, you know, you suddenly lost vision or your ability to move. So, I think that also comes into play.

[00:25:17] But yeah, I think it's a, it's a topic that we're all very interested in searching for, for better answers to, we're doing a lot of research here and collecting biological specimens, whether that's blood or spinal fluid,

or doing more types of imaging studies, including higher resolution MRIs to see, you know, is it possible in, in places where, you know, we didn't see anything in the brain, but on a, on a much, you know, stronger magnet scanner that we might, might see that there is inflammation elsewhere.

[00:25:48] So, yeah, it's a really interesting question. I don't know if we've had enough time to, to work out the, the answers to that quite yet.

Peter Fontanez: [00:25:57] Thank you for that. So we've talked about the disease, the diagnoses and their cause. What about... this, this question is a two-part. What are, what are the methods of, methods for testing to help determine psychological baseline? And which type of doctor would be best suited for testing this, maybe a neuropsychologist over an immunologist, or neurologist, or a neuroophthalmologist? Which doctor would be the best?

Dr. Alison Wilkinson-Smith: [00:26:22] Neuropsychologist, of course. I mean, I'm obviously biased, but you know, this is really what we do. I think when we talk about determining a baseline, you know, that is something that is, can be a real challenge for us because we don't see kids until they're having problems. You know, in my fantasy world, we would have every kid do a full neuropsych every two years so that if everything, if something happened to them, we'd have a baseline ready to go.

[00:26:48] But I don't think insurance wants to pay for that. But, you know, a lot of things that we do in terms of looking at, 'okay, how much do we think this particular child has changed from their own baseline pre-illness or pre-onset?' We, we rely a lot on things that we gather from the interview and history, right?

[00:27:11] So we want to know, is this a child who met their milestones on time? Is this a child who maybe was getting some supportive services in school prior to this onset? Is this a kid who's ever had any psychological, emotional, behavioral symptoms before? So a lot of what we do is talk to families and try to really get a sense of, you know, what was your kid like before this happened? And we also want to review records. So it's really helpful when parents can provide, for example, records from school where we can see, you know, what this kid was like in the classroom before all this happened.

[00:27:50] You know, we look back at past medical records, even just having access to like their well visits from before can sometimes be helpful, because sometimes you'll see, you know, hints of problems or not beforehand. So, you know, trying to figure out baseline is really, it's really just a guesstimating process, and we try to do the best we can.

[00:28:12] This is particularly challenging in younger kids because they just, they just have less of a history, right? They haven't lived as much life for us to figure out their baseline. You know, and then, to have something happen to you early on in your development means it's going to affect your trajectory as you continue to develop.

[00:28:28] Whereas if you have an older child who has already experienced some development, and then, you know, this is sort of how they're going to finish out their developmental process. But, yeah, I don't even know if I would say that testing helps us establish a baseline so much as history and interview.

[00:28:46] You know, we don't always have good tests that say, okay, what was your kid like six months ago? That's just not something we can do very well. So it's, it's always a little bit of an estimate.

Krissy Dilger: [00:28:59] That makes sense. Yeah. Our next question came in from a parent. Children with rare neuroimmune disorders may struggle in school due to these behavioral or psychological issues. How

can parents help their kids from an educational perspective? And is there any advice for maybe working with school psychologists or anything like that to make their experience in school better?

Dr. Alison Wilkinson-Smith: [00:29:25] Yeah, I would say, as a neuropsychologist, this is a big part of my job, is figuring out how to help kids in school. You know, that's the place where kids spend a big chunk of their waking hours. You know, if we're talking about kids in the U.S., which is the only kids I work with pretty much, you know, we have special education laws in place that can help kids who have medical conditions, emotional/behavioral problems, you know, all sorts of things.

[00:29:53] We have laws that are set up to make sure that kids with disabilities can get appropriate education. So, you know, as a neuropsychologist who works with kids, my job is to really know those laws inside and out. And so, I help parents understand the law as it applies to their child and their child's needs.

