Building Your Healthcare Team for Successful Symptom Management for Those with ADEM

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[00:00:00] **Dr. GG deFiebre:** Hello, everyone and welcome to the “ADEM Academy” podcast series. This is an ongoing series about ADEM or acute disseminated encephalomyelitis. This podcast is titled “Building Your Health Care Team for Successful Symptom Management for Those with ADEM.” My name is GG deFiebre from the Siegel Rare Neuroimmune Association and I am moderating this podcast. SRNA and The MOG Project are collaborating on this podcast series. We're both nonprofits that are focused on support, education, and research of rare neuroimmune disorders including ADEM and MOG antibody disease. You can learn more about us on our websites which are wearesrna.org and mogproject.org.

[00:00:43] For this podcast, I was joined by Dr. Linda Nguyen and Dr. Benjamin Greenberg. Dr. Nguyen completed her MD and PhD training at West Virginia University in 2017 and then, completed a pediatric neurology residency at UC San Diego in 2022. Currently, she is a neuroimmunology fellow at UT Southwestern. Dr. Greenberg is the Director of the Perot Foundation Neurosciences Translational Research Center within the O'Donnell Brain Institute and Vice Chair of Translational Research for the Department of Neurology at UT Southwestern.

[00:01:21] Thank you both so much for joining us today for talking about building your health care team for successful symptom management for those with ADEM. I guess just to start, Dr. Greenberg, do you mind talking a bit about what type or types of physicians are responsible for diagnosing ADEM?

[00:01:43] **Dr. Benjamin Greenberg:** Yeah, happy to GG and I like the fact that there's a plural in types of physicians because it really is plural. Acute disseminated encephalomyelitis or A-D-E-M, ADEM is a condition that more often than not affects children more than adults but it can affect adults as well and often the symptoms have an acute or sub-acute onset such that somebody goes from being well to having a symptom in a relatively short amount of time. Things can evolve in a day or less. And so, usually patients are first being evaluated by either their primary care physician, whether it's a pediatrician or an internist or going to an emergency room and for that first physician who's evaluating a patient, the key is for them to recognize that somebody's having a neurologic symptom and then, bring in help from neurologists and radiologists. The diagnosis of ADEM is heavily related to a neurologist, evaluating data and a radiologist acquiring and helping interpret MRI findings. And so, while the neurologist at the end will confirm or make the diagnosis of ADEM, there are a lot of different clinicians involved in patient care before the patient arrive at the neurologist.

[00:03:05] **Dr. GG deFiebre:** Got it and then, when someone is having this initial ADEM attack, what types of healthcare professionals will be on their team? I know you mentioned a neurologist, a radiologist, Dr. Greenberg, but are there any other types of physicians, Dr. Nguyen, for example, maybe say if someone goes to the emergency room or something like infectious disease, you just talk a little bit about what those other health care professionals might be?

[00:03:31] **Dr. Linda Nguyen:** Yeah, certainly. So, once you go into the emergency room, depending whether you're a pediatric patient or adult patient, you can see a different provider there, but really once you get into the hospital setting depending on the symptoms you're presenting with. If you have fever associated with your symptoms, then certainly the infectious threshold becomes higher. And so, additionally, in addition to getting imaging to go into the diagnosis, then you would get CSF studies too to rule out the mimics and in ruling out the mimics, if there's a stronger concern for inspection, then the infectious disease team could be involved, but certainly depending on the severity of the presentation that could be in the hospital floor or they can be in the ICU. And so, you can have also involving intensivists rather than just the hospitalists. So, certainly in the acute period those are the additional players that may be at play.

[00:04:31] **Dr. Benjamin Greenberg:** And then depending on the treatment patients get, for example, specifically and we may talk about this, the use of plasma exchange in ADEM patients, different hospitals handle plasma exchange in different ways in terms of which physicians are responsible for managing that procedure. So, here at children's, it's actually run through the hem. path. group, in some places, it's run through clinical pathology and then, in some places, it's run by our nephrologists or kidney doctor colleagues because it's similar to the dialysis. So, the team may look a little different at different hospitals depending on who operates the plasma exchange unit.

[00:05:13] **Dr. GG deFiebre:** And in the early setting, are there any - do you typically - do patients see physical or occupational therapy or is that later on in the diagnostic process?

