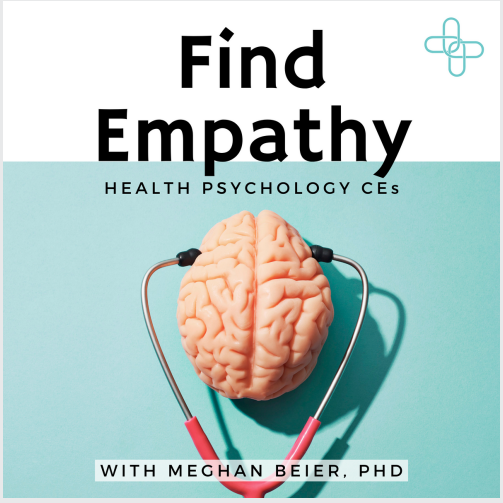
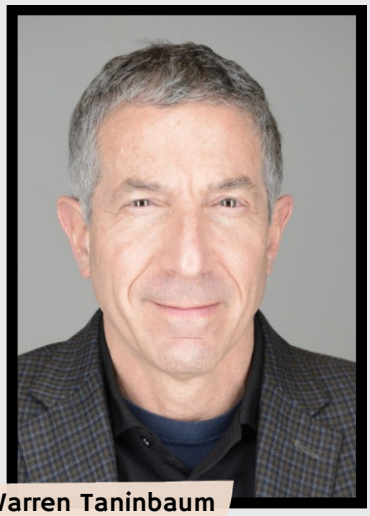
Find Empathy

Multiple Sclerosis Support Partners

EPISODE 4



Meghan Beier, PhD



Warren Taninbaum

Abbey Hughes, PhD

Rosalind Kalb, PhD

Course Highlights

The needs of Support Partners are often ignored or under addressed

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Support Partners are at higher risk of mood symptoms

Mental Health providers can help improve communication between support partners and people with MS

The importance of couples and/or family work

Multiple Sclerosis Support Partners

Meghan Beier, PhD: [00:00:00]

Welcome to the Find Empathy Podcast, where we discuss the interaction between health and emotions. My name is Dr. Meghan Beier, and I'm a clinical psychologist with training in health psychology, rehabilitation psychology and neuropsychology. In this first series, we are going to focus on a population close to my own heart, individuals and families living with multiple sclerosis.

We would love to list your practice in our directory and being listed is free. We're trying to help families and people living with chronic or acute medical conditions find the providers that can help them most. If you would like continuing education credits for listening to this episode, please head over to www.findempathy.com/learn.

Introduction

Meghan Beier, PhD: In today's episode, we're going to hear from three experts that will talk about support partners. These are the individuals that are often in the background who are often the invisibly affected in many chronic conditions. They include spouses, family members, parents, and friends, the conversations that you're going to hear focus on topics such as how family roles shift over time, grief, loss, healthy communication, the value of proactive planning and strategies for managing emotions in a healthy way.

Our experts include Warren, a husband supporting his wife who is living with multiple sclerosis.

Warren Taninbaum: My name's Warren Taninbaum My wife, Loretta has, been diagnosed with MS since 2012. We have two daughters, both grown and out of the house now. I have been in the military 28 years, retired 2014, owned my own business. Um, and that's kind of in a nutshell.

Meghan Beier, PhD: We also have Dr. Abbey Hughes, a psychologist and researcher at Johns Hopkins with a specialization in multiple sclerosis.

Abbey Hughes, PhD: I'm Abbey Hughes. I predominantly work with individuals with MS and my training background includes post-doctoral training in MS Rehabilitation. My research interests have evolved over time to really focus on health behavior changes that are easily accessible for people with MS and people affected by MS, including support partners.

Meghan Beier, PhD: And finally, we're going to hear from Dr. Rosalind or Roz Kalb one of the country's most specialized MS psychologists. She's a clinician, educator and author who has

dedicated the majority of her career to supporting the families of individuals living with multiple sclerosis.

Roz Kalb, PhD: So quite a few years ago, at the beginning of my career, I actually worked at one of the first MS Comprehensive Care Centers in the country.

That was in the early 1980s. And I was at the beginning, primarily doing group work with individuals, living with MS which is my favorite way to work with people. And gradually their family members came into greater focus. And I didn't know anything about MS when I started, but it seemed really clear that family members were living with this disease as well.

And even though the focus of the healthcare team was primarily on a person with the disease the needs of spouses, partners, children, and even older parents of these patients were huge with nobody paying much attention to them. So that became a very early interest and focus of mine.

