Rehabilitation and recovery in rare neuroimmune disorders

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[00:00:00] **Dr. Jacqueline Rosenthal:** I'm Dr. Jackie Rosenthal, I spoke with you all earlier. But we're talking about rehab today, which is so important. Obviously, we've talked a lot about diagnosis and treatment, but after someone has had that initial diagnosis and has had their initial treatment, there's still residual symptoms that you're dealing with, right?

[00:00:25] What do you do about that? Any improvements that we achieve in these situations really are going to be accomplished through your body getting the chance to heal itself as best as it can. But we know that's an imperfect process, and so other improvements really are going to be accomplished through rehabilitation.

[00:00:45] So I'm excited to be up here with my colleagues today from Shepherd Center. They're going to introduce themselves and then tell you about each of their respective therapies and what they do.

[00:00:57] **Jasmin Brumby Smith:** Hello everyone. I'm Jasmine Smith. I'm an occupational therapist.

[00:01:05] As an occupational therapist, I am working with my patients to get them as independent as possible with their everyday activities and skills. That can be through strengthening, it can be through adaptation, or it can be through education. Giving them all the information they need to be as independent as possible, and that can look different for so many people.

[00:01:28] I personally work with multiple sclerosis, so we are looking at activities of daily living, how well you bathe yourself, dress yourself, do your grooming skills, what makes you feel good to start your day. And then we look at sleep, we look at bowel and bladder, we look at organizing your way through brain fog.

[00:01:47] We look at vision, which is really important and something that a lot of people who are diagnosed with MS struggle with. And then we also look at overall wellbeing. How can we get you to be confident to go through your day? And obviously with occupational therapy, we do focus on any symptoms that come from hand instability, so coordination, dexterity and sensory awareness or sensory deficits that also may arise.

[00:02:13] **Quincy Whittle:** My name is Quincy Whittle. I'm a speech language pathologist. I also work at the Shepherd Center with these great people. As a speech therapist, what we work on is communication skills, so that’s speech and language, also cognition, so that's brain function, attention, memory, problem solving, and then swallowing. And we do all of that through different ways. With swallowing, we can work on muscle strength, as well as if you have some speech deficits, we can work on muscle strength and speech intelligibility.

[00:02:45] Cognition is going to be a little bit more intricate, with strategies and working on time management, looking at schedules and to-do lists and trying to help your memory, trying to help attention skills through that aspect. And that's speech, swallowing, and cognition.

[00:03:06] **Dr. Jacqueline Rosenthal:** Before Brian gets started, I think he's going to talk about physical therapy, but when we think about rehab, I think we first think about physical therapy a lot of the time, and a lot of patients and clinicians don't realize how much our occupational therapists and speech therapists do.

[00:03:22] There have even been patients where we refer them to speech therapy, and in my mind it's for cognition. And maybe I didn't fully explain that. And they get called and they're like, “Speech therapy? I talk fine. I don't need the speech therapist.” I'm like, “Just wait. You’re going to love it.”

[00:03:37] They do so many tasks that are so meaningful to just the day-to-day quality of life, which ultimately is what we're trying to enhance for our patients.

[00:03:46] **Brian Smith:** Thank you. I'm Brian Smith. I'm a physical therapist. As Dr. Rosenthal said, that's what most people think about with therapy.

[00:03:52] On day one, when I'm meeting people, because I work with such a great team, I'm always screening for these cognition and other difficulties that people are having so that I can really divide and conquer. I’m really blessed to work with the team. You should be blessed to work with a team that can cover all of those needs.

[00:04:14] As a physical therapist, I'm focusing on the building blocks of strength, endurance, range of motion, coordination, [and] putting those together to work on balance and mobility. Primarily walking or standing balance tasks but also working on transfers. We're working on your independence from getting in and out of a chair, getting in and out of bed.

[00:04:37] I specialize in dizziness, so the vestibular system and how that relates to function. And then all the assisted devices that go along to help with mobility, whether that's bracing or different walkers or mobility devices or different chairs or functional devices to help with some of that mobility.