[00:05:27] **Dr. Benjamin Greenberg:** What do you hope happens?

[00:05:06] **Dr. Linda Nguyen:** So, certainly, what we hope happens is that they begin in the early days of OT, the PT, even the speech therapist come early involved with the physical medicine team becoming early involved. So, that's always the hope because, you want to be able to help them at the very beginning in terms of the recovery process, but certainly a lot of the times when they're in the ICU that gets into the back burner, and we forget about that as we manage them acutely.

[00:06:05] **Dr. GG deFiebre:** So, following the initial onset of ADEM, what kind of doctor should a newly diagnosed person prioritize seeing and are there any special considerations for someone who tests positive for the MOG antibody, Dr. Greenberg?

[00:06:21] **Dr. Benjamin Greenberg:** So, I'll take the first part of this question in terms of who should they prioritize seeing, my answer is going to be, it really depends on your situation and if a cause of the ADEM was found and you bring up the MOG antibody, there's another antibody, the anti-aquaporin-4 antibody, which rarely can cause an ADEM presentation, but if you have one of these known underlying auto antibodies, a neurologist is pretty important early on to establish with because you're going to need long term neurology, neuroimmunology follow-up if no cause is found and a person is told that this was an idiopathic event, likely a onetime event, then really the person that prioritizes based on what symptoms you have.

[00:07:06] For our patients who have a lot of motor symptoms, affecting walking or balance, a psychiatrist is probably at the top of the list for who to establish with. Some of our patients present with seizures and perhaps an epileptologist would be helpful in the care and then, some patients are left with significant cognitive issues and establishing with a neuropsychologist early on or somebody who specializes in even traumatic brain injury might be helpful at managing your overall symptoms. So, it depends on which of the symptoms are lingering for the individual and what the underlying diagnosis was. I don't know Dr. Nguyen, if that changes for you, for somebody who does test positive for the anti MOG antibody, do we treat them just the same or do we change their care team in any way?

[00:07:53] **Dr. Linda Nguyen:** That's a good question. We're learning more and more about the MOG antibody mediated disease. And so, certainly, if you have an underlying cause, certainly if you have MOG, I think it does change our outlook in prognosis and management of these kids. And so, in having an underlying diagnosis and like MOG antibody mediated diseases is important in trying to stratify patients. And so, I think when they have like an underlying cause, it helps us in terms of figuring out who to best reach out to. And so, if they have that, I think a neuroimmunologist or neurologists, is probably the key player going forward, but certainly all those symptoms management will dictate what other specialists they also see concurrently.

[00:08:45] **Dr. GG deFiebre:** Once someone has passed that initial onset of ADEM, we talked a bit about the different specialties that they might see. Does this change over time as someone goes from being diagnosed as a child into adulthood and does the medical team have to look different based on different ADEM patients?

[00:09:08] **Dr. Benjamin Greenberg:** Yeah, it's definitely different based on different ADEM patients and I'll say it's also different institutionally. There are some institutions or regions where a lot of our patients are getting care from a psychiatrist as the primary medical manager for issues related to ADEM and in other parts of the country or institutions, the primary person is a neurologist. To me, importantly, the credentials of the person, is less important than their experience and/or their desire and ability to partner up with the patient to manage whatever issues come. I did not have formal training in physiatry. I am not a rehabilitation expert, but I've been extremely lucky to have wonderful colleagues over years teach me a lot thought about rehabilitation medicine and about physiatry. So, I know enough to know when I need them to get involved and how to handle things just as I have wonderful physiatry colleagues who are wonderful at neurology and know enough on when to get us involved. And so, I wouldn't be as hung up on the background or training of the individual more than the experience and the willingness to partner up, but in general long term, either the psychiatrist or the neurologist tends to take the lead in the medical team.

[00:10:35] **Dr. GG deFiebre:** This is a question for both of you. Is there a difference between the medical teams that adults build versus for those that parents build for their children and then, children, I guess, eventually build for themselves too? I don't know which one of you wants to start.

[00:10:57] **Dr. Benjamin Greenberg:** I mean, so the respect I have for my pediatric neurology colleagues in the world is there's always at least two if not three patients in the room who are pediatric patients. It's our kiddos and then, moms, dads or whoever, legal guardians or caretakers are, for any child and there is a different dynamic in caring and different issues when caring for children with this condition versus adults, but do you think the care team is dramatically different between kids and adults?

