

Care for the caregivers

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[00:00:05] **Rebecca Whitney:** Thank you Paula for joining and for being a part of this session. It's one that's particularly of my heart being a mom of someone with transverse myelitis myself but I know that you've also presented on this topic in Dallas at our live session as well. So, if you have anything that you would like to start off with as far as how you speak to and relate to the caregivers who come into the clinic and words of advice you may have for them as far as how they manage.

[00:00:48] **Paula Hardeman:** Yeah, no, that's a great question. Usually, the way I approach it is actually just I share my own personal story as being a caregiver too. My mother has dementia and so it's me and my brothers who have divided up the task of providing care and it's this emotional toll you have to go on or you go through where you're angry, where you're sad, where you're mad and you're grieving. It's a grief process and so what I share with all the caregivers and with the patients too is it's okay to be angry. It's okay to be mad, it's okay to be frustrated.

[00:01:37] It's okay to be sad and to allow your body to go through that emotional process and talk about it, talk about it with your loved ones, talk about it with your family, talk about it with your friends and if you feel it's needed, talk about it with a professional mental health person but it's okay. And then at some point you eventually, after you process all those different emotions, you get to a point of acceptance. And when you're in that point with acceptance, you see things as a different way. And for me what there is through this process and this process can take people a couple of days or it can take people a couple of months to maybe a year or something.

[00:02:20] So, don't get concerned if you feel like it's taking a long time to get to an acceptance phase. But for me where I find myself is I look for the good in things and so, I feel blessed that I get to spend a lot more time with my mom now that she has dementia that I probably would have otherwise if she were healthy. I would have been, who knows where I would have been running around the city or whatever. But it's also caused me to think of my life and prioritize what is important and what's important to me is finding unique and different ways of making memories with her and cherishing those moments, cherishing those times when she'll smile at me when I'm working at her house and she'll walk up to me and say, are you okay?

[00:03:00] And I'm thinking, no, I'm not, I'm very frustrated. But so, she still has her own unique way of communicating and showing me that she's still my mother and everything. So, I think I'll stop there and see if there's any specific questions from people or comments or anything of that nature.

[00:03:29] **Rebecca Whitney:** Yeah, if there's any questions at all, please feel free to pop them in the chat. Or if there is an opportunity for you to come on, you are welcome to join us on the screen as well. So, we would love to hear from you and see what questions you may have. I really appreciate that you've mentioned too that it is a grieving process, right? And for anyone who cares for, loves someone who's been diagnosed with, you know, whether it's one of the rare neuroimmune disorders or like you said, your mom with dementia or cancer is also something that comes up so frequently.

[00:04:13] We all go through our own process of grief because it's such a change in our lives even if we are not the ones being diagnosed. And I've often found that that is a cyclical event depending upon what may be going on at any point in time. If there's a setback, a hospitalization, I will find myself asking the questions and processing and continuously going back through that cycle.

[00:04:45] But also understanding and knowing that there's still so much joy to be found even in the midst of what may be a very difficult time that it's okay to have those moments of laughter and fun and hope and keep understanding that there's life for both of you to continue to live.

[00:05:23] **Paula Hardeman:** The other thing that I find it's very important for the caregiver, especially if you're a spouse or a partner or even as a parent where you're with the loved one, the patient with the rare neuroimmune condition 24 hours, seven days a week type of thing is to make time for yourself. And so, with a lot of my caregivers, especially like I said, if they actually live with the loved one, I actually give them a homework assignment or I give them something that I say, okay, and at our next visit, I expect for you to come up with the time for yourself.

[00:06:03] And I say it doesn't have to be anything formal. It could be simply going for a walk in the park, going to a yoga class, whatever your heart's content but I want you to have a date with yourself once a week and you make it a priority. And I think that is important when taking care of someone that you don't forget who you are or what brings you joy, and you seek out to still experience those things that bring you joy.

[00:06:37] **Rebecca Whitney:** Yeah, that is so true. That is so true.

[00:06:42] **Paula Hardeman:** Because I think we would all say if the situation were reversed and we had a close friend who came to us and said, oh my goodness, my loved one has been diagnosed with transverse myelitis. And now they're more of in a wheelchair or in need assistance with doing different things of that. You as the friend would make sure you're telling that friend, hey, are you taking time out for yourself? And are you doing things? And are you asking for help? Are you using your resources? So, we need to be our own best friends as well and our own advocates and think about the advice that we would give others to say, am I doing what I would tell someone else to do?

