Hybrid Session

Care for the Caregiver

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[00:00:05] **Jeff Harrington:** My name is Jeff Harrington.

[00:00:07] **Paula Hardeman:** And my name is Paula Hardeman.

[00:00:09] **Jeff Harrington:** I am a caregiver.

[00:00:12] **Paula Hardeman:** I am a caregiver as well, but I'm also a PA, physician assistant at UT Southwestern.

[00:00:19] **Jeff Harrington:** I became a caregiver about 17 years ago. Really, my wife became the primary caregiver. My daughter was 19 years old when she was stricken with acute disseminated encephalomyelitis right after her freshman year of college, which was quite disabling for her. Everything, she needs assistance with. She needs 24/7 care. My wife was teaching at the time. I'm a sales guy. I just retired this year actually. And so, she left her teaching job. We were thrown to the wolves.

[00:00:55] There was not a book out there that you readily get to look at. How do we take care of somebody, and more importantly, and what this session is about, 'how do you take care of yourself?' And the thing that I learned -- we went to a camp through the association and a psychiatrist was there and talking about the fact when you get on an airplane and they do the safety announcement, they talk about that oxygen mask. If we lose pressure the oxygen mask will pull, put it over your head, pull that cord, but make sure when you're doing that you put your oxygen mask on first, because if oxygen is going away, if you don't take care of yours first, you're not helping anybody else that you're with.

[00:01:45] And that really became the thing that resonated for me in the last 17 years. Learned the hard way. From the standpoint of, you just want to say, "Yeah, okay, I'm ready for this, I could suck this up," or "We're going to be fine, we're a team with my wife, and we'll make this happen." We had one other son. He was three years younger. He was quickly out off to college and doing his thing independently. So, it was the three of us.

[00:02:15] But very quickly, it's starts to take a toll on you. My daughter is not really verbal, so it can be very trying when communication is a factor, and it starts to wear on you. And the thing that we learned very quickly was we need to take advantage of every resource that's out there. We're not gonna just say, we're sucking this up. We are gonna take advantage of every resource because it's just like not putting fuel in the tank. You've got to put fuel in the tank.

[00:02:48] My wife and I realized very quickly; we had to take care of our relationship. We proactively went into marriage counseling just to say, “Okay what should we be watching for?” Not that we actually had an issue, and the counselor was just reassuring us on things and just saying, “It's got to be the communication and making sure that you're both talking to each other and you're not starting to close-up and holding anything in. You've got to be sure that you're expressing the frustrations in that and that you have an outlet.”

[00:03:24] And it's just like anything else that we do in life. We all have stress regardless of what we're doing, what we're pursuing. And so, it is literally that balance. And we immediately found out that oh, we could get respite care. So, one of my wife's sisters comes in during the middle of the week and spends literally a 24-hour shift. My wife can schedule the things she wants to do: she can go out with her friends, doctor's appointments, go shopping, things like that.

[00:03:53] And now that I'm retired, we really make a concerted effort of planning our days and making sure what we're doing. It's really become intuitive now of how we tag-team on things. We read each other, and as soon as we see the other one maybe getting a little bit stressed, it's tap-out time to recognize those types of things and taking advantage. And I think another big important thing is the friendships you have, the family you have; when they're offering assistance, say yes and to not feel like, “No. Again, we've got this.” We've always have, with open arms, accepted offers of assisting in whatever manner because, again, it's just a matter of trying to manage that stress level.

[00:04:49] **Paula Hardeman:** I agree with you 100%. So, to share my story, my mother was diagnosed with Alzheimer's. It's probably been about eight years ago, and my father passed away, oh my gosh, almost 20 years ago. So, my mom was fully independent, active, living by herself.

[00:05:09] And then, her astute daughter of a PA who works in neurology started noticing certain cognitive difficulties that just didn't seem in line with normal aging. Went through the process, got the testing and confirmed the diagnosis. And so, for the first couple years, she was still able to live by herself but my brothers -- and I have two older brothers -- we started putting in plans in place of putting the house together in a way where she could maneuver through the house and still take care of herself. And then, as things became more challenging, we recognized she was going to need someone to be with her 24/7.

[00:05:47] So, I am very blessed in that I have the two most wonderful brothers because we have been able to come up with a schedule where we stay with her. Each of us stay with her part of the week to make sure she can still have her care and not have to put her into some other facility, because we can recognize very quickly she does exceptionally well at home in her own space. You can tell she's just very comfortable; she knows where to get the plates, the different things. She knows her home, but as soon as you take her outside of her home, it is very confusing for her.

[00:06:21] But I agree exactly what Jeff has shared: of we have to work as a team to make this work, and communication is the key. And so, there's certain things with my job. I'm thankful my job has allowed me to work remote when I'm with her, but there are certain different events I have to go in just because I have to go in, and it's reaching out to my brother saying, “Hey, can you come down earlier?” My brothers live in Houston, so that complicates the things as well. “Can you come down a little bit sooner? I need to really go into work for this thing.” And my ask with my job is, “Please just give me about four to six weeks advance notice. I can make it work. I just need the advance notice.”

[00:07:03] So, communication is key when you're feeling tired, when you're feeling overwhelmed, just please reach out and communicate your needs. It's okay, it's a grieving process you go through. I thought my mom was going to live forever, and she still may, but I thought she was just gonna be 100% independent, and that has changed. And so, my picture for my mom's later years in life is gone, and so I've lost that vision, and I've had to go through the process of grieving that loss for her -- being able to travel with all her friends and doing what retired people are supposed to do.

[00:07:42] But I also look for the good in it. I'm thankful I do get to spend the time with her. And even though she's not able to talk much because of the Alzheimer's, her facial expressions will tell you everything. So, you find the positive in things. And it is key that I also do things to take care of myself. I ended up getting a dog. She goes with me over to mom's house, and mom loves the dog too. And I make sure every Saturday morning, me and my dog go for a long walk out in nature.

[00:08:13] I am a big proponent with all my patients and when I'm talking to their families of saying, “Spend time out in nature. Nature is very healing, it is very restoring, vitamin D, getting that sunlight.” And so, I have realized that's an important -- I don't want to call it task -- but activity that I really enjoy. And so, I make it a priority to make sure me and my dog, Susie, -- I'll show pictures -- are able to go out Saturday morning to the lake, if the weather cooperates, and do a long walk.