[00:11:29] **Dr. Linda Nguyen:** I mean, I've been able to work with both the pediatric and adult team in my experience and I would say in terms of the medical, the team that is managing these patients, I don't think it's much different. You still need that constellation of people, whether it be psychiatry, be psychology, psychiatry, and both of the patients, they can have a similar sequela in terms of dysfunction and disability. So, certainly the medical team is dictated by whatever symptoms they have as sequela.

[00:12:07] **Dr. Benjamin Greenberg:** Yeah. I mean, if I had to pick only one difference when I think about our teams on the adult side and the ped side is on the pediatric side, we have a school liaison. We don't have that for the adult side. And so, that's probably the one unique area is the educational aspect. Now, on the adult side, there are occupational issues and workforce related issues that don't impact kids. So, that might be the one distinction between the two, but I agree overwhelmingly for us, they overlap quite a bit.

[00:12:34] **Dr. Linda Nguyen:** I certainly think, I mean, training at different institution, the school liaison is a unique aspect, I think to some certain institutions, some neurologists have to do it on their own to connect

with the school to help with the families and it’s I think just for a local neurologist or someone that doesn't have a school liaison that they can talk to right away, it may be just a lot more patient parents have to reach out to the school to do that. So, it's I think it's varied depending on where you are in terms of that aspect of the horizon, but it's a key component certainly for pediatric patients, making sure the school is aware of what the diagnosis they have.

[00:13:22] **Dr. GG deFiebre:** Definitely and then, Dr. Greenberg are there considerations for older adults with ADEM? For example, ADEM may not be the only medical condition they experience they can experience like a stroke or Alzheimer's dementia, what kind of doctor will give patients the best chance of distinguishing these disorders from potential brain involvement with ADEM, for example?

[00:13:49] **Dr. Benjamin Greenberg:** So, in this situation, having a neurologist who's comfortable in the space is critically important. With all respect to my psychiatry colleagues and internal medicine colleagues, when we're talking about the potential for somebody to have two overlapping different causes of pathology in the brain, it's a challenge for anyone and a neurologist definitely needs to be involved and in general, even though somebody has had ADEM it doesn't mean they can't get something else. Now of the diseases you mentioned stroke, dementia, Alzheimer's, stroke is one that's on our list. It's an equal opportunity offender based on vascular risk factors. And so, if you had ADEM at age 25, it doesn't reduce your risk of having a stroke at age 50 or 70. And so, doing all the things we need to do for prevention is true for our ADEM patients as well as everybody else our ADEM patients, it's worth noting to my knowledge, I've never seen literature that says they are at a higher risk for other neurologic diseases. I'm not aware of any study that says an ADEM patient has a higher rate of stroke or Alzheimer's than the general population, but if there were concerns later in life that you were developing other diseases, seeing a neurologist would definitely be prudent.

[00:14:32] **Dr. GG deFiebre:** Got it and then, Dr. Nguyen, how do people who are diagnosed and caregivers coordinate between medical team members, who takes on the role of that coordination?

[00:15:22 **Dr. Linda Nguyen:** That's a great question because a lot of the times they can have multiple providers and they don't really know, who to reach out to. So, I think it depends really on each patient too. Certainly, at the forefront of all of this is certainly having a primary care provider because certainly they can have other medical conditions that they need to be managed and not necessarily be just related to ADEM or occurrence of the ADEM. So, really key component is having a good primary care provider that knows the whole patient and then, certainly depending on the symptoms that they're having, if it's new neurological symptoms, having their neurologist involved, asking of their neurologist is very important if they have a worsening of some of the symptoms that may be managed by the other specialists asking them, but I think in terms of coordination of who, in terms of all their - the primary contact, I think it's always good to ask the neurologist. Like if there's a certain problem, the neurologist can also direct them to the appropriate specialty and referral.