[00:30:14] And then I try my best to give them the tools to advocate for themselves so that they can go to the school and say, 'Hey, you know, I, my child should qualify for an IEP as a child with other health impairment,' or, you know, whatever. 'My child should qualify for a section 504 plan.' So, my job is to really know those rules backwards and forwards and to help give parents the information so that they can go and advocate for them.

[00:30:40] I also am happy to help parents by talking directly to schools. And I think most of us who work with kids do this to some degree, because again, that's where our kids spend a lot of their time. So, you know, I can help families get the type of documentation that they need to make sure that they're getting services. I can talk to schools directly.

[00:31:00] Especially with some of these rare disorders, I don't expect the schools to know, you know, some of these disorders. I don't expect that they've ever necessarily had a kid with, with that before. Even, you know, special education departments, where they are dealing with all of the kids with disabilities, they may have never seen a kid with autoimmune encephalitis before.

[00:31:21] You know, they've, they've probably seen kids with dyslexia, and they've probably seen kids with ADHD. But, you know, they don't necessarily know anything about, you know, anti-NMDA receptor encephalitis, for example. And again, that's, that's my job. That's my job to know about that condition.

[00:31:37] And then it's my job to take the knowledge that I have about that condition and use it to work with the family and figure out, okay, what are this child's specific needs in the school environment? And then how can I translate that to the school, both in terms of, you know, speaking their language enough to provide the necessary documentation.

[00:31:56] But also to, like, describe their needs in a way that is like, you know, doesn't use jargon and in a way that schools can understand. I also think it's really important to get information from schools. So I think of it sort of as a two-way process, as much as I can, I try to get information from a child's teacher, for example.

[00:32:17] So then I can say like, "Hey, the teacher is saying that this child is having this problem in the classroom. And I know, because I know about this disease, that this is probably related to their disease. So this is something that we need to address in their education plan." So.

Denise Maddox, RN, BSN, MSCN: [00:32:33] I would also add on that, from a parent perspective, because I get a lot of calls from especially parents with teenagers that the teenagers don't want to be treated differently. And so for them, having a 504 or an IEP sort of sets the (inaudible), it, it makes their friends ask questions that they don't necessarily want to answer. So, I would encourage you, I talk to a lot of my parents about, you

know, this is something just like if your child has strep throat, you would give them an antibiotic.

[00:33:03] Getting these accommodations in school is like that. I mean, we want to give them every opportunity to succeed, and it's not a black mark on them or, or their abilities. It's just helping them do the best that they can, just like a coach helps you in basketball and, you know, in sporting events.

[00:33:22] But I know it's really challenging for parents. And so, I would encourage you, if you're having a problem with a teenager, you know, talk to your neurologist, talk to your neuropsychologist. They can help communicate with your teenager and get them to, to understand why this really is in the best interest of their learning environment.

Dr. Alison Wilkinson-Smith: [00:33:39] And in some ways, that's totally at a normal developmental stage for an adolescent. They don't want to be different. You know, and they're... one of your developmental tasks as a teenager is to figure out your identity. And if you are someone who has a chronic illness, then you have to figure out, 'how does my disease or my disability or whatever it is, how does that fit into my sense of self?' And so part of what we have to do is help our adolescents - and this can come up for younger kids too, but it really is key for adolescents - help them develop a positive self-identity that includes this piece of it.

[00:34:17] And then also translate that into how do we help this teenager advocate for themselves, right? Because a lot of our kids are going to have the problem where they might be entitled to an accommodation on paper, but the teacher hasn't seen that paper, they have a substitute that day, or who knows what. So the kid has to learn how to advocate for themselves.

[00:34:35] And eventually, they're going to become a, an adult who needs to manage their own environment and manage their own healthcare. So figuring out how to understand themselves and advocate for themselves is, you know, it's really just as important as a lot of other things that we do, because eventually you want this person to become a successful adult.

Peter Fontanez: [00:34:54] Thank you for that. From a personal perspective, everything you guys said was huge because my daughter was in the same situation, and it was the neuropsychologist who helped her through school and set her up, and everything you guys said was exactly a lot of what we went through and got her on, on a plan.

Dr. Alison Wilkinson-Smith: [00:35:11] We like to hear that!