[00:08:47] **Jeff Harrington:** I love that we say the same thing about the Vitamin D, getting outside when the weather allows. We live in Northern Indiana, so there are certain times when we're not doing that. And another thing that with who I'm caregiving for with my daughter, even though now she's 37 years old, she's still staying in touch with high school and college friends and the high school friends that live in town. They're getting together on a regular basis, and that from a caregiver standpoint is awesome from a standpoint, we're preparing for that and it takes some effort.

[00:09:25] But what it's doing for her, to still have some activities that she's used to, is really taking a lot off of her mother and I because her spirits are lifted, that's lifting our spirits. So, it's that combination a lot of times of whom you're caring for and say, “Okay, what are the things that are gonna keep them focused and keep their spirits up?” That, in turn, helps you to do exactly the same.

[00:09:57] It's like the rising tides raise all boats. So, it's not just looking at, okay, what are the things I have to do for myself to make sure that I'm taking care of myself, but thinking of it holistically. It is now that household of what you're doing, and when you're raising kids, kind of the same thing. You always have to look out for them and taking care of them, but it's a matter of, well, we're doing family activities and finding those things that you all are enjoying with. Even though my daughter's in wheelchair, she can balance herself. I actually walk her up the stairs every night, sleeping in an upstairs bedroom.

[00:10:38] So, she has some mobility, and we like to travel, and that's something that the three of us have enjoyed. My wife and I aren't getting younger, so we're taking advantage of that now, and we're starting to think about those things, and it's like eventually, obviously, we're not going to be around forever, she's going to outlive us. Her brother, she has a very loving brother. He's got a young family now. Hopefully, we're gonna be around for quite a while, but we're already talking with him and about that next stage and with his wife, our beautiful daughter-in-law, of stepping into the role and making those preparations.

[00:11:18] So, a lot of that, just addressing all of the issues that you have. And again, just looking for what are those other resources and not necessarily just the traditional resources of respite care, whether you're funding that yourself or you have the ability through state agencies to get some funding for that, that's something very important. But again, relying on family and friends, and taking advantage of when offers are made of how that can work out, and it's almost like -- I hate to say the word 'take advantage of' -- but you need to do that and think about how you are yourself. We don't wanna be selfish with things and asking for things, but it's like, most people, they want to help out, they want to be there, want to assist. And so, it's a matter of -- it's almost becomes a courtesy sometimes.

[00:12:16] And we've had situations with family members that are out of town, that are coming in, and the time that we spent with them, and we've gone out. My wife and I have a date night or gone for a weekend, and coming back and just what a great time that they had together, and it's like, "Wow." We maybe initially were pooh-poohing that idea and it's like, "Wow, this was great for everybody." So, it's really to leave no stone unturned, thinking outside the box a little bit of what might be, things like different activities that you can do, of just making sure that everything is being addressed, and I think that's what really helps to keep things less stressful than they have to be. Yes, please.

[00:13:07] **Audience Member:** I just wanted to share a resource. My name is Ros Kalb. I'm a clinical psychologist --

[00:13:12] **Jeff Harrington:** We're gonna get a microphone for you.

[00:13:19] **Audience Member:** Just testing.

[00:13:20] **Jeff Harrington:** Yes.

[00:13:23] **Audience Member:** I just have a resource for everybody. My name is Ros Kalb. I'm a clinical psychologist, and I have been in MS for 40 years and now with Can Do MS, but we partnered with Accelerated Cure Project and created a website that's a resource for care partners. And although it's focused on care partners of people with MS, the resources are --

[00:13:51] **Jeff Harrington:** Universal.

[00:13:52] **Audience Member:** Universal. Right. So, it's https:// and it's called mscarepartnerconnection.org.

[00:14:04] **Jeff Harrington:** mscarepartnerconnection.org.

[00:14:06] **Audience Member:** Sorry, mscarepartnerconnection.com, and it's set up like, it's almost like cafeteria style. So, whether you come in because you just became a care partner yesterday or you're dealing with very significant issues, you can look for resources related to financial planning or your own health and wellness or legal issues, transportation, getting help in the home, just it's a menu, and you can visit it at any point and time and find resources that may be helpful. So, just wanted to pass the word.

[00:14:47] **Jeff Harrington:** That's fantastic.

[00:14:48] **Paula Hardeman:** That's great.

[00:14:49] **Jeff Harrington:** Yeah. And the thing is finding those things. We stumbled for years of finding out, "Oh, you actually called." My daughter was 19 years old and so was an adult when she was stricken, but qualified for disability. And so, we were finding out things years later. My wife quit her job, and it turned out we didn't know for seven years: 'Oh, yeah! In our state, my wife could be compensated for being my daughter's caregiver.' We had no idea because no one told us. And so, it really is you have to become that advocate for yourself, looking for those resources. That's fantastic; I can't wait to go out and pull that up.

[00:15:40] **Audience Member:** There's one other point to keep in mind and that is that, because caregiving or being a care partner is so universal, just don't restrict yourself to the places you go for help. So, the National MS Society has fantastic resources for caregivers, so does Can Do MS, and so do some of the other MS organizations. So, don't be shy about reaching out because those issues are the same.

[00:16:17] **Jeff Harrington:** Thank you.

[00:16:22] **Paula Hardeman:** Oh, got another question or comment.

[00:16:30] **Audience Member:** Just a comment. Can you hear me?

[00:16:35] **Paula Hardeman:** Yeah.

[00:16:35] **Jeff Harrington:** Yes.

[00:16:35] **Audience Member:** With the lady on stage, just wanted to share my experiences with you. I lost my mother in January of 2010, Alzheimer's. We, before that in December of '09, my wife and I were going on a trip to Rome, and we're just about ready to cancel our trip when my brother-in-law and my sister told us to go ahead and take the trip at Christmas time, said she'd be fine, and so we did, and we took the trip. We came back and my sister, when we got to Atlanta, I noticed she texted me and she said, “Frank, where have you been? They've put mom on a morphine drip,” and I thought to myself, “Oh, shit.”