Warren Taninbaum - Support Partner

Meghan Beier, PhD: Let's start by hearing from Warren. In this rich discussion, which I was privileged to have with him, he describes what it is like for him to be the support partner, to his wife, Loretta, who is living with multiple sclerosis. Many of the themes he raises are discussed in greater detail by Dr. Hughes and Dr. Kalb in the following sections. Some of the themes that he brought up include how relationship roles shift as MS progresses, communication successes and challenges, managing the uncertainty of living with MS, whether you're the person with MS or the support partner, feeling invisible. Finding resources, which can be challenging, and ways that support partners can continue to recharge their own batteries.

Warren starts by sharing what it has been like for him to be a support partner.

Warren Taninbaum: Um, definitely a lot of challenges, um, frustrations, small victories. Um, I think the biggest thing about it is, uh, there's kind of this unknown kind of amorphous. Description of [00:05:00] Ms. No one really knows what that progression will be, if at all, uh, it's different for everybody. You know, I've met many different folks with MS and everyone's unique and has a different story.

Um, and, and, and so you just almost have to take it day by day, I think is really the way I look at it. Um, I try not to think about. Um, how long she's had it or how long, much longer she might have it. Um, what it'll be, what each day will be like. And I just wake up every day kind of renewed and ready to take on the day.

And, um, so that's the biggest thing about it is you just really don't know what path you're going to be following. Um, so.

Meghan Beier, PhD: I wonder, how have your roles shifted since Loretta was diagnosed with MS.

Warren Taninbaum: Well, in the beginning, when they diagnosed that she had very minor symptoms. If, if anything that you could tell she had MS. And so in the beginning, it really wasn't. Any kind of change in, I was in ignorant bliss about what, what might come to be. Um, and Loretta's role was always, one of, kind of homemakers took care of the kids, took care of the house, the shopping, the cooking than I did the traditional role of, of working and, um, and other things.

Um, And eventually that, that started to shift as she became, uh, um, less functional in her movements and daily activities. Um, and I, I became much more of a support person to her. So I ended up taking over all the household activities, um, along with everything else that I was doing. So, you know, today I'm basically the cook.

I try to clean the house as much as I can. Um, and I physically have to assist her with most of the activities of daily living. Um, so it definitely been a significant change in, in our roles

Meghan Beier, PhD: Emotionally, I hear from a lot of people that that can be a really difficult shift that people, um, With MS feel guilty about their partners taking some of these roles on or having to take more on, or sometimes they describe feeling frustrated because they don't want to lose that independence. Has that happened with you all as well?

Warren Taninbaum: Uh, absolutely. Um, you know, my wife always again, felt. She had this traditional role and it was important to her to keep the house clean. And in order she was a great cook and certainly is still a great mother. But I think she has struggled, to not be able to do those things anymore.

And I've struggled a little bit in having to do more of those things. I accept modern relationships where maybe the wife and husband equally cook and do laundry and everything else, but ours was a more traditional relationship and I was happy and fine with that. And now I'm struggling to do more, but really for my wife, it's been a tremendous loss of, of, of things that were important to her that she can no longer do.

And simply accepting that that fact, um, has been a challenge.

Meghan Beier, PhD: How have you helped her through that loss? Or, I mean, how have you communicated about these things together?

Warren Taninbaum: That's a good question. You know, somebody just happens because it has to happen. Um, so I've definitely taken on the roles that are needed to keep the house functioning and, and our lives moving forward. Um, I've not done it to the scale or the, the level of expertise that my wife has. Another she's a far better cook. I cook, uh, out of necessity, um, housecleaning, a house as clean as, as we need it to be, but not nearly as good as she did. So there's a bit of that struggle.

There's a bit of a frustration for her too that i, I can't do those things to the level that she does, although, you know, she's taken care of. Um, and, and more so the loss of her ability to, um, do those things. And at times it comes out in frustration or sadness for her, sometimes just sad that she can no longer do these things.

Me sometimes frustrated that I have to do these things. Um, So I, I think we're okay in our communication, but I don't know that we proactively talk about those kinds of role reversals. Um, other than when one of us is perhaps feeling sad or frustrated. And that's a challenge, I think, because things are just happening in a way that drags us along as opposed to planning for like a vacation or planning your life, your, your retirement. This is more we're being dragged along into these [00:10:00] various roles her having to give up certain responsibilities and me having to add to my, my role and list of responsibilities. So I wish we were really in some ways, a little more proactive, but it's so gray and fuzzy out there as to what our future looks like. That it's just so hard to be proactive in dealing with, uh, role reversals with MS.