[00:04:57] **Dr. Gabriela Bou:** Can you all tell us a little bit more about what recovery looks like from each of your standpoints in these diseases?

[00:05:09] **Brian Smith:** For physical therapy, I think about recovery of function. How can we help you recover lost function or maintain function? That might be, like we talked about with the transfers, with getting in and out of bed, with your sitting balance, standing balance or walking, anything along that spectrum.

[00:05:32] We really try to identify patient-specific goals, what's important to each person individually and then talk about where we are currently through our initial assessment. And then the recovery really is, how do we work on getting back to those goals or maximizing that functional independence.

[00:05:54] **Quincy Whittle:** The same for speech. Most of my patients are coming in, and there is some adjustment to the diagnosis, there's some adjustment to change and how life is now. Also from a speech therapy standpoint, sometimes I'm the first person they're talking to about any kind of work-related issues.

[00:06:14] At Shepherd Center, we're really fortunate that we have a vocational rehab department that we work really closely with. We also have neuropsychologists that we work with, so I can tap into them, and they can help me also to give a much bigger picture of what's going on for the patient and then help them to be tailored to what they're really looking for, if it's work related, if it's home related, if it's just “I need to get up out of bed every day because I'm not doing that anymore - how do I get to that?”.

[00:06:41] And it's just helping the patient to make goals that are achievable. And each week that they come and see me, we are working on new goals and hopefully building on what we've already done.

[00:06:54] **Jasmin Brumby Smith:** I feel like they really touched on what recovery can look like. And what I can add is that if someone comes to me and they may have been newly diagnosed and they are maybe going through a flare, then I look at “What can't you do?

[00:07:06] What does your current function look like?” Then I help them try to figure out what accessible items you need. Do you need a tub bench now? Do you need a railing for your bed now? Do you need certain things to change in your kitchen so that you can maybe do things that are very low risk by yourself? I look at that. Yes, you're recovering, but in this current state, how can I make you the safest?

[00:07:34] **Dr. Jacqueline Rosenthal:** And I'll add that I rely on the team. We talked earlier about what's a relapse versus this concept of a pseudo relapse, whether even if it's not a new lesion or new inflammatory disease activity, if there's been flu or COVID or some sort of insult that has a patient maybe take a few steps behind, sometimes it is hard to get back to that previous baseline.

[00:08:00] And so we depend on them as well to help re-establish that. I had another thought - it escapes me. It'll come back after someone else starts talking. Happens to everybody, right?

[00:08:20] **Brian Smith:** I guess one other quick thought on recovery. Sometimes when I'm talking to patients about recovery, if their goal is to walk again, but they haven't walked in five years, it's really a discussion about what is the underlying reason for that, [such as] “I want to be able to get to my grandson's baseball games.”

[00:08:43] Recovery is the functional purpose of what is the real end goal and how do we get there? I have some people that are adamant that they don't want to use braces, but if we can use braces and that improves your walking, that gets you to your son's grandson's baseball game, that really is the goal, the functional recovery.

[00:09:08] Other people never want to use a chair because that's giving in. If the goal is to get to your son's baseball game or whatever, and we can use some of these substitutions and compensations, it doesn't mean that we're not going to work on walking or standing but [we're] really trying to identify what is most important.

[00:09:29] For some people, what's most important really is walking. Then absolutely, we're going to walk for the purpose of walking, but if we can identify the why, maybe that helps broaden our view of what true recovery might be, recovery to some of those activities that you can participate in that really make life meaningful.

[00:09:50] **Dr. Jacqueline Rosenthal:** I remembered, I just needed two seconds. I was going to compare what we do. At Shepherd Center, we have a lot of spinal cord injury, brain injury, and our patient population really is different. And it's not necessarily a one-and-done with rehab. Our patients reengage frequently.

[00:10:08] They do check-ins. We want everybody to try to incorporate what they learn in rehab on a day-to-day basis. That's helpful because as someone living with symptoms like what you can experience, it's difficult to know what that looks like in terms of maintaining activity and exercise routines because it's very individualized.