[00:17:31] If anybody knows what a morphine drip is, that means you have like four days to live, and I thought again to myself, ballgame because Gwen says, “What's going on?” -- That's my wife -- and I said, “They just put mom in morphine drip. She's got like four days to live.” So, we got back to the house, and we jammed to the hospital, and when we got there, she was gone.

[00:18:24] Anyway, I just wanted to share that with you. You're doing an admirable job, what you're doing for your mother. Mothers are beautiful, and your comment was you wanted to see your mom -- I wanted to see my mom live forever -- and you wanted to see your mom live forever. God bless you for that, but we all can't live forever, we all know that, but God bless you. I hope what you're doing is great, you're doing an admirable job, keep doing it.

[00:19:08] **Paula Hardeman:** Thank you. I will admit, it wasn't an easy process to transition into. There was a lot of anger in the beginning, and a lot of guilt, “Did I do something wrong? I'm in healthcare and I thought I'm in neurology. I should have been able to do something to prevent all of this.” That's where the process is of grief.

[00:19:32] So, when you look through, you go through this anger, and resentment, and denial, and bargaining. And then, finally, when you cycle through all those different things, you come to acceptance, and you say, “Okay, now this is the cards I've been dealt. What can I do to make it -- I don't want to use the word ‘enjoyable,’ but I'll use the word ‘tolerable’ experience or whatever.”

[00:19:53] To Jeff's point, my mom loves to be outside and she loves listening to music. Although, she can't because she just mentally can't understand to help out in the yard, we still take her out there and be like, “Hey mom, hold the trash bag, you're really helping us.” She just smiles and like, “Yeah, I'm doing something.” You do have to be creative and think outside the box too, because I can feel from my mom, she still wants to be my mother.

[00:20:22] When I'm working from home, and she can tell I'm frustrated with something, she'll come up and she'll hug me. So, she still wants to be my mother, she still wants to feel like she has a purpose, she still wants to be helpful. So, we've had to learn, let mom wash the dishes. Yes, that sometimes means you have to go behind her and really wash the dishes, but at least let her feel like she's washing the dishes, she's putting up the dishes. You just want to make sure they get put right in the right spot, but still just going through that.

[00:20:56] We try to find time throughout the day just to turn on the radio and listen to classics, and I've never seen my mom dance, and now it's just a joy to see her sit there and listening to the music and dancing. I'm like, “Why didn't we do this sooner?” And so, it is a different -- I didn't expect to be here. I can't really say that I'm happy to be here, but I am doing the best I can.

[00:21:21] **Jeff Harrington:** No, I agree with that. It's like, I didn't wish for it, that's for sure, but being able to take where you're at and say, “Okay we're gonna grab the reins and ride this,” and making sure that you're taking advantage of everything that you have access to and finding those things, other resources, and not just being stuck with, “Okay this is the way it's got to be,” to staying open-minded. And that's the thing, a lot of it is. You're just sharing, calling that if who you're taking care of is in better spirits, you're gonna be in better spirits, and you're gonna feel some affirmation of what you're doing, and again, take some stress off of yourself.

[00:22:12] **Paula Hardeman:** Are there any questions from our virtual participants or comments?

[00:22:17] **SRNA Staff Member:** No questions from online right now, but if you are listening online, feel free to put something in the chat.

[00:22:34] **Audience Member:** Hi, so you've talked quite a bit and quite admirably about taking care of your loved ones. Do you have a care plan for yourself? There's a significant physical and psychological burden involved in being a caregiver, and so I'm wondering who takes care of you?

[00:22:53] **Jeff Harrington:** Well, that's a great question. For us, it's not something we have documented. It's really something that we've worked on over the years with my wife. And again, it's with the coordination of -- so, we have her sister coming in for respite care, as I mentioned earlier, so that's some scheduled time. I just retired the last year, so we've changed what we're doing during the day. And so, it's again, it's not something that we've really scheduled, but it's more of, again, the communication, and making sure that we're staying in tune to ourselves of what needs to be addressed, how we're doing that versus if we were just empty nesters now, it's just the two of us, how we're caring for our daughter.

[00:23:40] So, it really -- I don't want to say that becomes intuitive -- but it's something that we're just very comfortable now in communicating, because we've had a lot of practice at it, so it really becomes more second nature. I talked earlier about it, almost like a wrestling match tag-team. We watch each other, and it's like, okay if one of us looks like getting stressed out, it's just a matter of coming up and saying, “Hey hon, I've got this.” Go do something for yourself or just leave the room when things do get stressful.

[00:24:16] Because as I mentioned, my daughter's, her verbal communication is quite limited, so it can become frustrating. She gets frustrated, she wants to get a point across. And my daughter has a great sense of humor, and so a lot of times, in the moment, it's something going on. She wants to share that, and so it's just having that patience of letting her get it out. And a lot of times it's just like, I thank her. I go," Ashley thank you for being patient with me and getting that across," because she'll put a smile on my face. And so, those are the things of just trying to remember -- there are a lot of rewards that can come out of being a caregiver.

[00:25:02] **Audience Member:** Hi, my name is Jose Franco. My wife was diagnosed with transverse myelitis in April 2022, and I was diagnosed with pancreatic cancer in the same month. And before that my wife was diagnosed with breast cancer in August 2021.

[00:25:32] **Paula Hardeman:** Oh, my goodness.

[00:25:32] **Audience Member:** So, it's been an ordeal. What I'm going to talk here about is first: the condition of my wife is not maybe as bad as the condition of other diseases because she still moves, she has good move. She is still working part time, remote from home. But I am Colombian immigrant, I have no family. We got retired, we had the dream home two years ago by the lake in Lago Vista in Austin, Texas, and all of this started happening suddenly.

[00:26:14] The only family member we have with us is our daughter, but she's independent. She works for immigration companies, and she works with the University of Texas. She's making a good job in social work and all these things. She's making a master, so she doesn't have our sake time. So, suddenly, we found ourselves by ourselves.

[00:26:39] And in my past life, I was an engineer. I don't know if you have heard about reverse engineer. I have been trained with the data one and a half years to imagine how to make reverse engineer to this problem, and I found the formula. Obviously, I most emphasize that my wife can perform every single thing, even drinking and dancing. Every single thing -- she's able to do anything. But what I have found in the last months is, if the mountain doesn't come to Mohammed, Mohammed has to go to the mountain.