Meghan Beier, PhD: Yeah. And well, it sounds like there's a lot of uncertainty, in what the future holds. How do you manage that uncertainty?

Warren Taninbaum: I've been doing counseling on an ongoing basis once a month, it used to be in person, of course now it's by video, just to kind of make sure my head's in the right direction.

I did talk to someone who's, uh, a therapist who specializes in MS, and I was really looking for the crystal ball. And when I came out of the session feeling was, there is no such thing that even a therapist, that is experienced in MS can't tell you what your future's going to look like. And I was trying to understand, at what point do I let go? What point do I say I can't do it anymore? At what point do we look for assisted living or some other form of professional care. Um, that's one of the big things about our future I'm concerned about, I'll be talking to a lawyer who's familiar with things like Medicaid assistance or how to preserve your assets and what type of care, you know, you can be looking at from a financial perspective. But for the most part, I just take it day by day. I just don't have any anticipation of where tomorrow will be.

Um, and, and that's one of the most frustrating things. There's no playbook that anybody, no matter how experienced they are, can tell you about your future. And, um, so I I've stopped trying to figure that out other than to be a little more prepared financially. Um, one of the things I've learned is to reach out for as much assistance as I can.

So you know, that I can't do it all that maybe, my kids were suggesting we have a housekeeper come in and help there. Um, I'm going to be having to look at maybe a little bit of respite care. I, my parents are still alive, but they're aged, they're aged. And, I still, I really need to go see them, but I've really struggled to leave Loretta alone for several days in the care of somebody that we don't know. But I'm finding, I have to learn to let go a little bit in that regard.

Meghan Beier, PhD: I'm pleased to hear that you said that you saw a therapist. I don't think a lot of people do that. What was helpful about that experience? You know, if there are other therapists that are listening to this. What, what do you think would be most helpful for them to work on with family members that are living with MS?

Warren Taninbaum: I think certainly to empathize and understand the roles and frustrations that a care spouse has. Um, you know, I would say the same in talking to the medical doctors that they think typically of how to treat the patient, but not the person that helps the patient.

Um, Uh, Def definitely, um, you know, to understand and to be able to help with the struggles mainly emotional. I think that care spouse goes through. Um, for the most part when I've done it, it's just a way of making sure I'm vocalizing my concerns or my feelings that may be, I wouldn't say, in front of my wife, that I can in front of a therapist.

And, um, I also belonged to, uh, an MS group. So you have both MS. Patients and their care spouses. Um, and you know, sometimes I'll grab a coffee with one of them because, you know, I think we can really empathize with each other. One of the biggest things I think I got out of my therapy was to reach outside of just, you know, my immediate family for help, but there are other resources and organizations out there that I need to call upon them to help to make it a more tenable situation. I think that was initially with a therapist, something I got a lot of benefit from. Uh, and now it's more kind of a maintenance role that. Uh, I have with the therapist we've gone to once a month and sometimes I come out of it and I'm like, okay, you know, I didn't get a whole lot out of it, but I still feel it's important enough to, you know, to see a person once a month, just to make sure my head's in the right place.

Meghan Beier, PhD: You talked about some of the challenges that you both have gone through. Are there any silver linings that you can point out, things that, you might not have experienced if Loretta had not been diagnosed with MS?

Warren Taninbaum: That was a question [00:15:00] I had to think long and hard about, um, you know, I don't know that I can really go, "oh yeah, absolutely. There was this silver lining." I think I'm a little more empathetic. Um, I'm obviously a little more caring, uh, certainly on a physical plane. I have to be in an emotionally I'm working at it. And, um, I think in some ways it's brought us together a little more, uh, certainly our lives are much more intertwined.

I called it doing the dance. Um, and a lot of that is physical. There are certain movements that I have to do to help her. And when it's something new and different, like one time we rented a car and the seating was different. And to get her in that car was much more difficult, awkward, and became very frustrating for both of us.

So we kind of have this dance of. When I get her up in the morning, I know how to kind of pick her up, remove or not something that a PT person would say is smart, but nonetheless, we do it and we do it fairly well. It's brought us together, in, in ways that ordinary couples don't, don't have, along with the challenges and frustrations, you know, the only thing, again, I can say is that I know other people can have it worse.