[00:10:29] But regular check-ins are something that we do frequently. They'll check in with each one of [their therapists] and address any symptoms, because goals may change over time as well.

[00:10:38] **Dr. Gabriela Bou:** What do you think is the general timeframe that patients should expect in terms of recovery of function [and] rehabilitation in these neuro immune diseases?

[00:10:47] **Jasmin Brumby Smith:** I can go first with that one. When I am seeing a patient. I am probably seeing them for six to 10 weeks. In that amount of time, if I'm working on strengthening, I will probably see a really good start at strengthening, but in those six to 10 weeks, I probably won't get you as strong as you can be or what your potential is.

[00:11:07] I always tell people, continue working on these skills that you gain in therapy for six months to a year. At that point you can determine - in three months you'll say, okay, I think I'm feeling some sort of a difference, then at six months you can be like, okay, wow, I really have a hang of this,

[00:11:23] I'm noticing that things are becoming easier, I'm doing things quicker. And then at that year mark is where you feel really confident, you see a change. I always give people three things that are very hard for [them] right now. And I tell them when they do those tasks, think about how it feels at three months, at six months, into a year.

[00:11:41] Then by that year mark, I feel like you should be confident doing these things. You should be safe doing these things. Maybe you've progressed in what accessible device you use, or maybe you don't use one at all. But I always tell people, give yourself six months to one year to see the skills and all of the work you've put in really at its max potential.

[00:12:04] **Brian Smith:** Whenever I get this question, I always think it's the crystal ball. Our systems are so unique, and our injuries are so unique that it is really hard to give a specific answer to any individual person. But I think what Jasmine hit on is absolutely right. To get those changes,

[00:12:22] it does take a long duration of consistency to get that neuroplasticity, to get our nervous systems to adapt, but also to get our muscles stronger, to improve our range of motion, all those fundamental building blocks. I think what often happens, because we're limited in what insurance will allow, is that people will come to therapy, will get on this road to starting the recovery.

[00:12:49] Really therapy is to give people the tools of recovery, but the real recovery comes with that daily implementation and that consistency across several months. Too often because of life challenges, it's hard to keep that consistency. Then we fall off and we see people six to 12 months later and we get going again.

[00:13:13] Maybe that's better than just this functional decline every six to 12 months, if we can keep this maintaining. But ideally the recovery would be learn the tools, implement the tools, and then continue it after formal therapy, [for] that continued recovery.

[00:13:34] **Dr. Gabriela Bou:** I think you've all done a great job of touching on and going into some of the things that you specifically do as part of physical therapy, occupational therapy, speech therapy. Are there any additional things that you want to add so that patients have a good idea of what are the differences between them and some specific goals that you have in each of those types of therapies?

[00:13:58] **Dr. Jacqueline Rosenthal:** I'll say in terms of goals, what I would recommend especially for anyone who is hesitant is, don't knock it till you try it. At least give it a chance. And I would even add as an asterisk that there's a lot of variability between the therapists that you may see in terms of their experience with multiple sclerosis or NMOSD or MOGAD or transverse myelitis or this whole host of potentially chronic neurologic diseases. So if you've been to one, you've been to one, and it is worth getting opinions from other people.

[00:14:36] **Jasmin Brumby Smith:** In occupational therapy, I'm very symptoms focused. No matter what the diagnosis is, if you come in and you tell me what your symptoms are, then that's where I like to start.

[00:14:49] I typically do see people coming to me who have lost their hand function - they have poor sensory awareness, they have numbness and tingling, so it makes them drops things, it makes them fumble things. They have poor coordination. They tell me, “I really have to think hard to do this one task with my hands.”

[00:15:07] So I'll start there. Then through a comprehensive evaluation we'll pick out some other areas that may also be symptoms, but they maybe have put those to the wayside because their hand function is the biggest barrier. So, I'll look at bowel and bladder. We do address that.