[00:27:23] I was waiting that the mountain come to me, trying to take care of myself with my wife. Fortunately for me, my cancer has been halt, so I am the healthy one. In our home, I am the healthy one. So, I said, "Okay what is affecting me and what can we do in this type of tight environment?" my wife and me. My wife would help with her pain, with her weakness and all these things. So, I decided to start taking her out of the environment, put it in another environment where I could find help.

[00:28:11] So, first thing, let's go to Colombia, let's go to visit our family, let's go to visit mom, let's go to visit my mom, let's go to visit my cousin, whatever. Boom, two weeks-three weeks in Colombia, come back. Then, I convince my son that lives in Thailand to spend summertime in Colombia this year. So, he traveled with his wife, his two daughters, my two granddaughters, to Colombia, and I told my wife, "Hey that's a good opportunity to meet them." One month to Colombia boom.

[00:28:50] Why? Because there was a family, everybody was trying to support that and everybody understood her disease. So, that's the way we have been finding help, because I have no help here, I have no friends, don't do many friends. I live far away. I live in the country here, so nobody or not many people visit me or not many people call me. So, I decided to find environments for my wife and me.

[00:29:22] I can relieve myself because I find some ways to escape sometimes and leave somebody in charge of my wife. And I would say, one and a half weeks something happened. One and a half weeks we were staying in the living room at home, I put some cheese, put some music, put some wine. We were dancing a little bit, and she told me, “This is not that bad,” this is -- I'm sorry, I get emotional because I think I found a formula. I think I found a formula and I must tell the people this.

[00:30:10] Sometimes you get, I don't know in a hole or somewhere, you get in a place where you don't see a way out. There is, there is. Look for that. I don't know how, I don't know when, I don't know who, but look for that. I'm pretty sure you can make it. I am trying. I am not saying I am being successful, but so far, I am getting results, and that's my message. I am getting results, and I think that's what's there for you now. Thank you.

[00:30:50] **Jeff Harrington:** That's fantastic.

[00:30:51] **Paula Hardeman:** Wow, thank you for sharing.

[00:30:57] **Audience Member:** I'm sorry, I don't know your name, but I wanted to go back to your question about who takes care of the care partner. And I think when you are part of a couple, then I think there are ways that you can do that in just how you described it, giving each other respite, recognizing when each other might be feeling just overwhelmed, or if you have the ability as Bernardo has, to bring everybody to gather in a wonderful place.

[00:31:38] But I think there are a lot of care partners who don't have those resources, and don't have those connections. And so, another resource I'd like you to think about is, the resources that care partners offer to each other in online venues for which you need no money, and no support right in the home, but you can come together and get tips, and tools, and strategies, and support from people who really get what you're going through, and I mean the highs and the lows, and the deep grief that goes with this.

[00:32:16] So, I would urge any of you who are looking for that resource, we have care partner meetups. This year, they've been six times a year. Next year, they're going to be four times, but you just come. You can register for them, you can come, be online, and be part of a community. And the care partners have gotten to know each other, they're very supportive of each other. And I would just welcome all of you, even though you're not caring for somebody with MS, to come be part of this community, so you don't feel alone.

[00:32:57] **Audience Member:** So, I have a question. So, I'm an elder millennial, and some of my friends just don't understand being a caregiver. And, I mean I've been a CNA since 2014, and I've been in behavioral health care before that, and had my bachelor's degree in these things. But my friends are like, "Yeah come and I only turn 30 once, come on out to my birthday party," and I'm like, “I wish I could be there but I'm dealing with,”-- at that time, I was dealing with my dad who had frontal temporal dementia when he was 58, and he passed in 2018, -- but I stayed home with him because he required a lot of supervision. And my friends just were like, “Can't you come out?” And I'm like, “Literally no.” So, what do you guys have advice for when they just don't understand, or I feel like I'm repeating myself like, “Can't come out,” they keep offering.

[00:34:14] **Jeff Harrington:** The friend can come over and help you.

[00:34:17] **Audience Member:** Yeah, you're right.

[00:34:19] **Jeff Harrington:** That's what friends are for.

[00:34:22] **Paula Hardeman:** Yeah, I think it's a double-edged sword. The friend, I think, is probably wanting to show that they're being there for you and including you and not just like, “Well, we know she's not available so we're just going to forget about her." So, I do think if you look at it from the friend's perspective, I think they're saying, "We are trying to reach out and help you the only way we know how to."

[00:34:46] And so, it goes back to the very beginning from the communication standpoint of just having the conversation. And even if you've had that over and over, I promise you, because I've been there with some of my friends, they will finally start to understand, and you just say, "Okay this is what I need, come to the home and we can make a cake together or whatever and I'll give you a special birthday party at my house or whatever."

[00:35:14] Invite them to your home, your atmosphere, because I think seeing is believing, If they can see some of the things that happen in which your day-to-day, you start looking at things differently. My friends had been told over and over, "My schedule is Sunday through Wednesday at my mom's." And so, now, they know my schedule, and I love them dearly because now they make sure I get out when I'm at home because they're like, you don't need to be just sitting at home by yourself. We are forcing you to come out and I kick and scream all the way, but then at the end of it, I am thankful that they forced me to come out.

[00:35:54] And so, back to your question of it is this I say, build your wise counsel. So, I am thankful for my brothers who can recognize like, "You do need to go hang up with your friends," and I am thankful for my very close friends who can recognize, "You need your gas tank refilled and we can do these things." I'm also just a firm believer being in tune to yourself and listening to your body, and so as a result, I have learned I need good quality sleep. I am not this type of person who can function on six hours of sleep. So, as a result, I've had to prioritize, even if I'm at my mom's, we're on a strict schedule of, "Bedtime is 9 o'clock because Paula needs eight hours of sleep, so she can function the next day." Just being outside, those little things that I've recognized that can help refuel my batteries very quickly, I've had to prioritize and make part of my day.

[00:36:53] **SRNA Staff Member:** We do have a question from online. Jodie is asking a question about how do you plan for a time when you're too old or if you have your own medical issue yourself to provide the care that your loved one needs? How do you prepare for that or plan for that?