I don't know that I call it a silver lining, but that's how I kind of get through this too. Um, is there other people that had it worse, they had it earlier in their lives that we've lived, you know, fairly good healthy lives up until recently, and we have to be thankful for it. So those, yeah, those are some of my thoughts on that question.

Meghan Beier, PhD: You mentioned grabbing a coffee with somebody who, you know, is a support partner, a family member. I, you know, I work with a lot of family members, maybe who I'm the first person they've ever really talked to about MS and I wonder if you have any thoughts or advice for family members, spouses of people living with MS who maybe haven't reached out for help or haven't gotten connected to those resources.

Warren Taninbaum: Yeah. So I have two thoughts on that. One is, when you're first diagnosed with MS and you go and you see the doctor and they say, this is what you have, and of course your, your mind is racing and, you know, here's the next step get you on medication and you're going to see this doctor.

There's really no guidebook that's given out for the care spouse. Um, nothing. It says, okay. Here's the things that you should be thinking about. Or as a couple, here are the outside resources you should be talking to. Like here's a MS group. Here's another spouse care group, all the things that I had to learn and struggled to find on my own, they should be documented made available almost as soon as you walk in the door.

So what I would tell them is you're not alone, that there are many resources out there. Uh, there's the MS Foundation, the MS Society, you can call them there's local chapters. They can give you idea of where there's community groups, uh, where you can get together once a month with other patients and care spouses.

That there's a lot of services even within the hospital or the MS center that you may not even know. It took me a while to, to understand that Shepherd had much more services than we were being told in the beginning. Um, and the other advice I would give for care spouse, and one thing that I've done really well while I've made a lot of mistakes and not done some things as well as I should, um, taking care of yourself, when we're at, um, uh, an MS group. Uh, I, I noticed a lot of, a lot of the care spouses don't take care of themselves and it's as equally important to take care of your spouse as it is yourself to charge your batteries, to go see your friends, to go play sports, to do whatever it is that gives you mental relief and, and charges the batteries so that you can be a better care spouse at the end of the day.

And sometimes I think we feel guilty if we do step away from our spouse, but equally, if we don't. And we don't charge our batteries. We're not going to be a good care spouse. So that's the other thing I would definitely say is still find a way to make sure you charge your batteries, um, with your own me time.

Meghan Beier, PhD: What do you do to recharge your batteries?

Warren Taninbaum: Sports is definitely one of the things I do. Um, so while my wife, she's in a, a power chair at this point. So, uh, you know, she has some freedom of movement, but, she can remain on her own for several hours of the day. So I'll try to go out as often as I can. I still play organized hockey, which again is a good kind of group.

Get out with the guys kind of thing. I think that's a big one for me. I will go have lunch with friends. I'll schedule my, my recreational activities around her needs, but it can be done. You can make it work.

Meghan Beier, PhD: Do you have anything else that you think would be important to talk about or anything that you haven't said that you think would be important for [00:20:00] mental health providers to know?

Warren Taninbaum: At the beginning, of course, like everyone else, I struggled, when my wife first needed some assistance, maybe she could walk a little bit, but not long distances. And I had her in a wheelchair in the beginning and we walked into a restaurant, uh, or I'd have to hold her hand.

I dunno. I felt a little, I don't know if the right word is exposed. You know, people looking and wondering what was going on with my wife. Uh, I had to work through that. It wasn't difficult. I didn't feel like, oh my gosh, my wife's handicapped and all that, but it was just more for her to just feeling like, oh, this isn't who I was or who I am. And there were some emotional struggles there. Now doesn't matter, we do what we gotta do. Uh, Can Do (Can Do MS), which is a very special MS opportunity for the wife and or for the patient and the care spouse to attend also taught us to be as proactive as we could, in getting help mobility being one key thing.

So from that we realized, okay, we need to get her a power chair. It was time. You know, again, here's another resource that I found out about on my own just one day. And next thing I know I'm in this four day program, that's educating me and providing me with the tools needed to make it a more meaningful life and experience for my wife and I, and, um, and then I could share that with other people in some of the groups I belong to that had no idea that it existed or, or its true value. Again, I think it just comes back to pushing the care spouse, to look for resources because they're not gonna come to you. And again, the thing I still struggle today with is giving up certain things. You know, my, my children are kind of intervening with me about, you know, make sure you take a day off from work. So I set Sunday aside, uh, get someone to come in to help, you know, do like cooking, maybe housekeeping, to help, my wife a little bit as needed. Again, just to look beyond ourselves and what we really don't know and what, what is out there and take advantage of it.