[00:16:32] **Dr. Benjamin Greenberg:** In this process we've heard from a lot of families can be quite overwhelming. In fact, it can be a full-time job. I have gone through, in my life, loved ones who've had health issues who either needed short or longer term involvement from clinicians and even as a physician navigating the health care system and trying to coordinate care it is really challenging, even when calling in favors or help on the sidelines as somebody on the inside and whenever I've been in that situation, I always take a moment and think about just the immense challenges our patients and families have just accessing the health care system and then, once you're in getting different parts to communicate with each other in a meaningful way, is extremely challenging . And so, this is where I definitely prioritize the thoughtful compassionate listening, attentive physician over whoever the "expert" is and now if they happen to be the same, that's great, but if not having that thoughtful attentive, willing to make phone calls, willing to coordinate care, that's the person

you want to make sure is up to date on everything because having that connection, is more important than anything else.

[00:17:52] **Dr. GG deFiebre:** Definitely. Yeah, it's a complicated system and difficult to navigate even if even if you know physicians, even if you work with - if you are a physician and it's just - so not having any knowledge about how teams work together, I think about that often as well and we hear it when we talk to patients as well. So, Dr. Greenberg, what resources are available for helping someone who's newly diagnosed build a care team, should they turn to a social worker, their primary care physician to try to build the team or some other medical professional for help?

[00:18:30] **Dr. Benjamin Greenberg:** So, it's a great question and I've got two answers. So, one is give yourself time to build the care team because how you're going to do it is going to depend on the players involved, not just their credentials and their experience, but their personalities. So, if you go into it with the assumption that your neurologist or primary care physician is going to be the leader of the team, temperamentally, they may be the wrong person. So, go in willing to basically meet interview, get to know all the different players and then, decide what makes the most sense for you and your situation and secondly, from a resources perspective, the families who've been through this before are invaluable for saving you time.

[00:19:19] And so I know we're doing a podcast with the SRNA and obviously, I've worked with the organization now going on 20 years and served on the board. And so, I have biases and I admit and own my biases, but the network, the SRNA has built up for families over more than 20 years are incredibly valuable and connecting with another family who's been through it, can really help you sort through priorities in how to handle things knowing that no two patients are exactly the same. So, there may be patient specific advice for one family that doesn't apply to all, but in terms of that general approach to care teams and navigation the families are a great resource.

[00:20:11] **Dr. GG deFiebre:** Dr. Nguyen earlier, you were talking about how ideally someone would get rehab right away at the beginning stages, but realistically, I guess, what often happens is people will get then discharged to a rehab hospital or to an outpatient rehab. So, how does someone get referred to rehab following their ADEM attack and are there special considerations for picking out rehab specialists for this disorder?

[00:20:40] **Dr. Linda Nguyen:** So, certainly if they had inpatient, already started with occupational physical or even the psychiatry physician, certainly that can get continued in the outpatient setting than when if they don't. And so, that would depend on if they have adequate follow up with their primary care physician and the neurologist to make sure that whatever means they require, they get that referral. And so, I think it's following up and how the patient is doing. Certainly there's, different aspects of physical therapy, there's different aspects of occupational therapy and speech therapy and they all work on different things too. And so, trying to figure out what you need is also important to determine what services are continued.

[00:21:35] **Dr. GG deFiebre:** Thank you and then, Dr. Greenberg, once rehab starts, does a person's care team change at all?

[00:21:43] **Dr. Benjamin Greenberg:** Yeah. So, particularly on the inpatient side, when somebody moves from an inpatient hospital where there's a neurologist, a hospitalist, an intensivist, a whole variety of specialists once you move to the rehabilitation setting, the team overwhelmingly is focused on physiatry, and rehabilitation medicine and the physiatrist takes the lead and works with a team of physical and occupational and speech language, pathologists, and therapists. And so, the care team changes while in the inpatient setting, but then zooms back out when people discharge to home, and I will say it's important. So, if there's any family

listening to this who's on the inpatient side right now and is sorting through a new diagnosis of ADEM you want to start working with social workers on the hospital side to identify options for inpatient rehabilitation.

[00:22:38] When the decision is made to discharge to inpatient rehab, it goes very quickly and you really want to have looked through with your insurance, with your region, with travel options what is going to be the best fit for you and for your loved one, yourself or your child. Because, once you get into an inpatient rehab facility, it is essentially impossible to transfer to another inpatient rehab facility. So, if you get discharged to A and you realize after the fact, "Oh, I would have liked to have done B." It's not happening. And so, really, it's never too early in a hospitalization to do discharge planning in terms of where you want to go for that rehab.