[00:15:24] We look at vision. Sometimes patients come in because they talk about vision, and then we see they have other symptoms that are there. But [I’m] just very symptom focused. When they tell me what their symptoms are, am I looking at strengthening? Are we at a point where we just need to adapt to that task?

[00:15:43] Are we at a point that we need to get someone to help us with it because it's going to be the safest? Because I'm all about safety as well. When someone comes to me, it's us looking at what your symptoms are and then it all goes back to what are your goals and how can I have you be as independent as possible with those goals. But safety, symptom management, and getting you confident with completing your goals.

[00:16:10] **Dr. Gabriela Bou:** I think we can move on to some questions from the audience members now. Does anybody have a question?

[00:16:15] **Audience Member:** Hi. I have noticed that I was doing so good with everything, therapy, I was able to exercise. And then I got COVID, I got my mom's disease, and everything was a mess. So, I start declining, declining, declining. The fatigue is something that I cannot manage. I can't, I can’t. And the tolerance for exercise is just down and down. I even bought a small machine to walk.

[00:16:52] Five minutes is the most that I can [do], and it's pretty much no elevation, and it's probably two. And before those things happened to me, I was at three or four miles, and I was walking up, walking down. And now the fatigue and the tolerance is just so bad. And I'm trying, I'm really trying to go, and I'm trying to have a schedule because I work from home.

[00:17:26] And I'm glad that I can work from home because I can be in my pajamas and nobody's going to see me. And if I have to show up, I just put something on, and that's it, I'm here. But the fatigue is something that is really bugging me, and I don't know how to deal with that. I ask and I ask, and the answer is always exercise, exercise. But how am I going to exercise if after five, 10 minutes I'm out of breath. I'm just [panting], how can I improve that, please?

[00:18:05] **Brian Smith:** I'm sorry for the challenges you're having right now. That's a real problem that a lot of people face as well, especially with post COVID, it really does a number on our bodies. Then you pair that with some of these neurological challenges as well, that neurological fatigue can really be difficult.

[00:18:28] When I first started as a therapist, it was very much three sets of 10 when I'm doing my strength exercises or 30 minutes a day for my cardiovascular endurance. As I was starting to learn more about some of these neurological challenges and the neurological fatigue, one of the clinicians for one of the courses that I was in said, “We always do three sets of 10.

[00:18:55] Why don't we do 10 sets of three?” At the end of the day, we achieve the same number of repetitions or that same challenge, but we're allowing ourselves to have breaks in between. I think with that neurological fatigue, that's really important. We do have to stress the system for it to get stronger, for it to get better. To push our endurance, we have to get a little bit winded, maybe a little bit fatigued, but if you start, crash and burn, then you're just crash and burn.

[00:19:27] So really allowing those breaks. And if you have the blessing of working from home, if you can do five minutes, if you know 10 minutes is exhausting, do five and then later do another five. Try to tweak it to where you can have those recovery breaks to let your system have a little downtime.

[00:19:49] **Jasmin Brumby Smith:** Something to add to that. A big thing that we harp on is energy conservation. There's five Ps of energy conservation - pacing, prioritizing, planning, position that you're in, and power adaptive devices. When you tell me that you have that neuro-fatigue, which is very common in this diagnosis,

[00:20:13] I would say plan. Like you said you have a schedule. I would plan the times that you want to exercise, and then as you plan, you're going to plan in the breaks that Brian talked about, planning in breaks. Then you want to pace yourself, making sure that instead of just “I need to get five minutes because I used to be able to do ten, I want to get five minutes”, pace

[00:20:35] that five minutes, like Brian said. You can make that five minutes look however you want to. Do I want to run or walk for one minute, take a break for two minutes, walk or run for one minute, take a break for two minutes? So pacing, planning, and then prioritizing, figuring out how do I feel right now?

[00:20:53] Should I prioritize a break, or can I continue to do my exercise? Just thinking about how you can really work in that energy conservation so that instead of going really strong and feeling good for 30 minutes, when you implement these strategies, then maybe you can feel good for two hours. We want to try to extend the amount of time that we feel really well by conserving that energy and using it wisely.