That's I think a huge thing I'd recommend for any therapist to recommend to their, you know, take, take care of yourself, but also make sure you find the resources out there to help you and your spouse.

Abbey Hughes, PhD - MS Psychologist and Researcher

Meghan Beier, PhD: This Next section we hear from psychologist and researcher, Dr. Abby Hughes. She shares what the research tells us about mood disorders, among family members and support partners of people living with multiple sclerosis.

She also discusses a recent study that she conducted, which examined the impact of teaching both people with MS and their partners, emotion regulation skills, and these emotion regulation skills came from the theory of Dialectic Behavior Therapy.

So we know that MS doesn't just impact the person who's diagnosed, but it also often impacts the entire family unit. Can you talk a little bit about the mood symptoms that are common in family units or support partners ?

Abbey Hughes, PhD: Sure. So support partners, this can include spouses, friends, family members, anyone who is in, uh, close to someone with MS who provides either formal or informal support to them. So it's a very broad definition. Um, and we know that when MS hits it, doesn't hit just the individual, it also affects the family and roles can change.

So when we talk about mood symptoms or emotional symptoms, and MS, that's not necessarily just the person with MS, but also the support partners as well. And we know that caring for someone with MS can be a very rewarding experience. It can bring people closer together. Um, it can really change the dynamic of the relationships and it can also be a stressor, right?

There are good stresses and bad stresses. There are helpful stresses and unhelpful stresses. And when we focus on maybe the unhelpful stressors, those role transitions, you know, going from maybe a, an equal partner where you're both working full time and co-parenting, um, to a support partner who's taking on more of that, uh, labor at various times in life, that can be an additional stressor and prolong stress without the same kind of social support, um, can make one vulnerable to developing mood symptoms and mood disorders.

We also live in an environment in a society where access to care is. Uh, a barrier and that includes support partners too. So one might think, you know, I would really love to meet with a psychologist, but I need to work full time. I need to pick up the kids. I need to pick up prescriptions. I have these other things.

And so support [00:25:00] partners can sometimes put their own needs second or last. Um, and then over time that can make them more vulnerable to a mood disorder like depression or anxiety separate from these diagnosis though. There's, there's also general emotional distress, right? There's all there's times in life where we all experienced heightened, emotional distress and our ability to manage that distress can also vary on our unique circumstances. Um, and so the research study that you had just alluded to, instead of focusing on just people with diagnosed depression or diagnosed anxiety, the way that a lot of mood studies typically are designed, we were more interested in looking at roots symptoms, right?

So feelings of sadness, feelings of worry, but also how both people with MS and their support partners are managing emotional dysregulation . When they do feel stressed, where do they go to for support? How confident do they feel like they can manage that distress? And what strategies do they use to try to manage that distress?

Meghan Beier, PhD: You know, and you had mentioned, um, that sometimes being a care provider can have rewarding aspects. So I wondered if you could talk about that a little bit more.

Abbey Hughes, PhD: Yeah, absolutely. I'll, I'll be frank. When we first started designing this study about five years ago, um, there was a real focus on caregiver, burnout and caregiver

burden, and these words, burnout and burden are, are really, um, pervasive throughout the literature.

Um, if you're looking at caregiver research, it's often focused on those words of burnout and, um, burden, and unfortunately that really misses a whole area of. Resiliency and improved communication and improved, uh, intimacy for people who, um, kind of survive a trauma together. And B you know, having MS or being diagnosed with MS.

Um, for some people is a traumatic experience. So having your, your partner with you to go through that experience with you can be, um, a real relationship building experience. Um, and so that's why when I talked to support partners, um, I try not to just ask leading questions of how stressful is this for you, or how much of a burden is this for you?

Because in some ways that's, um, that is a ablest way of thinking, right? It's a way of discriminating against people with disabilities. And instead acknowledging that there is some, uh, benefits. So what are, what are some. Benefits that have come out of this experience. That doesn't mean that you wouldn't change it.

If you could go back in time and not have MS, that doesn't mean that people wouldn't change their course. However people do tend to acknowledge when they have the space to do so. Um, some of the growth that they've been able to experience.

Meghan Beier, PhD: You recently wrapped up a study looking at emotional health in people with MS and their support partners. It's very unique in the fact that you had both partners enrolled in the study.

Abbey Hughes, PhD: Yeah. Um, so just to summarize the design of the study, we recruited people with MS and one of their designated support partners as a pair. So typically in studies, we think of participants as a single person. Um, but in this study we treated them as pairs and they attended all of the groups together as a unit.