[00:23:19] And then the last thing I'll say on this is having conversations with your insurance early about rehabilitation benefits is very important because most insurers will limit the number of days that somebody can do inpatient or outpatient rehab and you may want to have conversations with them about what deals you can strike to maximize those days and how you can leverage them over time. And so, it's a resource, it's an asset, it's a finite asset that you're going to use, and you have to look at the calendar and figure out how do you make it last for as long as you or your loved ones may need.

[00:23:56] **Dr. GG deFiebre:** Okay and in my experience is never as much as it needs to be, basically, just in talking to folks and personal experience so, but Dr. Nguyen is occupational therapy, something that is recommended and if so, what are some of the goals that ADEM patients should have in this type of therapy?

[00:24:22] **Dr. Linda Nguyen:** So, in my view of things, physical therapy is more the whole body, walking, mobility and strength of the limbs, but the occupational therapy is more for motor function of the hands and use of the hand function by motor control. So, it certainly if they have deficits there, occupational therapy is very helpful and what do you think in terms of occupational therapy? Is there a distinction between the different specialists for therapy?

[00:24:55] **Dr. Benjamin Greenberg:** No, I agree with you completely and occupational therapy really is integrating not just upper extremity work, but activities of daily living and the basics that with all due respect to myself and physician colleagues who aren't in rehabilitation medicine, we don't think about. How am I going to move from my wheelchair to a car? How am I going to put on my seat belt and maybe I only need the wheelchair for a couple of months because I'm learning to walk again, but I got to get in my car during those couple of months and how do I take a shower safely? How do I get dressed safely? How do I tie my shoes if my hands were affected and just those activities of daily living and occupational therapists are just a wonderful group of professionals who aren't just there to help people recover, but they're there to help people problem solve how to get through the day functionally.

[00:25:46] And one of the things I got frustrated about early on in my career was I was very optimistic, hopeful, pushing every patient and every family towards recovery, recovery, recovery, restoration of function, restoration of function that I forgot early on that while pursuing that goal of improved function you still have to function today with whatever deficits are there. And so, while I'm not asking my patients to accept their current state, they do have to adapt to their current state and an occupational therapist goes a very long way at helping people adapt to their current state while working to improve function. So, they can be a critical group for a lot of our patients.

[00:26:32] **Dr. GG deFiebre:** Yeah, that's exactly what I also tell people in terms of figuring out, that that balance between figuring out how to live currently now to get through the day, get yourself dressed, learn how to brush your teeth, those important things while also striving to get stronger and potentially regain function.

There's that balance there, but it's an important one and occupational therapists are great at helping figure that out too. So, in addition, is there a need for psychiatric care or therapy to help manage the emotional, potential emotional strain of being diagnosed with ADEM? Is this something that you recommend to those who've been diagnosed with ADEM, Dr. Greenberg?

[00:27:14] **Dr. Benjamin Greenberg:** Yes, I guess you want a longer answer.

[00:27:16] **Dr. GG deFiebre:** Yes.

[00:27:18] **Dr. Benjamin Greenberg:** So, I'm making it a finite answer to make the point that there is not a human being on earth who can get punched in the face by something like ADEM and not have some need for help in coping skills. It's a biologic fact. It has nothing to do with how strong somebody is, how emotionally healthy they are, it has nothing to do with their faith. It is a biologic certainty that this unwanted, unwelcome guest of ADEM is going to push people in ways emotionally where they're going to need an objective third party coach to help them with the coping of getting through this and it can't be a mom or a dad or a sister or brother or a husband or wife or significant other or teacher. It really needs to be a trained individual.

[00:28:13] Now, whether it's a psychologist or a licensed therapist, all sorts of wonderful professionals to fill the role of a counselor to help manage and I will push that people should be early on aware that the emotional strain that's caused I refer to as demoralization, not depression because in those first six months after this punch in the face being upset, being sad, being frustrated, being angry are appropriate emotional responses to the situation. So, it's not depression. There isn't a role for an antidepressant there if you're really upset and crying. The first few weeks after this happens, I would be too, that's called normal, but if six months or 12 months after it's happened, the coping skills hasn't caught in and everything is sad all the time, that's when psychiatry should be involved to say, has this changed from a demoralization to a true depression, but having that help early on should be a standard.