[00:07:25] **Rebecca Whitney:** That's a very good point. That's a very good point. And Jennifer has actually put in the chat a question. How would you counsel parents of young kids on a child that had a severe onset attack and suffered significant disability? The parents worrying every day about relapse that may bring on even more disability. So, any words for Jennifer?

[00:07:52] **Paula Hardeman:** Yeah, that's a tough one and so I'm a little, I'll be truthful I'm not a parent, but I can definitely empathize because I've dealt with parents of patients and everything. And what I tell parents to

do is to focus on today. We can't worry about what tomorrow may bring. Let's focus on what's in front of us today. Let's focus on the good day of today. Let's focus on what we're accomplishing today and if a relapse occurs tomorrow, we'll deal with it then.

[00:08:26] Today, let's just look at what the blessings we have of today. I think if you just take that approach one day at a time, the fears, and anxieties that you have internally finally start to quiet down because you're shifting your priority to focusing on today. Rebecca, do you have anything to add considering you are a parent?

[00:08:52] **Rebecca Whitney:** Yeah, I feel her question. I feel it's been there, and it is hard because you do try to balance, you're managing everything that's going on. Today, you're also not wanting to feel that slap again, right? Of having been through a rare diagnosis and just coming out of nowhere and changing everything that you know about your world. It is hard but I would say continuing to focus on today, ask your questions, know that you are doing your absolute best, you're putting a plan together to, you know, if it's a child with MOG or NMO to prevent those relapses, right?

[00:09:52] We know that there are things that we can do and we're just planning for what could happen within our control. I know I have tried to plan for things that are outside of my control, and it only makes a bigger mess. So, and by bigger mess, I mean, a mess of me and a mess of my child. So, it is a tough one but really focusing on this is the here and now. This is what is within my circle of influence. This is how I can and have prepared. We'll have a plan should something happen but right now we're focusing on the child, what we have and trying our best to enjoy life.

[00:10:49] Taking that step away I know for me, especially in the very beginning it was so hard for me to step away. I literally had to have people come in and say you need to go home; you need to take care of yourself and that was so hard. But it also gave me that opportunity to work through that grieving process without being right in front of my child or my other children at the time as well to be able to start processing what was happening for myself. So, I'm not sure if that is helpful at all.

[00:11:26] **Paula Hardeman:** One of the things you've mentioned is very I think important. Is asking the questions to get an understanding of what's going on, what's happening. I think it is okay to ask the questions, certain questions of plan of care of if this were to happen, what do I need to look out for? The more you educate yourself on whatever the process is, the more you can feel prepared and have that plan of action if it comes to the point where you have to use it. I think a lot of with the coping and the difficulty is all of a sudden, you've lost that sense of control. So, to me one of the ways to get a sense of control it's just I'm a planner by virtue.

[00:12:16] And so, it's just to have an understanding of what's going on. And if I start seeing things, when do I need to act, when do I need to start implementing this other plan? And it's the same concept of in the event of a fire, what would you do? And so, whether you're at work, school or even at home, you should have your fire escape plan. And so, I think it is worthwhile to speak over with the healthcare professional in the event this happens what could the plan be? But at the same token, it's that balancing of not fixating that you're going to have to actually implement your rescue plan.

[00:12:56] **Rebecca Whitney:** Yes, that's it. I really like how you've put that. That rescue plan, that fire escape plan. So, that's great. And we did have a couple of other questions coming too or some folks that have shared. We have Sandra who has said my husband has TM and next month will be four years grieving the loss of a part of my husband and looking forward in a positive way, can't plan to retire now, need to keep working to help with finances and balance home, work, and family as seniors. She's in a different season of life at this point with different complicating dynamics as well, Sandra. So, thank you for sharing that. I know that is a challenge as well. So, let's see here. And then we also have Janet who has said daily bowel management has

been problematic, timing isn't working, and the only caregiver has full time job at home, what can be done to alleviate necessary needs? The caregiver has been doing this for over a year. That's a great question. When the resource of another individual really isn't available do you have any suggestions, Paula?

[00:14:22] **Paula Hardeman:** That's a hard one. And this is where you have to, depending on the situation and what the exact needs are, you may want to... And depending on your insurance. So, if you're on Medicare, don't quote me 100% on that, respite care where you can actually have someone come into the home and provide additional services and insurance can cover aid to come in. If you're financially able and feasible, there's different agencies that will provide for someone to come in that can help offload.

