

Building a health care team

You can view this presentation at: youtu.be/9Uh8tVB9VOk

[00:00:04] Dr. Grace Gombolay: I know it's just a couple of minutes after 1:30 I just want to make sure everyone's here for track two. The first session is about building a health care team. My name is Grace Gombolay. I'll be talking about that and happy to take any questions and comments. I know there's a question and answer session at the end, but I think that we'll definitely have time during this 20 minutes of talking about it, because I want to make sure that all your questions, concerns, strategies, and I also definitely want to hear from the group, because I feel like a lot of us have gone through this before and then they have come up with other strategies and other techniques that may have worked. I think we talked about a few things in the session yesterday, which I'm happy to go over again. But this is definitely really important is having a team, so not only a health care team, but just your support team outside of what we consider in health care.

[00:01:00] With no further ado, I don't have any fancy PowerPoint slides or anything today. I'm just going to go off of this handout that you guys have. Feel free to take notes and like I said, feel free to interrupt me as I'm going through with questions and concerns were trying to make this pretty informal talking about each of these issues as we move on. Okay, let's start off with the beginning. A lot of people hopefully have a primary care provider or PCP or in my case I see a lot of children so they should have a pediatrician. And the idea for a primary care or pediatrician is that their general practitioner. Sometimes they can take the role of being able to coordinate your health care team, identifying issues or health problems that you're having, and then if that's not something that they're comfortable with then referring you to a specialist for that. I find that some primary care providers and some pediatricians are less comfortable with any neurological disorder in addition to neuro-inflammation. I'm seeing lots of nodding in the room.

[00:01:59] And so whenever any symptom happens, they tell-- if my patient calls their pediatrician or PCP, they say, "Call your neurologist and ask them about it," which is totally fine, so I find that I've taken on that role as your neurologist of being that person to help think about these issues. And if it's an issue that I'm not a specialist in, referring you to those providers. I often find myself taking that role. That brings us to our next person. The neurologist is also pretty important in your care if you have a neurological disorder. And so, what they should do is be helping to monitor your physical functioning, your mental functioning, which I'll go into in a little bit, because I think that's such an important part of brain health. Like I said, helping you to coordinate and navigate the system. And then if you need any referrals for any sub-specialist helping you with that. The neurologists will help focus on the neurological aspects too, so not only your motor function,

but mental functioning, like I said. If you need any tests or blood studies, if you need any other additional studies, whether it's additional imaging test of your brain or your spinal cord, and other things to help you be healthy, they'll help you with some of those things.

[00:03:11] A lot of you may have already experienced this, but there we have what's called rehabilitation doctors, or physical medicine and rehab. They're also a very, very key player in this, because as you know, the brain affects the entire body, because it connects to everything in the body. And so, because of that, the rehab doctors help you with your functioning, especially not only motor, but just like your day-to-day skills, what we call activities of daily living. They can help you with that. And they can also help with thinking about strategies, especially with cognitive issues too. There are multiple roles that the rehabilitation doctors will play. I find that I'm working hand in hand with them. And one thing that we know we've proven over and over with multiple studies is that rehabilitation is really key in terms of not only recovering function but helping to reestablish some of those connections that have been lost during any brain or nerve or spinal cord injury. And so that's going to be one of your biggest toolboxes into helping you recover.

[00:04:14] We're going to skip down a little bit below rehab to talk about the therapists, because there's a lot of different therapists that will be involved with your day-to-day, week-to-week recovery. I think this is true, because we're talking about-- I know the focus is we can talk about either the acute immediate recovery, because I think that's important, but the intent of this session is talking about if you've had your injury for more than two years ago, I still think it's important to think about what rehabilitation exercises, what kind of therapies that are necessary not only to keep up your function, but maintain it, because-- I have a four-year-old son who watches PAW Patrol. I don't know if anybody watches PAW Patrol, but there's a dog there who drives this recycling truck and he says, "Don't lose it, reuse it," and I think about that. If you don't use your functioning, if you don't use your-- Yeah, exactly.

[00:05:09] And so if you don't use your functioning, if you don't work out, if you're not exercising those muscles, whether it's your actual muscles or your brain muscles, you're going to lose it. And so, it's really important to think about those things. So, in terms of therapists, there's different types of therapists that can get really confusing. There's a physical therapist, and they're usually more about the bigger muscles to help you with walking more of your trunk, so your central control and some of your leg muscles, that sort of thing. So, they're more focused on that. The occupational therapists can help a little bit with muscles, but they're more focused on the hands and the arms and helping you with your day-to-day mobility of using your arms and hands to be able to accomplish tasks that you need to do. And then speech therapy, or speech and language pathologist as they're called, just like their name, they help you with speech and communication.