[00:29:21] **Dr. GG deFiebre:** Got it and then, Dr. Nguyen, so behavioral issues can be a sign of relapse in those with ADEM from with MOG antibody disease, what are the ways in which people who are diagnosed with ADEM can work with mental health professionals on their care team to be aware of these signs and I think also just in general, what health care professionals are working with those with potential behavioral issues for specifically children with ADEM?

[00:29:55] **Dr. Linda Nguyen:** So, that's a great question, but in terms of what we think about behavioral issues related to possible recurrence, I would have to say that these behavioral issues are extremely out of the norm for the kid and it would be something persistent and be different from their usual day to day tantrums or agitation and usually it would be also accompanied by perhaps confusion or lethargy or drowsiness. So, certainly there's a distinction there in terms of behavioral symptoms causing as a signal for relapse, but in terms of symptom management, I think certainly in the pediatric world, we have to think about the patient and the parent in terms of talking through and making sure each person understands what's, the underlying cause.

[00:30:56] And sometimes it's hard to talk to the pediatric patient to figure out what symptoms they're having to understand, why they're agitated, why they're depressed. So, I think it's very important to connect with the family too. So, not only having a psychologist, but perhaps if - not sure where I'm going with this, but perhaps making sure like the family understands and if there's any disconnect in the family, it's stressors in the family and that's affecting the patient too. That's also addressed, but, in terms of the management, I think it's very important to connect the psychiatrists early on. It's hard to start medications from a neurologist standpoint if they need medications for psychiatric care.

[00:30:12] **Dr. GG deFiebre:** Got it and then Dr. Greenberg for patients with relapsing ADEM due to MOGAD, are there precautions that should be put in place to ensure that possible changes in behavior are thoroughly investigated to rule out relapse before a psychiatric cause is determined? If MRIs are negative and the change is sudden, should a patient have a doctor on board willing to reevaluate in a month or two with an MRI or how would you approach that situation?

[00:32:24] **Dr. Benjamin Greenberg:** Yes. So, I think it's important to note in my experience, a patient with anti MOG associated ADEM having a behavioral change would actually be an unusual presentation of a relapse. So, I definitely want to set the stage. This is not a common issue. So, most of our patients with anti MOG associated disorder, the relapses will either be myelitis or more commonly optic neuritis and Dr. Nguyen spent a lot of time looking at our cohort and in your review of our cohort to my recollection of behavioral change as a prelude or sign of a relapse. I'm trying to think of one that we had. I'm not thinking of any. And so, I know there's a specific question here, but I just want to set the foundation. This is a very rare event.

[00:33:09] So, to broaden out the question a little bit, if somebody's ever aware that a child is having a relapse, new inflammation, an MRI is indicated. So, let's just start there. So, whatever the symptom is, whether it's a walking issue, a vision issue or in this example, a behavioral issue, an MRI is indicated, an MRI is an extremely good, not perfect, but extremely good test to look for new inflammation if it's a high-quality MRI and you take a picture of the right thing. So, if somebody's having walking issues and you only do the brain and not the spinal cord that doesn't count as a complete MRI. So, it has to be context specific, but assuming you have an appropriate MRI, that's good quality that's negative and a child is having behavioral changes, I'd be treating it as a symptom and not as new inflammation.

[00:34:00] And I do want to remind all of our families that children's brains are evolving over time and when MOGAD or any other condition causes ADEM, we change the arc of development. So, the brain may have been doing this and now it's going to do this and this and this and take a different turn and our children's emotional development is going to change being critically ill in the hospital. So, we see this and I'm sure Nguyen in your residency exposures to pediatric oncology patients, no brain involvement. So, a child with lymphoma or leukemia, there can be behavioral issues after they go home and after they get treated because the trauma of being in a hospital is a big deal. And so, there are a lot of reasons for behavioral changes that need management from the family side and perhaps from the therapist side, independent of new brain inflammation and I would argue more often than not, it's that and not new inflammation.

[00:35:06] And just to tell one funny story, one of our patients that we both know, but before you got here, she had had ADEM as a very young child and then, a couple of years after she was doing well and developing, and she and her family came to the clinic and her mom's there and I'm getting caught up. I said, "How are things going?" She said, "Not well." I said, "What's wrong?" She said, "She's fighting with her sister all the time. She's a very picky eater. We have to argue about bedtime." She goes on and on, and I said, "So, you have a normal five-year-old?" She goes, "Oh, I have a normal five-year-old." So, there are a lot of behavioral issues that just happen with development that have nothing to do with MOGAD or ADEM.