[00:37:13] **Jeff Harrington:** That obviously, that's an issue that I'm looking at right now, because I know that my daughter is going to outlive my wife and myself; I'm pretty confident with that. So, for everybody that's going to be different. If you have family, and I'm fortunate that I do, and a cooperative family member that will be that transition. But then, you have to look at if you don't have those resources, it can be a tough pill to swallow, but you've got to look at what is community-based, and what are you going to be able to do, and you got to get proactive. It doesn't do any good to procrastinate and hope that day doesn't come, that day is going to come, and you have to look at all the resources that can be available, and start to have a discussion of what that's going to be.

[00:38:17] **Audience Member:** I'm Donald Campbell, my wife and I are caregivers for our daughter, Leah. We definitely are not getting any younger. We have planned, one of the things that we've done anyway is, we've found an estate lawyer, and that's taken care of. We don't really even worry about that anymore because we know exactly what's going to happen financially.

[00:38:50] **Jeff Harrington:** Right.

[00:38:52] **Audience Member:** Our daughter was disabled, blind as a child. So, she qualifies for disability. And then, because of misdiagnosis and wrong medication, it paralyzed her in 2001. So, the extent of her disability is great like yours. We're retired, so she gets some social security off of my retirement, and she gets disability. And like, Don said, we've set up a revocable?

[00:39:52] **Jeff Harrington:** Irrevocable trust.

[00:39:55] **Audience Member:** Irrevocable trust.

[00:39:53] **Paula Hardeman:** Trust.

[00:39:57] **Audience Member:** Okay. And so, because she's on Medicaid, and she gets Medicare and Medicaid. Then, if she has any finances, she has to spend them all before she gets them again. So, we have tied up our savings in something that will take care of her after we're gone. There are facilities that will -- it's not a rest home or anything like that, but it's a facility that will care for people that are in between mobility and non-mobile, and so that's a possibility, and it's up to her to start looking for a spot in case something happens to us.

[00:41:08] As long as there's two of us, this works. When one of us can no longer do anything, which was me, when I had a muscle spasm, everything came to a screeching halt. And so, we tried to plan for that, so she can continue to live like she is right now and stay out of facilities.

[00:41:45] **Audience Member:** If you don't know anything about Leah, just very quickly, she keeps us going. We have an advocacy trip about every other month in which we are required to fly to Washington DC to Los Angeles, Chicago. Anyway, and my wife doesn't like to fly, so that also adds to a little of the stress, but she keeps us busy because of what she wants to do, and we've said this is going to be our focus. We want to focus on allowing Leah to be the best Leah she can be, which is to advocate for herself and others who can't or won't, and it's just been quite a process.

[00:42:35] We also found a program through the state that allows her to have a personal care assistant who comes in a certain number of hours a day and frees us up to do the dishes and go to Walmart, which is our typical date now to go to Walmart and that sort of thing. So anyway, I've talked too long but that's what we've worked on together.

[00:43:01] **Jeff Harrington:** And that's the thing, you're a team. And it's going to be different for everybody. And every situation is unique, and it's a matter of coming together and having those open lines of communication of what's going to work best for us.

[00:43:16] Was kind of funny in coming down here, my daughter was the one that said, “Hey we're going to be down here. Let's go to San Antonio, let's go to the Riverwalk.” And the first time I've been there, 20 some years ago, and it's like I flew from Dallas to San Antonio. I was like, “It's going to be an 8–10-hour drive” and it's like, “No It's not that bad.”

[00:43:35] **Paula Hardeman:** It's not that bad.

[00:43:35] **Jeff Harrington:** So, Sunday we're getting a rental car, and we're going to drive down to San Antonio, fly home from there, I was like --

[00:43:39] **Paula Hardeman:** Can I give you a little piece of advice on that? So, Austin traffic is notorious for being bad every single day.

[00:43:47] **Jeff Harrington:** They don't have a bypass, unfortunately.

[00:43:49] **Paula Hardeman:** They do, you take…

[00:43:51] **Jeff Harrington:** I think you have to go through town.

[00:43:52] **Paula Hardeman:** No. Take the toll --

[00:43:53] **Jeff Harrington:** I'm going to have to take notes here. Do you mind if we take a time out?

[00:43:56] **Paula Hardeman:** Take the toll road. It'll be the best ten dollars you've ever spent. Take the toll road.

[00:44:01] **Jeff Harrington:** Got it. Will do. And that's the thing that you could, because my wife and I realized we're not getting any younger, so we're doing everything we can do now that we're staying active and able to do, and we're enjoying ourselves. It's not easy as you know traveling with your daughter and the same for us. We had a delayed flight, we were running through O'Hare Airport to catch our next flight. I was really proud of my wife. Man, she was running, I haven't seen her move like that in a long time.

[00:44:43] And again, everybody's has a different situation that they look into, and it is just, boy, leave no stone unturned. Look for those resources, and when you hear of a resource, really dig into it, and get the most out of it. And as many have shared, and we have this, we were finding out things years later of resources we had access to and had no idea because well, no one told us. We didn't know the right questions to ask apparently, so ask those questions, and never give up.

[00:45:25] **Audience Member:** One more word about that website that I told you about. It was put together by care partners. So, we had an advisory board and they sat around and talked about all the things you're talking about today: What are the things that are most on our minds? What are we worried about? What questions are we trying to ask? And then, after we come up with all these topics that were top of mind for them, whether they were parents or older folks or young parents of older adults, then everybody set about hunting for resources and vetting them.

[00:46:10] So, they went through, found all these resources, decided which ones were credible, which ones were -- and that's how we ended up with this menu of resources. So, it was really put together by folks just like you, and we intend to keep it up to date. So, if you decide to use this resource, and you have something that you found that is not there or that's new, we want to keep adding and growing, so you become detectives like everybody else here.

[00:46:50] **Jeff Harrington:** It's nice when you don't have to recreate the wheel.

[00:47:01] **Paula Hardeman:** Any other questions or?