[00:21:20] **Quincy Whittle:** I just want to add one thing I did not mention when I was talking about speech therapy. My practice also involves a lot of respiratory strength training that we speech therapists are working on because you need respiratory strength, a good exhalation for speech and swallowing.

[00:21:34] In my practice with MS patients and working with my team, I have realized that it is so important for that exercise, for that endurance, for you to build up that strength again. If you're post COVID, we neglect our diaphragm. I haven't had one patient come in my office yet that really understood diaphragmatic breathing.

[00:21:54] So I'm doing a lot of teaching on that so that you can learn, relearn, or learn again how to use what you have in your body that can help you have that strength and endurance that you're missing out on. For my patients, particularly with MS, that neuromuscular component, if you are less mobile than before, you're not exercising as much before, you're using a rollator or in a wheelchair, we're not using our core strength like we should be. So, focusing on that type of breathing can really help as well.

[00:22:28] **Dr. Gabriela Bou:** I think we have time for one more question.

[00:22:31] **Audience Member:** It's not so much a question as probably a related topic that doesn't seem to ever get discussed, and that's the physical deterioration of the caregivers.

[00:22:44] **Quincy Whittle:** Very good [point].

[00:22:47] **Jasmin Brumby Smith:** A big part of occupational therapy, and I think actually all of our professions up here, all of our disciplines, is that we all do work on family training because sometimes it is forgotten about. The patient or client comes in, we treat them.

[00:23:04] Since we're so focused on symptoms, we don't stop and think about: I know if you are struggling with this with me here, only imagine how it looks like the rest of the 23 hours that you're at home. I always try to bring in family training into my sessions and ask: “How does this look at home? What are you doing?”

[00:23:25] So that I can look at body mechanics, I can show them or teach them what adaptive equipment we have to make something easier. Because we definitely want to decrease that burden of care on the family member as much as possible. If you are getting therapy, I would make it a goal or just remember to ask, “Can you please help us so that this is easier at home? This is my caregiver.”

[00:23:50] So, we can see what your caregiver looks like and what we think they may want help with. Even if they don't know how to ask it, even inviting [the caregiver] into therapy sessions to realize, “Okay, you're doing this here. Oh, that reminds me, something at home looks really different. Can you help me with this?” So definitely keep that open line of communication.

[00:24:08] **Brian Smith:** I am grateful for amazing families and amazing caregivers. I know some of you out there have amazing families and amazing caregivers. It really is a definite team approach when, like Jasmine was talking about, we're doing therapy, trying to teach them the right body mechanics, teach them some good self-care as well.

[00:24:30] The caregiver, if they're in a better position physically, mentally, emotionally, spiritually, all these areas of wellness, that benefits the person as well. A lot of family training and education. If you have a caregiver and you're in therapy, invite your caregiver along. They will learn some things that will benefit you as well.

[00:24:54] **Quincy Whittle:** One more thing to add. I think maybe we're really fortunate at the Shepherd Center to have some of the resources that we do. When this particular kind of request or suggestion or, I wouldn't say complaint, comes to mind in my office, we have case management that can help because there are resources out there too for caregivers, a lot of times through the organization or through your insurance company, that can help with having an extra caregiver come in to give you a few hours during the day.

[00:25:30] I recently had a patient whose husband really wanted to go play golf on Saturdays, and he couldn't leave her. So, we're trying to figure out a way for him to have his life too, because he deserves to have that positive aspect in his life. So trying to find ways to go about doing it, having some help for you.

[00:25:46] **Dr. Jacqueline Rosenthal:** And I would just encourage, just briefly if maybe you're not plugged in with therapy, just talking with your neurologist as things change, maybe the abilities of the caregiver and the care partner has changed, the needs are different, to bring that up with your neurologist so that you can get that conversation started and get linked in with the appropriate resources to try to get some help.

[00:26:13] **Dr. Gabriela Bou:** Let's give a round of applause for our panelists.