Peter Fontanez: [00:35:13] Thank you for that because you guys do play a huge part, especially in the younger kids and how they're going forward. So again, I can't thank you enough for everything that you guys do. My daughter wouldn't be where she is educational-wise if it wasn't for the neuropsychologist and setting her up on those plans.

[00:35:28] Going forward, the next question, what type of research is currently being done in this space?

Dr. Cindy Wang: [00:35:36] Yeah. I can mostly speak to our institution in which, you know, we have an excellent relationship with our neuropsychologist. And again, we want to make these, these findings more visible to the community and to other physicians that, yeah, there, even though a lot of the kinds of conditions that may affect the brain can look invisible, if you don't have a, kind of a motor disability that goes along with it, that they are there, that they're concrete, that they're reproducible and, you know, make up a better case that, yeah, these kids should routinely be screened, followed over time, and that school accommodations should be tailored to their particular assessments.

[00:36:14] So, definitely neuropsychological research is happening here. We're also doing some studies. Again, I think I mentioned earlier, imaging the brain on higher resolution scanners to see if on a, you know, if we can see inflammation on a level, if we look with more clarity at the brain. And then we do collect a lot of biological specimens.

[00:36:35] And I think a lot of that is just because we're humble and we know we don't have all the answers. We don't, you know, we don't have all the tests. And if we can save important specimens, maybe in the future, we'll be smarter and be able to go back and then, you know, answer some of these questions. So that's mostly where things are going.

[00:36:51] I think it's really inspiring with neuromyelitis optica with, you know, three FDA-approved treatments that have come out in recent years, that that might translate to other things. Specifically, I think anti-MOG disease is one where research could definitely be furthered in that field because, yeah, it's, again, it's, it's something that we've been able to test for and that makes it easier and more, I think, you know, attractive to pharmaceutical companies to come in and, you know, ask very directed questions of what, how we can intervene with those diseases through treatments.

Krissy Dilger: [00:37:23] Great. Thank you. We had a question come in, this person would like to know more about the role psychology and psychiatry play in the treatment of altered behavior when the cause is typically considered neurological or physiological?

Dr. Alison Wilkinson-Smith: [00:37:40] I think I, yeah, I mean, I think for me as a neuropsychologist, I kind of have one foot in each world because I'm trained as a psychologist, but I've worked with neurological disorders. I think the most important thing to remember is that we don't have a neurology brain and a psychiatry brain. We have one brain. And so, you can understand it from different perspectives. You can approach it from different places, but it, this is all happening in the brain.

[00:38:09] And so, you know, humanity, society, I don't know where this came from, but historically we have just made this distinction between what is "quote unquote" medical and what is "quote unquote" psychological, and it's a completely arbitrary distinction. And so, you know, I think that... I think that sometimes families feel that when we are recommending psychological or psychiatric treatments like CBT or psychiatric medications, you know, some families find that to be, I guess, dismissive like that we're saying, 'okay, your problem is not real, and so your kid is just crazy and you just need these mental health treatments,' but that's, that's not the case at all.

[00:38:55] It basically just means these are effective tools that we know about that can help your kid. It doesn't make your problem any less brain-based, because all of these problems are brain-based. And there are lots of disorders that we approach from that lens. You know, there are lots of disorders that have to be managed by a psychiatrist or a psychologist, and/or psychiatrist-psychologist, and/or neurologist, because it just takes all of those different perspectives to promote the best outcome.

Dr. Cindy Wang: [00:39:26] I can echo that, Dr. Wilkinson. Yeah, and I think sometimes I use this analogy with my patients. You know, when, when you have transverse myelitis and you, you know, lose function of a limb, or you have optic neuritis and you lose vision, you know, sometimes there is natural ways, you know, for rehabilitation for instance, physical therapy, occupational therapy. Those are often recommended, and no family ever balks at, you know, getting those recommendations, because it, it makes sense that if you are having trouble walking or, you know, manipulating things with your hands and you need a therapist to help. You know, I think the closest analog for somebody who's had a brain disorder is, you know, you know, a therapist, a cognitive behavioral therapist, somebody who knows the techniques, how to, you know, retrain

and rewire the brain so we can try to get someone back to, you know, as normal a baseline function as they were having.