[00:15:08] If the main caregiver is at home but needs to work then someone else can come in and help with some of those duties. If cost is a problem, another inexpensive way to sometimes get help, especially if you're in a big city, anyone who's like in nursing school or something like that, Rebecca, they're always looking for extra money or different type of funding, whatever.

[00:15:37] And so, you can sometimes network with those different types of programs. So, just personally hiring someone to come in the home and help and that's usually a good pool resource of getting someone that's in nursing school for instance to come into the home and help.

[00:15:54] **Rebecca Whitney:** That's a great idea. Being a nursing student, I do have classmates who I know actually do that type of work. So, yeah, that is an excellent idea. I know it is tough when you do need those additional resources and the funds, or the individual may not be available. It looks like we do have Phillip and Mrs. Reeve joining us as well. So, thank you so much for being a part of the session. Did you have any questions or wish to add anything? There we go. Are you muted? Oh, no, I still can't hear you. That's okay. That's all right.

[00:16:57] You can use the chat too if you'd like but, yeah, I think it's when we talk about caregivers, I think we often talk about parents or spouses or hiring someone from outside. I think sometimes we need to also remember that siblings can also be caregivers of their siblings. I think often too of my children when they were in school together, how they played a key role in watching over their brother and what was happening and going on. So, it definitely changes the family dynamics when you introduce the need for additional assistance for a person. It's complicating but it can also be beautiful if that's.

[00:18:02] **Paula Hardeman:** Yeah, I think it allows to make for just the way you view things in society differently especially for the siblings. Someone with a rare neuroimmune condition, I think it provides for a lot more empathy and just looking at the world in a different way. This is coming up more and more with just the different autism spectrum disorders and how people engage with children in the public which you wouldn't normally have thought that's just an unruly kid.

[00:18:37] I think a lot of people are taking a step back and say no, maybe this is just a kid with autism, and this is the way they communicate. And just being more gracious towards the parents or whomever is with that child and if you see a way of being able to step in and providing support for them in that wherever they may be, I think it's something that families should really share with your neighbors, with your extended family and everything because it can help just change how we look at the world.

[00:19:14] **Rebecca Whitney:** That is so true. I have to put a plug in for our SRNA family camp. I think for just as much fun as the kids who attend have, I feel like it is also refreshing for the caregivers as well to be able to connect with other parents, other guardians, medical professionals who really know and understand

because you often do feel that you're going through so much of this in your own bubble. You're just floating around in isolation, and it is incredibly lonely.

[00:20:00] So, being able to connect with others who can meet you up on that same level of understanding what you go through on a daily basis as a caregiver or as a parent or spouse who is having to face additional challenges that even when you said those vows did not necessarily anticipate would include this. Or when you brought that baby home that they might be paralyzed for the rest of their lives.

[00:20:36] So, it looks like our time is coming up. If there's any other questions or comments, please feel free to put them in the chat and I know you are welcome to email me, SRNA at any point in time or give us a call if we can be of assistance. And Paula, if someone wants to get in touch with you at the clinic, how should they go about doing that? Is that a tough one?

[00:21:05] **Paula Hardeman:** It's a tough one. I don't have a good way of getting directly in touch with me. I would say is there a way that they could go through you, and you could forward it to me?

[00:21:16] **Rebecca Whitney:** Absolutely. So, if you have any questions for Paula or just want to make some comments, please feel free to email us. We have info@wearesrna.org or you can email me personally at rwhitney@wearesrna.org.

[00:21:43] **Paula Hardeman:** Yeah. I guess my take home message as the caregiver is just to remember take care of yourself first. It wasn't until I was, I don't want to say my age, but recently really understanding of putting my oxygen mask on first before helping the others. What they say when every time you get on a plane, it's always put your oxygen mask on first. And now being in the role of a caregiver, I completely understand what that phrase means. I have to take care of myself first if I'm going to be the best caregiver for my mom.

[00:22:14] **Rebecca Whitney:** Yes, and also how difficult it truly is to do. Thank you so much Paula for being with us today.

[00:22:24] **Paula Hardeman:** Thank you for having me.

[00:22:24] **Rebecca Whitney:** We really appreciate you. Yes, of course any time. All right, have a great day.

[00:22:34] **Paula Hardeman:** You too, bye.

[00:22:35] **Rebecca Whitney:** Bye-bye.