And we thought about their symptoms as not being the person with MS who has depression, but both the person with MS and a support partner are both experiencing some kind of emotional distress. And so the design of the study was to see if a, uh, group based intervention that we ended up doing entirely remotely, um, because of the COVID pandemic, if an emotion regulation skills training group would be more helpful than traditional peer support for helping partners, so these pairs, Learn skills for regulating their emotions more effectively. And if that then translated to better mood, so less depressive symptoms, less anxiety symptoms, more satisfaction with life, better quality of life. Um, and so what was unique about this study is typically we focus either just on the person with MS or just the support partner.

And by combining this, uh, both of the people with MS and their support partners into the same study, we were hoping to acknowledge that this is what happens in real life. In real life, in everyday practice, when you're, when you're feeling down, your partner might also feel down with you or when you're stressed, your partner is stressed.

And when you feel great, your, your partner is excited with you. There's that empathy and transactional aspect of it. Um, and so we were interested in, if we can. Help partners learn these skills together. They might help coach each other throughout the week. And so in that group, the experimental group was this emotion, regulation skills training group that was, uh, adapted from dialectical behavior therapy or DBT.

Each week the partners and people with MS would learn a new skill. This included skills like mindfulness, um, [00:30:00] emotion, regulation, distress tolerance, they would learn these skills and then practice it. They would practice with each other. They would practice with other people in their networks. They would practice with people in the group, um, and they would come together each week to do that.

The other group that we were comparing it to was a traditional peer support group. Like you might find in your community, if you were to look on the National MS Society website for a peer support group, what was a little bit different is these groups were also led by licensed clinical psychologist.

Um, but they weren't really intended to be therapy groups. Um, they were just meant to be a place for people to come and get social support with one another, um, and complete some, uh, general activities together with some resources from the MS society. So that was the setup of the study of comparing these two different groups.

And after, uh, the 12 week groups, so each, each group attended weekly for 12 weeks. We compared mood, mood symptoms. And also for the caregivers, we looked at caregiver, um, symptoms as well. And that included things that were stressful about caregiving and also things that were resilient about caregiving. And those were the outcomes we looked at.

Meghan Beier, PhD: I'm curious about the emotional resilience skills. How did you choose which skills to teach in the, in the groups?

Abbey Hughes, PhD: Sure. So for emotion regulation, there's a very specific protocol from DBT. I'm not an expert in DBT, we had a consultant and collaborator researcher on this program who led the DBT groups.

Um, and so he was able to lead these groups true to form the way that a DBT group would be run in the community. But the skills, if you go through a DBT standardized protocol, there's a progression of skills where mindfulness is usually, uh, the core. It centers everyone at the very beginning where you learn different ways of practicing mindfulness. And then from there, it expands beyond mindfulness to other forms of emotion regulation. And then another skill set is called interpersonal effectiveness. So not only are we being more mindful of our emotions in our bodies, then we start to be more mindful of how we're interacting with others and the ways that we communicate, um, because we don't always communicate effectively, especially when we're experiencing stress and heightened emotion.

Meghan Beier, PhD: You know, it's, it's funny because we just spoke recently spoke to Dr. Alschuler at the University of Washington, and he spoke about mindfulness as a strategy that could be used in the beginning of an MS diagnosis for people to sort of understand what their emotions were and what was bringing up different emotions. And so it seems like

this theme is very helpful throughout not only getting a diagnosis of MS, managing changes that you might experience as you live with MS, and also in your relationships.

Abbey Hughes, PhD: Yeah, absolutely. I wholly agree with Dr. Alschuler and also that mindfulness can be effective throughout the lifespan of the condition, including for support partners, because at the core of mindfulness is a open curiosity of observing your surroundings and accepting.

What is as opposed to trying to have judgements against what's happening. So when we started to get into more of a judgmental state of mind, then that can be really ineffective and an ineffective way of coping and, and an ineffective way of interpreting our surroundings. So whether it's early in a diagnosis of accepting that one has the diagnosis or accepting that, you know what, this sucks, this is really not what I had planned for my life.

Um, that, that in itself is an acceptance, right? To say that, um, I'm not happy about this and I'm not having pleasant emotions right now. It's not to say I'm okay with this. And I think that's where acceptance and mindfulness sometimes, um, get a misnomer, is that it's the idea that I'm either surrendering or I'm giving up or that I'm okay with it.