[00:40:21] So, yeah, I think maybe some, some of the, the stigma is tied into sort of how these fields have been viewed over, you know, over history. But yeah, I think everything that we recommend is based on knowing that it works for people who have similar symptoms and syndromes. So, yeah, kind of just treating this as rehab for the brain I think might be helpful for those families that don't quite get the connection there.

Peter Fontanez: [00:40:48] Thanks for that. Now, a question coming off of what you guys just spoke about, what are, what's some advice you could give to families who have, like family members who have, caretakers who have to deal with the symptoms, the symptoms that neurology, that, that feel are psychiatric errors or needs psychiatry? Like, what is some of the advice you can give to families?

Dr. Alison Wilkinson-Smith: [00:41:09] I would say, you know, one of the best pieces of advice that I could give would be to, as much as possible, take parents out of the role of having to manage that. So if at all possible, if families can receive care maybe in a multidisciplinary clinic, but at least from providers that are within the same institution, that's really going to allow your providers to communicate with each other, so that, you know, you as the parent don't have to be the one shuffling records back and forth and, and, you know, facilitating that communication.

[00:41:45] You know, care works best when multiple specialties can coordinate. That's true for, you know, pretty much every disease. And especially for these rare conditions. So if you can get care within the same institution, you know, especially because within the same institution, there's probably a good chance that your providers actually know each other and can coordinate.

[00:42:06] But if you can't get care from the same institution, you should at least be able to assign consents for your doctors to talk to each other. You know, someone who works in a hospital, I want to take that burden away from my patients as much as possible. And I want to talk to the other providers to help coordinate their care so that the family doesn't have to do that.

[00:42:27] And so even something like just making sure that all the medical records are shared within, within different providers so that, you know, this person can have access to that person's notes. You know, I think there are a lot of disorders that can sort of fall between two different worlds. And really the best way to do that is to have everybody on the same page. And if you as the parent are not the one trying to get everyone on the same page, you know, that's, that's really the best way to do it.

[00:42:57] So if you can't coordinate within the same institution, at least. And you, you know, one of the best things that you can advocate for is you can ask them to talk to each other. Can you call Dr. So-and-so and, you know, talk about what we're going to do?

Denise Maddox, RN, BSN, MSCN: [00:43:10] That's what I was going to add on, Dr. Wilkinson-Smith. That was perfect. Is that for parents to be able to sort of quote, when you're interviewing doctors, which is kind of what you do, right? You're making sure that you're getting along, that you trust them, make sure that they're willing to have those conversations. And our Dr. Wang has had many, a phone call to a psychiatrist or a psychologist to talk about one of our patients.

[00:43:35] And I've actually had parents that will say, you know, my doctor won't talk to anybody else. And I really encourage them to maybe find another doctor, because there has to be that willingness to learn from each other and to both want to present what you know about to help further, you know, their treatment. And

so, I would encourage you to just ask very specifically your doctor and your therapist, 'are you willing to have that relationship with my other provider?'

Krissy Dilger: [00:44:05] Okay, great. Thank you. Our next question is, to the extent that behavior issues are static and seem to be due to an acquired brain injury, what treatments are effective? Any evidence for less typical treatments like EMDR, neurofeedback, or hyperbaric oxygen therapy? And we actually had a question come in about Tai Chi or yoga, if there's been any research done on those as well?

Dr. Cindy Wang: [00:44:33] Yeah, and I think that my understanding of the question is, you know, to what extent that it's not new inflammation causing new behavioral and psychological changes, to what extent, you know, some of these treatments can be helpful. And yeah, I think, you know, this, this is an answer that I am always tired to give, but you know, the research isn't out on a lot of the, some of these types of interventions that have been listed.

[00:44:56] Hyperbaric oxygen therapy, I know of only in certain acute situations, mostly having to do with strokes and other things where it could be helpful in the short term. But yeah, I think a lot of times, you know, after the fact, after the injury has been done, there may not be a role. I think there's probably more. I have more optimism, optimism around things that have to do with like neurofeedback and retraining and rewiring the brain.