[00:47:15] **Audience Member:** So, I had been in healthcare for a very long time, and I realized when my dad went to hospice that not everybody knows what hospice means. I assumed everybody, even non-medical people knew what that meant, but it really dawned on me like, “Oh I have to actually tell them what this means.” I don't know, but not everybody knows what the most basic medical things are so sometimes.

[00:47:51] **Paula Hardeman:** That's a good point. I'd like to point out that palliative care is different than hospice. So, there are different programs that will talk about their palliatives. So palliative care is really focused more on, I'll say, the comfort, the quality of life, and everything. And so, you may want to look into your different insurance plans and see if there are palliative care centers in your area, as just as avenue for resources, because they will have connections to different -- whether it's in-home care or needing certain devices or assistive aids -- palliative care people, they know a lot. A lot of the different things I have learned to help my patients has been through talking to palliative care individuals.

[00:48:37] Hospice is typically referred to as when a person is terminal, in those end stages of life. A lot of patients don't like to hear that you're going on hospice. Hospice doesn't necessarily mean that you're going to die tomorrow. It just says you're at the end stage of whatever disease process, and I believe the Medicare you have to be re-certified every 90 days or six months or something. There are people who go into hospice. Jimmy Carter is in hospice. I think he's going on two years now of being under hospice care. The good thing about hospice care is it gets you more resources. Don't be scared if your healthcare provider says we should look into palliative care services or hospice. It is usually a way of getting additional resources for the patient.

[00:49:38] **Audience Member:** Sorry.

[00:49:39] **Paula Hardeman:** No.

[00:49:39] **Audience Member:** I think focusing on resources and how to do the tough job that you're trying to do is really important. But I also think it's important for care partners of, which I am one, not because my husband is ill but because we're both getting old. So, we are losing abilities, we are watching each other change, we are feeling all kinds of things about that. Pay attention to what you're doing with your feelings, there's going to be a lot of grief as you change yourself or as you watch someone you love change or lose abilities, you're going to be frustrated and angry and impatient sometimes, because it takes so much time and energy and work, and grief is just part of all of this.

[00:50:34] And so, frequently, care partners tell us that there's no place for those feelings. They feel selfish feeling them. They feel like, “Well, it's not about me, it's about them.” But part of self-care and part of being the healthiest human you can be is recognizing the full range of positive and negative and painful feelings, and figuring out what you're going to do with them, how you're going to express them, how you're going to share them with others, and how you're going to get support. Because the hardest thing for care partners is to ask for help or support, because they feel selfish doing that, and that's not being selfish, that is self-care, and it's self-sustaining, and you can't do what you're trying to do without that.

[00:51:28] **Jeff Harrington:** And that's why I always like to think back to it. I always think that oxygen mask, it's not selfish to breathe. And so, it's all a matter of, if you're taking care of yourself then you're taking care of everybody else around you. We just have that innate feeling of that selfishness and it's like, “No, no. It's not being selfish, it's being smart.”

[00:51:53] **Audience Member:** We have made out a travel list and there are certain things that we look for. Don's in charge of hotel and transportation, if we fly from the airport to the hotel. I'm usually in charge of packing. Leah is one searching out airlines, and the best deal for those. But one thing that we have found is, try to find a system that works for you. I'm going to pick on this hotel, the beds are too tall. I'm 5'7." When I sit on the bed, my feet don't touch the floor, that's too tall for me. I can't sit on the bed and try to put my shoes on because I fall off. So, I have to go sit in the chair.

[00:52:57] **Audience Member:** My feet never touch the floor no matter what hotel I'm staying in, just saying.

[00:53:02] **Audience Member:** Well, talk to your genetics about that. So, that means we have to lift Leah from her chair to the bed. That's a long rise.

[00:53:17] **Jeff Harrington:** I did that too here. I agree with you, I had to pick my daughter up to get her into the bed.

[00:53:23] **Audience Member:** So, we rented a patient lift, had it delivered to the hotel. And the problem is, these stupid beds are on platforms, so it won't go under. However, it does have a little bit of an edge, and we thought of it, and we tried it at home, and so we tried Plan A. And we always have different ones. We tried Plan A: we'll lift you up out of the chair, push you over on the bed, and then lower -- we got the electric -- then we'll lower you onto the bed, and at that point, you may fall, but you're not going anywhere, because you're in that sling you're not going to hit the floor, you may roll. So, it did and it was kind of okay.

[00:54:21] Well, he thought about what if we go in from the corner because the legs will spread. Now we can get you further up onto the bed, and we have our little pads, now we can pull you wherever we need you.

[00:54:44] **Audience Member:** That little plan only cost me about an hour and a half of sleep last night that I could have better spent sleeping.

[00:54:51] **Jeff Harrington:** You needed the reverse engineer.

[00:54:52] **Audience Member:** I was about to say that.

[00:55:01] **Audience Member:** So, I mean, don't be afraid to look for other things. I know they lost. Well, they couldn't find it, and we finally did. And as people came through the lobby that were in wheelchairs they go, "Where did you get that?" "We ordered it." "They'll bring it to the hotel?" "Yes."

[00:55:29] **Audience Member:** Is that a hospital supply?

[00:55:31] **Audience Member:** Yes. So, we went to a DME -- and you called I don't know how many?

[00:55:37] **Audience Member:** I called about four or five in Dallas.

[00:55:40] **Audience Member:** Cheapest price and electric was what we were looking for, and so we got it. So, what does that do? It saves our back of getting her in bed. Getting her out of bed, gravity is our friend, and that is not a problem, we have a sliding board. So, we can use that if we need to go from bed to chair or you can just move her.

[00:56:11] But it's that chair to the bed that is a killer. And hotels think the beds have to be tall and fluffy, and they don't. But that is not an ADA requirement. It's a suggestion, and they don't follow those.

[00:56:32] **Jeff Harrington:** And they don't have a handheld shower in her room. I'm like, “Really?”

[00:56:37] **Audience Member:** We do.

[00:56:38] **Jeff Harrington:** You do? Oh, we don't. They had I could see where the hooks were for one, but it doesn't look as ever set up that way.

[00:56:47] **Audience Member:** The other recommendation, and you're talking about saving your backs, that we always talk about people with the rare neuroimmune disease or MS or whatever, going to physical therapy or going to rehab. But the rehab folks are eager to see you as well to teach how to lift safely, how to pick somebody up from a fall safely, how to do all those things to protect your neck, back, shoulders. So, if you haven't seen a PT, they're awesome.