[00:06:04] But one thing, which I think we've touched upon during this conference is that the way that we consider routine communication is by spoken language by verbal language. But as you all know, there's many different ways to communicate. There are so many nonverbal cues that are important, and especially for those who are unable to use their speaking voice, how do they communicate? And so, there's lots of non-spoken ways or nonspeaking ways. You can have verbal communication whether it's through written language, whether it's through-- They make these apps now where if you're not able to talk or even write, you can actually point to pictures and have the device actually help you communicate what you need, because communication is so important for us, not only to voice what we need and what we want, but on top of that, it defines us as individuals, right? Everybody needs to be heard. And so, it's important to realize that, I think for everybody, that it's not just speaking is how we communicate, we need like these additional devices.

[00:07:06] The speech therapists can help you with that. One thing that is also important that I think I touched upon yesterday that gets lost in the shuffle is the cognitive and mental functioning. That's such a huge component. It doesn't matter where in your nervous system you've gotten affected. I have lots of patients

with purely spinal cord disorders and they have cognitive issues, and you're like, "Why is that?" Because it affected your spine, not your brain. Why is that? There are so many theories, so many reasons why that is, but it's so common. And I feel like the cognitive issues is something that people-- We were talking about this earlier, a silent issue. A silent injury. So eloquently put, that people don't realize and don't think about, and I think that's such an important piece. There are speech and language pathologists who specialize in cognitive rehabilitation.

[00:08:02] Yes? Yes. Oh lovely. Yes. Yeah. Thank you for clarifying that. Just to repeat for the recording, cognitive function can also be done through with your OT as said by lovely OTR occupational therapist in the room. But one thing about the cognitive rehab piece that's really important, right? There are many different things in cognition that you don't realize if you do it day-to-day without being affected. But there's lots of things, there's planning, right? Can you remember to do the tasks that you need to do? How do you actually accomplish those tasks? Can you remember to do them? Right. There are times where you plan things, this happens to me all the time. I plan to do something, and then five minutes later if I don't write it down, I forget that I was planning to do it. And so, there's lots of different aspects of cognitive functioning of the mental health that gets broken down to different pieces. And for some people, some of those pieces are easier than others. And it also can fluctuate day by day or hour by hour, right? Something that we're fine on one day may be affecting the next day, and you might be able to do it again the day after that.

[00:09:12] And so one thing about these therapists is they can help you navigate some of those issues, come up with strategies to help you, because the idea is helping you to live your best life. And so, how do you get there? What are the strategies that you need for that? Is there a question or comments or anything? Okay. One of the comments from the audience was that she just had neuropsychological testing done and she thought she was having a cognitive decline and poor memory performance. But turns out her memory was really, really good. It was just the executive functioning piece that was affecting it, and that's the piece that came out in that testing, and that's something that commonly happens. A lot of patients come in, they're concerned about their memory, they're forgetting things, they're forgetting stuff, whether it's words or actions or the to-do list or what you're planning. But it turns out it's not the memory that's the issue. It's either an attention issue. You are not able to focus enough to pay attention to encode that memory, because memory is very complicated.

[00:10:11] And I'm not a memory expert, but you have to be able to pay attention long enough to look at something or to hear something and then store it in a part of your brain that's called short-term memory. And then on top of that, after a time, the short-term memory becomes long-term memory. And so, your brain has tried to figure out what things are important for short-term versus long-term, because your brain can only hold so much. But I just find it fascinating what things ends up encoding as long-term memory versus short-term. And sometimes it feels like your memory is terrible but turns out it's an attention or an executive function issue. That's totally true. Executive functioning, that's a great question. It has to do with some of the things I talked about earlier, so like the planning, the actual carrying out of your tasks that you were planning to do, prioritizing exactly. Management of time, multitasking. That's exactly. Consider higher level of functioning.

[00:11:14] There's a comment about making lists has been helpful or else that you're feeling like a squirrel or lost. Yes. Absolutely. So, one of the comments was from the same person was that 10 years ago there was a diagnosis of adult-onset ADHD that have been made related to her MOG antibody disorder. And so, she was taking a medicine that's for attention deficit disorder, or ADD or ADHD, but it turns out that while that treatment probably does help executive functioning, figuring out that it's actually executive functioning and not an attention issue is surprising. It sounds like having to rethink and regroup of how do you tackle that instead? Right. When something you thought was an issue for 10 years it turns out it was something else changes.