[00:45:23] You know, we, we're always learning about how, you know, there is neuroplasticity. Especially with younger individuals, you know, children, their brain is developing well into adulthood. So, and I think that's why we really emphasize the importance of, you know, appropriate therapy, appropriate accommodations to help facilitate, you know, that child and achieving their most potential.

[00:45:46] In terms of other questions like, you know, Tai Chi, I think there's a lot of, you know, techniques where that is a part of therapy, whether that's like mindfulness, you know, meditation, other like dialectical behavioral therapy. I'll probably start to defer to Dr. Wilkinson-Smith. But yeah, I think, you know, people are interested because there is this, you know, big surge in interest in brain health and how a lot of things that may not be considered medical, but more just like daily habits, like getting good sleep, getting good exercise and diet where those are sort of the fundamentals of brain health and, and, you know, trying to encourage the brain to be as healthy as possible, especially in people who've had a setback, like one of these autoimmune brain disorders.

Dr. Alison Wilkinson-Smith: [00:46:28] Yeah. I mean, sometimes some of the most effective things that we can do are just the things that you want to do in general, to keep your body healthy: eat healthy food, get enough sleep, get some exercise. There's a, you know, fairly robust amount of research looking at exercise for emotional behavioral symptoms.

[00:46:49] And so we know that exercise is important for brain health and emotional wellbeing. I believe there is a smaller bit of research looking at yoga specifically. I don't, you know, I don't know, like off the top of my head, but I want to say that there has been some research on yoga. I don't know of anything on Tai Chi. Doesn't necessarily mean it's not there, but I just don't know off the top of my head.

[00:47:12] EMDR is something that does have empirical support for PTSD and trauma-related disorders. You know, it hasn't quite been studied for more broad applications. So it's not necessarily something that I recommend outside of trauma. Neurofeedback can be sort of a broad umbrella term that can refer to lots of different things, some of which are supported and some things that aren't.

[00:47:37] You know, I think it's always important to consider risk/benefit as well as, you know, what is the science telling us? So, you know, there aren't really side effects from getting enough sleep. There aren't side effects from eating a healthy diet and getting exercise. There aren't really, you know, there's not a lot of risks to doing yoga.

[00:47:56] There are risks to doing something like hyperbaric oxygen. You know, the risk for things like EMDR and neurofeedback is mostly to your wallet, but it's probably not going to hurt your child. So I think that those are all things to take, take under consideration. And so, I understand that a lot of our families, if they've done all of these sort of scientifically recommended treatments, right, we've done CBT, they've tried psych meds.

[00:48:21] You know, they've worked on getting their kid the right supports at school and at home and, you know, their kid is still just struggling, which can happen some of the time. And they're really sort of like, what else can we do? You know, my advice is always just like, okay, is this something that is potentially going to, you know, is there, is there a risk involved, right?

[00:48:42] And if there's not a risk or if it is a risk that you're willing to take on, then by all means, see if it helps your kid. But, you know, especially for something like hyperbaric oxygen, you know, that, that is definitely not a risk-free treatment. And so, you know, I, I would not necessarily recommend that somebody tries something that's risky when we don't have any science. But, yeah.

Dr. Cindy Wang: [00:49:04] Yeah. And I think sometimes it's helpful to know, you know, how are these treatments covered? Insurance is structured in a way that, you know, they're, they're more likely or should approve things that have been proven, you know, by scientific research. So I always get a little bit skeptical when families are approaching a treatment where they have to pay thousands of dollars out of pocket, or, you know, it just seems like, you know. Or, you know, they go to a clinic they're not willing to accept insurance.

[00:49:32] I feel like, you know, the potential that somebody's, you know, trying to take advantage of, you know, families that are really struggling is always something, you know, I am cautious about.

Dr. Alison Wilkinson-Smith: [00:49:44] This is something we sometimes also talk about in terms of things like supplements and those sorts of things. And again, it's like, there are some supplements that are potentially dangerous and some that aren't, where you can just say, okay, you know, try it and see if it helps. And maybe it will, maybe it won't. You know, these are things that you should always talk to your doctor because your doctor is going to be the one who knows the science best and can give you, you know, an understanding of, of what those risks and benefits could potentially be.