[00:57:32] **Paula Hardeman:** Any other, I guess we still got a few minutes.

[00:57:42] **Audience Member:** Just leave it here. You're talking about going to see a PT for them to teach you how to move, and that's okay, but you got to remember that they're in a sterile environment when they do their movement with people. They can only do it certain ways, there are other ways, there are ways around difficulties.

[00:58:09] And we were in the hospital with Leah. A quick story, very quick, I guess I'll be quick. Physical therapist came in to show us, "How to move Leah." And we had been moving her for probably 10 years already. And he comes in, very young guy, full of knowledge and he says, "Well, I brought a gait belt," and we both shook our heads. And he asked Leah, “Can you stand?” “No, I can't.” “Well, how about your legs? Can we block your legs?” “No, you can't, it doesn't work."

[00:58:49] And he proceeds to hook the gait belt on and go around in front and attempt to stand her. If I had not been where I was, we would have been picking them both up out of the floor, and I caught her, and placed her back in her chair, and I showed him how to move, and I don't know if he was impressed by it, if he ever used it again or not, but that's just some of the things that happened to you when folks don't listen. And they'll listen to the patient. Okay. All right. Another one? Okay.

[00:59:27] **Audience Member:** Okay. So, I hear you, only like my uncle, he built the slightest backwards wheelchair ramp, he tipped all the way over in his manual chair. And we killed our backs that day, me and mom, but it was terrifying and traumatic, but you'll notice he has a different chair now, so. And that also happened once. A physical therapist years ago. I happened to be home that day in my room, and I come out and I hear a noise, and he's on the floor. And I'm like, trying to figure out what happened, and I think they were trying to stand or the guy wasn't listening, and it was like, that's not going to happen but with the gait belt and everything and it was like --

[01:00:33] **Audience Member:** Just sit.

[01:00:34] **Audience Member:** Exactly, just straight down on the floor, straight down.

[01:00:39] **Paula Hardeman:** I think I take for granted working with the patient population that I do, and I think other healthcare professionals will have the same exposure, same thought process of understanding some of these different limitations. And unfortunately, this is still a rare condition and everything, and even from the MS perspective when you get advanced MS patients, it is still rare for different healthcare professionals to be exposed to these different difficulties, and that's where as the care partner to care to be that patient's advocate and really educate and just point out some subtle obvious things of like, “That's not going to work because of,” and hopefully, the person will start to think and say, "Okay, I get where you're coming from, we've got to look at this a different way."

[01:01:32] I'm always trying to think outside the box to help people with different problems, and even the physical therapist that I'm honored to work with she is great about thinking outside the box of, from a rehab standpoint. I always get insurance asking me, “If someone is wheelchair bound, why are you sending them to physical therapy?” And I was like, “It's needed. They need to be able to just move their body to a certain extent or whatever.” But as the care partner, the caregiver, be that advocate too with the different healthcare professionals of really conveying of what they functionally can and cannot do, the different safety issues, and be that voice for them.

[01:02:13] **Audience Member:** Well, and I think it's important to pick as carefully as you do your neurologist, right? So, some rehab professionals are trained in orthopedics primarily, some are trained in neurology. So, you start there. And then, it's perfectly okay to interview a PT in the same way that you would interview a neurology provider to make sure that they are on the same page with you and that they have the experience and the skills to deal with whatever you are dealing with, because, again, if you can't advocate, they will do what they think is right, and sometimes they are dumb.

[01:02:55] **Paula Hardeman:** Yes.

[01:03:00] **Audience Member:** So, this is from a -- I'm sorry, I have a warped sense of humor. We're supposed to be at 3 o'clock?

[01:03:09] **Paula Hardeman:** Yes.

[01:03:11] **Jeff Harrington:** Yeah, keep it coming.

[01:03:11] **Audience Member:** If we quit now, we got 25 minutes to ourselves.

[01:03:14] **Jeff Harrington:** That's right.

[01:03:16] **Audience Member:** Oh, sorry. Did I say that out loud?

[01:03:20] **Paula Hardeman:** Were you going to say something?

[01:03:23] **Audience Member:** I was going to say what she did.

[01:03:25] **Paula Hardeman:** Okay. No, I agree 100% with Ros. Please interview anyone that's going to be on your loved one's care team. Ask them just point blank, how many patients do you have with fill in the blank, disorder or whatever? If you're in a big city and there's a major academic institution -- at our facility we are happy to talk to any other healthcare professional to educate them on what's going on with the person, sometimes the limitations and different things.

[01:03:57] My rehab team, they're happy to help coordinate things with local physical therapists or OT just to the approach -- Ros is right, I get so annoyed when the PCP has sent my patient to physical therapy, and they're orthopedic trained physical therapists, and you're like, “No that's not.” I just saw a patient in clinic the other day, and I was talking to her. I sent her to PT because I wanted her to get evaluated with the AFO because she had a foot drop. And she mentioned that to the physical therapist, and they're like, “Well, it's not gonna fix the problem.”

[01:04:30] I know it's not gonna fix the problem, but it's going to help her A) conserve energy when she's trying to walk B) prevent her from falling and just be safe for her so why aren't you doing what I asked you to do? But in that person's defense, they probably didn't understand what I was trying to do for her. And so, I told her, I was like, “We can do a different way, let me just send you to an orthotic who can build the AFO,” and then give her some resources on how to practice using it at home and everything. Anything else?

[01:05:10] **SRNA Staff Member:** I see a raised hand from somebody, but I don't see anything in the chat. I'm giving them a moment to if they wanted to put anything in the chat. If we need to wrap up early, that's okay too.

[01:05:21] **Paula Hardeman:** Well, I think what I will, just summarize the different things that I've heard that it's important for the caregiver, the care partner, is communication with your loved one that you're taking care of, or your other, whether it's a spouse, a partner, whoever is in the home, or your support system. Be willing to tell your friends, family, the help that you need. Ask for help, take the help when it's offered.