[00:12:10] Right. Yeah, exactly. To focus our intention, but it turns out it was a different aspect. Exactly. I only have a few more minutes, but I will definitely. The comment is that if you are seeing a neuroimmunology specialist who specializes in patients with other related neuroimmune disorders like multiple sclerosis or MS, they're going to be occupational therapists or other therapists who are skilled at helping patients manage, because that's something that we've recognized as an important aspect of life in general and the brain health. All right. I have three minutes left, so I'm going to go through some of these other things, but we'll definitely have some more time for a question and answer towards the end of the session. So, a few other additional specialists that you may be seeing is an ophthalmologist. And this is different from an optometrist. Sometimes it can be confusing because they're both eye doctors. Optometrists are mainly focused on glasses or contacts so helping you see clear.

[00:13:06] Ophthalmologists are medical professionals who are more specialized, especially in the nerves that affect your eyes, so including the optic nerves, which are the ones that does mainly vision. There are other nerves that affect your eyes in terms of helping you move your eyes around, and they help with some of those disorders too. Sometimes, if you're fortunate enough, these are even rarer, there's a neuro-ophthalmologists who can specialize in both brain and eye disorders. And so, if you're fortunate to find somebody who you can actually see, that will be the recommendation, but they help monitor your eye nerve or optic nerve health. Psychiatry and psychology super, super important. I don't have a lot of time to talk about it, but we talked about mental health being a huge piece. There's so many studies showing that patients with neuro inflammatory disorders, it doesn't matter if it was just your spine or your brain or both, you're twice as likely to develop anxiety or depression than the general population. And there's lots of factors for that I don't have time to go into, but just know that's very, very, very common, and it's something that can crop up later on.

[00:14:06] I've had patients who are like, "I thought I was doing fine, and all of a sudden I had this panic attack, and I didn't know what a panic attack was. I thought I was going to die." And that's the common thing I hear. We have the sudden onset of this panic attack where you can't breathe, your chest is tight, your heart is racing really fast, you can't think you're flush, you're sweating, you might feel like you're going to pass out. That's the feeling that people feel and it's a terrible feeling to have. That's terrible, and it's one of those things that can come out of the blue without even realizing. Something very, very common, something very, very important. So mental health is very important. Mental health is part of brain health. Moving on. Some patients with neuro-inflammatory disorders, where your immune system attacks the brain, can have your immune system attack your whole body. And so, rheumatologists can help you manage some of those things help manage some of the symptoms. The most common ones are going to be things like lupus or rheumatoid arthritis. I have a couple of patients with inflammatory bowel disease, like Crohn's disease, that sort of thing, ulcerative colitis, that can also have brain issues. so that'll be important.

[00:15:08] Something else is orthopedic doctors are really important, because bone health is really important, especially as we get older and as we age, and especially if you have trouble walking around, trouble bearing weight. You have to bear weight to help keep your bones healthy, especially your leg bones, that's a part of the bones if they don't, they start getting weaker and brittle. And so having somebody monitoring your bone health, sometimes in the orthopedics, sometimes as an endocrinologist, I didn't put that in here. But just monitoring bone health, making sure that you're getting your calcium and your vitamin D, and additional supplements medications to help that. That's really important, because if your bones are brittle, then you're at risk for fractures, and healing from fractures is terrible. It's painful. It can take a long time, so that's not fun. A lot of patients will have bowel, bladder dysfunction, especially if anything affecting the spinal cord. Seeing a urologist to monitor your bladder health, especially if issues with your bladder, whether it's incomplete voiding like unable to pee all the way, whether or not you have bladder spasms, and sometimes you have incontinence where you accidentally pee on yourself not meaning to, that sort of thing.

[00:16:14] You want to make sure that you're able to get rid of your urine, because then that reduces the risk for things like urinary tract infections or bladder infections, because bladder infection can also affect your brain. And one thing I didn't mention is that if you get sick or you get hot, because-- I'm from Georgia, it gets hot all the time in the summer. Some of your old symptoms can come back, and that can feel like an actual attack or relapse, and that's very common. And so, if you get an infection, you can feel like you're having another immune attack, even though it's not directly, but can definitely affect your functioning and all of those things. I find that cardiologist and pulmonologist are people I refer to less frequently related to a neuroimmune issue. A lot of people have heart issues in this country in general, so then you end up seeing a cardiologist because of just normal life and aging, not necessarily related to that, but that's something that I definitely keep an eye on.

[00:017:04] If I have a patient who complains about either chest pain or palpitations, meaning your heart feeling like it's beating fast skipping a beat, that sort of thing, I'll definitely refer to a cardiologist. And so, it's hard to navigate the system. It's hard to find somebody who specializes because that's the ideal. Right? Having a specialist who knows other patients with neuroimmune disorders. But definitely thinking about all the other parts of your body and your health is really important. Okay, I'm going to stop there, because I think there's another speaker. But I really appreciate your comments and your participation, and then we'll have time at the end for a question and answer. Thank you very much.