[00:35:45] **Dr. GG deFiebre:** That's a really good point. So, as in terms of children going back to school, we talked a little bit about this once they're ready to go back to school after an ADEM diagnosis, how does their medical team coordinate with educators to get the child in a learning environment suitable for their needs, Dr. Nguyen?

[00:36:07] **Dr. Linda Nguyen:** So, this is a great question. So, this is really where the school has to - we have to step in, the school has to step in, the parent has to step in to make sure that the patient in terms of their

academic needs are met. So, this is the best way to do this is try to have an individualized educational plan or a 504 set in place for these kids and to get that started, it requires asking the school to get a neuropsych evaluation for these patients to see where their deficits are so that we can best optimize their learning strategies. And so, making sure that the school is aware that they have this diagnosis and their needs dictated by the neuropsych evaluations.

[00:36:58] **Dr. GG deFiebre:** All right and then for adults, Dr. Greenberg, if adults are unable or - sorry, if adults are able to work after their diagnosis, but have to work with some modification, what's the role of the medical team in helping them communicate reasonable adaptations to an employer? How does that work?

[00:37:17] **Dr. Benjamin Greenberg:** So, just like for children with an IEP or 504, there are federally mandated approaches to workplace modification to enable individuals to stay employed and stay in their position and adaptations can be allowed at work in order to keep somebody employed. There's a trick to it. However, so you do need a physician involved often a physiatrist is excellent for this often they have much better training and experience around it than neurologists. And so, on the adult side, while a neuropsychologist might take the lead for the pediatric patient, a physiatrist probably at the top of the list for workplace accommodations, but the caveat is, it's really important for the adult for the patient to bring a very good description of their job duties and the environment because it needs to be personalized to what the expectations are around job performance.

[00:38:18] So, if somebody has an office based rather sedentary desk-based computer interface work where their deficit is vision; their adaptation might need to be large screens or text to voice software or something along those lines. Whereas if somebody is working outdoors and they're a power line technician, they may need very different accommodations. And so, you will enable your psychiatrist or neurologist to make good recommendations based purely on that job description coming in. So, come prepared so that your adaptation recommendations are best suited for you.

[00:39:06] **Dr. GG deFiebre:** Got it and then if someone is no longer able to work, whether that's temporarily or more long term, what's the role that the medical team plays in helping them get the disability support they need? Is it similar to what you just described and what's the best way to get them help in a short period of time?

[00:39:24] **Dr. Benjamin Greenberg:** This is hard. So, even though patients will clearly qualify for disability benefits, whether it's through a private insurer through Social Security disability benefits, there are lots of obstacles to getting approved. So, first and foremost, you have to communicate with your practitioner, particularly your neurologist and physiatrist that you do not feel as though you can meet your job expectations that you do not feel as though you are able to work in any capacity and the reasons why and then, they, your practitioners need to do assessments and document very carefully in the note, the medical notes get read very carefully around this issue on why that practitioner feels as though you're unable to work and even then, you are likely to get denied the first go round and will have to go through an appeal. It's at this point that considering getting a disability attorney is often worth the investment because they know the system and what needs to happen in terms of evaluations in order to get appropriate coverage from a disability perspective.

[00:40:34] I know you asked a way to get them help in a short period of time. I don't know about the short part of that, but in some period of time, working through the system is important. I will tell you at our clinic at UT Southwestern one of my colleagues, a PA named Crystal Wright, who's been in this space for many years and is very good in neurology and ADEM and myelitis and multiple sclerosis. She does a day a week disability clinic where all she's doing are disability evaluations for our patients. And so, they bring in their job descriptions and either modifications or disability. I should say it's all of it, but it's a very employer focused

assessment where she can go muscle group by muscle group function by function and say can or can't the person remain employed, and those types of evaluations are invaluable for navigating the system. And so, asking your psychiatrist or neurologist, if there are any of those services around is a worthwhile thing to request.

[00:41:34] **Dr. GG deFiebre:** Definitely, that's great that that's available there. So, the last two questions are for both of you. So, the first one is how does care of an ADEM patient look five years down the line and 10 years and beyond and does this differ based on if someone has the MOG antibody or not with an ADEM presentation?