Um, and in fact, it's, it's the opposite. I'm saying I'm very much not. Okay. And I am. Moving forward and I'm trying to learn and figure out ways to cope with this. Um, and that carries on through well, beyond the early stages of the disease. And it's also relevant for support partners. When, you know, you might get thrown for a loop when, um, your partner has a fall and, and now you're dealing with an injury and pain and, and these other things that maybe you haven't had to face together before.

Meghan Beier, PhD: Absolutely. Yeah. I'm wondering if you had any sense of, um, the individuals in the group, uh, did they did both sets, so the active group, as well as the support, session groups did they enjoy their time in the groups?

Abbey Hughes, PhD: Yeah, it's a great question. And one that I was very interested in learning. we measured satisfaction with the groups in both conditions and overwhelmingly both groups reported that they really liked the groups and that [00:35:00] they found the groups to be helpful for them.

This with the caveat being, this was also during the beginning of the pandemic all the way through the early part of this year of 2021. Um, and so in many ways, this was some of the only social outlets that folks had and that they would come together with people who were also support partners or were also people with MS.

Um, and so that was one unique aspect, um, that, that we'll never have that in history again, in that same way. Um, but in terms of satisfaction with the group, both, whether it was the peer support or the emotion regulation skills training, we had high levels of satisfaction, um, and perceived helpfulness of the groups, particularly using video conferencing.

I think we are in a completely pivotal moment in mental health where use of telemedicine. Um, I, it will be really frustrating if we go back to exclusively in-person days, given how accessible this modality is,

Meghan Beier, PhD: I agree, 100%. I'm interested to know about the support partners specifically, you know, many times I think that they often get forgotten. So when you walk into a medical appointment, if a support partner is with an individual with MS. The appointment really focuses on the person with MS, as, you know, maybe it should be, but they rarely get asked how they are doing. So I'm wondering about the support partners. Did they have anything unique to say about getting some focus and attention?

Abbey Hughes, PhD: Yes. Overwhelmingly the participants in this study were really, um, Happy and glad to be part of a group where they could speak with other support partners and also learn from other people with MS.

Um, we know that MS has such a heterogeneous disease. And, um, even if you understand, or you think you understand your partner's, uh, experience of MS to hear it said from someone else, uh, was really impactful. So when I was talking to some of the support partners, one thing that they said was, um, you know, when, when my wife talks about her fatigue, I know she has fatigue. I know that I'll never fully understand the fatigue, but it really, really affected me to hear that every other person in the group talked about their fatigue and any time I may have had a preconceived notion that they were exaggerating or you know, in the, in the worst example, they were trying to get out of doing some household chores that they wanted to do, right? Um, it, it really validated it for them. So that from, from an understanding, MS. And understand the perspective of someone with MS, that was something that the support partners really commented on.

From their own sense of support. We had some of our participants exchange numbers and plan to, continue meeting in other online formats after the study and potentially visit in person, um, in a, in a different pandemic, post vaccination world.

So, that connection I think was really, uh, powerful and something that they enjoyed. And, um, I believe 90% of our participants said that they would join a similar group again.

Meghan Beier, PhD: Do you have any preliminary results from that study?

Abbey Hughes, PhD: We do. I had mentioned before that. The vast majority of our participants did report enjoying the groups and finding the groups helpful.

What was interesting though, was it was the experimental group, the DBT skills group or the emotion regulation skills group that actually led to more or stronger improvements in depression and anxiety symptoms for people with MS and their support partners. So it, it begs the question of, we can all do things in life probably that make us feel better or things that we like to do, and the second question could be, is it really changing the thing that we most want to change or is it really treating the problem that we most want to treat? And I think that's a very individual question, right? Um, there can be. Many benefits of a social support group, um, that at least from the results of our study suggests that it's not effective for treating depression or treating anxiety, um, or improving, uh, acceptance or emotion regulation skills, but an emotion regulation skills focused group absolutely does do those things and did reduce anxiety symptoms and depression symptoms. What we don't quite know yet. This was a, this was a very small pilot study. Um, we really need a much larger

multi-site randomized clinical trial, um, to be more confident that the group that we're testing is actually effective.

We only had 40 participants, so it was 20 pairs and 10 pairs in each group. So that's from a statistical power standpoint, we were severely underpowered. We really need more data with a larger multi-site trial to determine whether this is effective and how long the effects last. [00:40:00]

Meghan Beier, PhD: And thinking back a little bit to the active ingredient here the DBT skills, what made you choose that type of psychotherapy, as opposed to many of the other kinds that we know of, you know, Cognitive Behavioral Therapy, Acceptance Commitment Therapy, well known couples interventions, you know, what made you choose that type of therapy as opposed to kind of all the others?