[01:05:52] Insurance is sometimes a bad word, but there are now insurances want, everybody's business and so they're coming up with different programs to help with the caregiver burnout and different things. And so, sometimes even turning to your insurance company and asking what can you help with these different situations? Look at from a resource standpoint, a spinal cord injury for instance, don't just focus on looking for things for TM, NMO but maybe go to something that's more focused on spinal cord injury, usually the needs are going to be the same, and they can plug you into areas with different resources.

[01:06:29] And then, the final thing, I think that everybody has hinted at or talked about is put your oxygen mask on first. As a caregiver or care partner, I am no good to my mom if I don't take care of myself first, and don't get me wrong, there's been some trial and error of me trying to figure out what exactly do I need to continue to be there to show up for her, and I've had to learn to communicate those needs to my brothers of, sometimes I'm going to need this from time to time. My one brother loves to play ice hockey, so we've made the schedule so that he's always able to be back in Houston on Sundays and Mondays so he can play his ice hockey because that is important to him, and I realize how important that is to him, and I want him to be in this process with us for however long we have to be in this process.

[01:07:19] **Jeff Harrington:** The mutual respect, it goes a long way.

[01:07:23] **Audience Member:** One last thing for me and I'll hush. One thing that I struggle with and I have a hard time with is keeping that natural relationship. I am a mother to a daughter who is disabled. I am her mother. I can be an advocate, but I have to step back and let her run her life. She goes to the doctor's appointment, she's blind, she's paralyzed, we go to a doctor's appointment and they'll ask how much does she weigh, and we stand there and say nothing.

[01:08:13] **Paula Hardeman:** Good.

[01:08:14] **Audience Member:** And she will speak up, and then they go, “Oh.” Yes, she does have a brain. So, you have question, you ask her. And they will start through the med list, and so, they will read it off. We're sitting there with the paper copy and we're checking them off, and then she'll look because she knows that's what we do, and then she'll look at us and she goes, "Did they get them all?" And I said, “Well, and go. Oh, yeah, they missed this one."

[01:08:57] And she'll name it or we'll check, but we let her take care of her doctor's appointments. He pushes the wheelchair, I'm the secretary. I try to keep the mother-daughter relationship. I try to keep a husband-wife relationship. We have to do that, or else this is all going to fall apart.

[01:09:31] When my mom was ill, then I had to keep that mother-daughter relationship in reverse and I did and with my aunt. I mean, we're not going to get out of this world alive, so we try to enjoy this world the best that we can and make it wonderful. And like they've said earlier, no I would not have chosen this, but I have met some fantastic wonderful individuals that are lasting friends that understand what my life is like without even questioning it. So, if something happens and we can't go somewhere, I don't get this, "Well, why? Can't you do this?" No, so for that I appreciate all of the people in this rare disease journey, it's been marvelous.

[01:10:55] I don't know why we're here, but we're here, and let's help each other. Yes, and we will continue to be here and help each other because we're friends.

[01:11:09] **Jeff Harrington:** Well, that's something that I with my daughter because she's really nonverbal that in any setting whether it's going to medical setting or anywhere that we go, I stay right up front. She understands what you're saying and if it comes down to a yes, no answer, you're talking to her. If it gets a little more involved and I need to interpret here, I'm getting in.

[01:11:30] And I always love going to the doctor. They'll put the little tablet in front of me and I go, "No, I don't have power of attorney." I have to literally help her make her mark but it's like, “No, she makes her own decisions. I'm the chauffeur.”

[01:11:52] **Audience Member:** So, like you had said, you had to keep that separate relationship. That time that my dad was sick I was 31, and I had to be his parent, and I was not prepared at all, and I still think back to that, “Did I do the right things?” The guilt and those things, of course, comes along with it.

[01:12:14] But in the beginning, we would take him to the doctor, get him evaluated, and things that they said, “Take him to his primary care doctor, get the blood work and everything.” And they would say, "Okay, Mr. Markham, do you know why you're here today?" And me and my step-mom we just sat back. I was curious to see what he would say and he said, "I'm here because they think something's wrong with me." But when he still had his speech and everything, we let him do everything he could, but then we had to start saying the things for him.

[01:13:02] **Paula Hardeman:** I think that's a really great point, Therese. Because it's even challenging for me being the daughter in taking care of my mother, but even as I said earlier, I can tell she still wants to be my mother, and I try my best to even just ask her questions that I know she's not going to be able to verbally explain things to me, but her facial expressions are worth a thousand words. And it's just so interesting, I can just look at her and I'll just tell her, "Oh, mom, I had a bad day at work today and doctor Greenberg did this to me and can you believe." And she'll frown and everything, and so I was like, "Yeah, I wish you could go and tell him that exactly for me or whatever." But I still try to make her feel like she's my mommy, and I still need her, and I still wanna go to her.

[01:13:57] **Audience Member:** I just wanted to say a word about powers of attorney. They are incredibly valuable things to have, both regular power of attorney and healthcare power of attorney and healthcare proxy. Even if you don't use it today because the person you love is capable of making decisions and planning and doing particularly with some of the conditions I've heard described here today, sudden changes can happen.

[01:14:29] Sudden changes can happen, and so within the family, I think you really want to have those powers of attorney in place in case an emergency situation comes up and your loved one, who yesterday was able to make sound plans and decisions, today can't. So, don't shy away from that because you're afraid of being insulting or demeaning. Just have the conversation about why you want to put it in place. And if you have a very smart, savvy daughter, she should also have your powers of attorney. So, you're doing it for each other until such time as you can't; living will, healthcare proxy, all that stuff.

[01:15:30] **Paula Hardeman:** Any other closing? Did the other person ever --

[01:15:35] **SRNA Staff Member:** No.

[01:15:38] **Paula Hardeman:** Okay. Any other closing remarks or anyone has any wonderful words of wisdom they would like to share?

[01:15:47] **Audience Member:** If you keep asking, people are going to keep coming up with something.

[01:15:55] **Paula Hardeman:** If not, I think we will come to an end a little early, give people a chance to go have a long potty break or go outside and enjoy this nice fall-like weather that Texas is having. So, thank you all for sharing. I always enjoy doing these different types of events because it's reaffirming for me as being a caregiver, and then, I learn things every time I hear from my patients and my patients' families. Thank you.