[00:42:00] **Dr. Benjamin Greenberg:** What do you think five, 10 years down the line?

[00:42:04] **Dr. Linda Nguyen:** I think in terms of pediatric patients, they're still developing their brain is still maturing. So, if they have an early hit early on, we want to continue to follow these patients, five years, even 10 years down the line, looking as they go through their schooling years, sometimes what we find is they have a hit at three years old and they're doing well, they have full recovery, but as their schooling gets more challenging, then we see them get more cognitive problems or more difficulties academically so, just trying to look at that as they grow and develop and face further academic challenges, thinking about that process and seeing if they can continue to get help from both their neurologist and/or the school for pediatric patients.

[00:42:58] **Dr. Benjamin Greenberg:** And that notion of growing into the deficit for a pediatric patient, we tend not to see on the adult side since we've already gotten past that development and educational stage that's different than a child. And so, in general, we see stability or improvement over time. I cannot think of a single ADEM patient I've taken care of who had a decline regression or degeneration later on. And so, what I tell patients is I'm not worried about this getting worse, it's a question of how much better does it get and a lot of that is dictated by the severity of the illness the parts of the nervous system that were affected and then, the rehabilitation that people do afterwards and how consistent they are and over how long a period of time they're consistent in that rehabilitation, but I tend not to see it get worse just the same or better. And in the setting of diseases like anti MOG associated disorder that holds true as well. With the one caveat is, has been mentioned, we're just making sure there aren't new events as people go forward.

[00:44:03] **Dr. GG deFiebre:** Great and then any final comments on the importance of assembling a great team for ADEM care initially and beyond?

[00:44:13] **Dr. Benjamin Greenberg:** I would make two comments. So, one is the - as I said earlier, the person is more important than the credentials. So, if there's a - often people are looking for an expert neurologist to lead their team. If you have a caring, compassionate, engaged, communicative PA in your primary care office who is very invested in your care and willing to network and coordinate, they are the most important person to your care team and I have nothing but respect for that individual, but the best clinicians are the ones who are willing to coordinate and collaborate and it's not based on what they come to the table with in terms of given knowledge. So, that's critical.

[00:45:01] And the second is to realize, no matter how wonderful or not the members of your care team are, unfortunately, a lot of this still falls to the individual or the families. It's important to be educated. It's important to be up to date and it's important to learn a communication with your health care providers that enables a healthy exchange of ideas and not defensiveness or dismissal. Your clinicians may know nothing about ADEM, and we don't like that feeling as clinicians. We got into medicine to help people, to serve, to make a difference and when a patient shows up and they have something, I have no idea what it is, I leave the office feeling bad about myself and the job I did. The key is saying, "I don't know, but I'm going to try and get you to somebody who might," versus, "I don't know, goodbye." Those are two very different things. And so, trying to

find a way for families, trying to find a way to communicate needs in a way that engages and collaborates with, and cooperates with, and gets clinicians to cooperate with them in their journey is extremely important.

[00:46:15] **Dr. Linda Nguyen:** I think one thing I would add only to that, in addition to having a caring physician and all that, it's okay to ask for a second opinion. So, certainly if you're not satisfied with whoever is taking care of your kiddo or your parent or your sibling, whoever it is, it's okay to ask for a second opinion at a different institution, a second member, in the same institution, et cetera. We're okay with that. We're happy to coordinate that as well.

[00:46:47] **Dr. Benjamin Greenberg:** And if somebody says they don't want you to have a second opinion, that's always a bad sign. So, if somebody says, “Well, if you're going to get a second opinion, I can't be your physician anymore or your health care provider anymore,” say, “Okay, thanks.” They've just told you they're not the right person for you.

[00:47:02] **Dr. GG deFiebre:** Yeah. As a non-physician, I very much appreciate when physicians are willing to say what they don't know because to me that indicates the willingness then to get another opinion or to let - that's incredibly important. So, it's good to hear both of you say that and give this really important advice to our patient community. So, thank you both so much. I really appreciate it and I appreciate it on behalf of the ADEM community as well. So, thank you.

[00:47:37] **Dr. Benjamin Greenberg:** Thank you. Appreciate it.