Peter Fontanez: [00:50:16] Thank you for that. I know we're running short on time. One of the last questions, what is the prognosis for a return of normal behavior or are the personality changes permanent?

Dr. Cindy Wang: [00:50:27] Yeah. And you know, there are quotes around "normal," because I think none of us can, you know, you know, that, I guess. The human condition is so complex and everybody's different, right? We're all, we're all very unique. So, that is something I think, you know, again, taking a lot of history, knowing what a child or individual was like before their illness and to what extent it's changed.

[00:50:49] And then, again, it's so hard because children are constantly changing. It's not normal for, you know, a child at grade school to be exactly the same in middle school. So in some ways, it's relying on, you know, what we know about typical development, but knowing that there is still, you know, room for individuality, but yeah.

[00:51:09] That's all I can kind of say about that. I think people as they get better from encephalitis, there is, you know, more things that come back in terms of like attention, ability to focus, remember things, and that's probably more, you know, kind of the brain getting back on track. But yeah, it's possible in some of these diseases that it is sort of like an acquired brain injury, the same way we think about like stroke or traumatic brain injury, where yeah something has happened in the brain and you may not be quite, you know, the path that, that was, you know, in place before, but that doesn't mean we shouldn't do everything we can to, you know, optimize that trajectory as much as we can.

Krissy Dilger: [00:51:52] Great. Thank you. Just to close out, we've gotten a lot of questions about specific, you know, behavioral and cognitive issues that people have experienced after being diagnosed. For example, a parent said that their daughter was diagnosed with ADEM and has long-term memory, reading, and comprehension issues. Another person said, during my MOG journey, I felt like I was having déjà vu and feeling like they're physically present but mentally absent, having brain fog. So I guess my question is, if people are experiencing these symptoms, what is your advice to them on how to, where to go to get it treated? Like, is there a specific doctor or physician they should go to, or what's your advice?

Dr. Cindy Wang: [00:52:37] Yeah, and I think it really helps to have a good relationship. You know, most of the, I think, people who've had these illnesses will have a neurologist, and hopefully that neurologist will kind of know you well and, over time, get a sense of what, you know, what, what is just kind of fluctuations of, you know, "quote unquote" normal day-to-day functioning and what's a new symptom that warrants investigation. You know, looking for a chance of a, a new inflammatory attack.

[00:53:02] But if it is, it is not like, you know, an episode or a relapse of inflammation, then I think it goes back to a lot of the fundamentals that we talked about, just, you know, just natural health, some you know, routine in terms of sleep and stress and coping with stress.

[00:53:20] And then, you know, kind of sometimes therapy and counseling. I think this year with COVID, a lot of us have been, you know, out of our comfort zone, and we've definitely seen more of these questions pop up. So, I think, environment is really important. So, yeah. And for most children, that's going to be sort of the school and the home environment and working on ways to improve and looking for patterns where, you know, negative behaviors appear and how we can approach that in a better manner.

[00:53:47] But yeah, I think a lot of the questions are pretty detailed. And I think, you know, if your neurologist, like Denise was saying, if your neurologist is not willing kind of to hear you out and validate your concerns, I think that may be a relationship that may not be the best one to preserve. And yeah, there, there are lots of neurologists, there are fewer neuroimmunologists, but there's definitely a lot of interest in the field.

[00:54:09] So yeah, I think you can be, you can shop around if you, you don't feel like you're getting your voice heard or, and you're not getting your concerns addressed.

Krissy Dilger: [00:54:23] Great. Thank you so much. We unfortunately are at the end of our time, but I think we answered a lot of questions and had a lot of great information come out.

[00:54:32] And thank you for your time and for, for spending this hour with us, we really appreciate it. And also thank you to Peter for co-moderating and The MOG Project for submitting questions. We really appreciate all your help. And hopefully we can continue this conversation more so that we can learn even more about this particular topic.

Dr. Alison Wilkinson-Smith: [00:54:55] Thank you.

Dr. Cindy Wang: [00:54:56] Yeah. Thank you both.

Denise Maddox, RN, BSN, MSCN: [00:54:57] This was really fun.