Abbey Hughes, PhD: Yeah. I asked myself some that's sometimes, um, for this particular study, uh, this came about, uh, because of my collaborator who has expertise in DBT and we've been talking for years about wanting to do a trial that tests, whether the skills could be effective for people living with chronic health conditions, including MS.

There was also around the time we were writing the grant, there was a recently published study, looking at DBT skills and particularly emotion regulation, and people with traumatic brain injury. Now, MS and traumatic brain injury are very different conditions, but the idea being that, when you have a neurologic condition that affects the brain that can affect your emotional processing of the way that you regulate emotions.

And so we were curious if having this approach to therapy could be effective, taking a more 10,000 foot view of psychotherapy in general, we have lots of data that Cognitive Behavioral Therapy, in MS is effective, for depression, for fatigue, for pain. We could have probably also done a CBT oriented program for people with MS and their support partners together, and that still would have given some novel data with the emotion regulation piece, though. It, it kind of comes back to what is the core difficulty that people often have just anecdotally when you're talking to patients or, when you're asking people how they're doing oftentimes it boils down to stress, I'm so stressed. I feel like I'm overwhelmed by all the things happening in my life right now, by the MS by work by the pandemic and DBT starts to distill down those skills for managing that emotional distress, and integrating that mindfulness component. Um, you mentioned Acceptance and Commitment Therapy. That's also a very heavily mindfulness based therapy.

So it would be interesting to continue to look at this in different modalities, right. We don't actually know if CBT, ACT, and DBT outperform one another. We don't know. Um, yeah. And for who, I think that's another piece that, uh, we haven't talked about too much in this podcast, but the, um, heterogeneity of MS and the diversity of, of people with MS.

It's not a one size fits all treatment. There may be different kinds of treatment that some people gravitate more towards some than others.

Meghan Beier, PhD: Right. One of the things that we talked about with Dr Alschuler earlier, um, in this podcast series was the idea that in MS, we're not always trying to, and I think this

is true for support partners as well, we're not always trying to make the emotions go away, right? We are not fixing this problem. It's more about learning to tolerate the uncertainty or tolerate the distress that comes along, um, and, um, tolerate changes in, um, your functioning or changes in your family roles. Right? If you're speaking about from a support partner perspective, um, and, and it seems to me that these DBT skills, that those skills for allowing somebody to tolerate distress would be very helpful.

Abbey Hughes, PhD: Yes. And I do want to provide the caveat that again, not, not a DBT expert here, um, DBT was really developed for people who have such severe emotional distress that suicide attempts and suicidal ideation are, um, a significant presence in their life. And, um, that DBT has been one of the few therapies that has really shown to, um, prevent a death by suicide, um, through, through the multiple factors that are, uh, involved in DBT, not just group therapy, but there's also an individual therapy component. Um, you have to have DBT certified therapists. Um, there's a lot of other components that go way beyond the focus of today's podcast. Um, but the idea being that tolerating distress as it is a really important skill that we don't usually learn in school. Um, sometimes our, our parents, aren't always great at teaching us these skills either.

Um, We do our best to kind of muddle through. And there are some effective ways of managing distress or tolerating distress. Um, Dr. Alschuler's work on tolerance of uncertainty is a huge piece of that. And within DBT it's called distress tolerance. So just tolerating, when you feel so emotionally charged that everything else feels like it's gone offline, like when we're so angry that we can't think clearly.

Meghan Beier, PhD: Absolutely. Now I know that this was a really small study and so we can't really extrapolate the results too far. But I'm just curious about whether, um, the [00:45:00] themes from the study change or change your own clinical care or have made you think about your clinical care in any different way.

Abbey Hughes, PhD: That's a great question. Prior to starting the study, while I would try to engage support partners in intervention, partners wouldn't often come to the appointments or it would be really hard to have patients and our support partners together in the room, um, or doing couples therapy.

And now, um, with telemedicine, there's so much more of an opportunity to have more of those joint sessions. So when I'm first meeting with someone, um, typically it's the person with MS, who I'm meeting with first, we have a conversation about how much they might want their partner to be involved in their care.

And if they might benefit from couples therapy, then we can make a referral to that. We could focus our work together on couples therapy and find a different therapist to do individual therapy for either partner. Um, I think I have that lens through which now I'm thinking of how do we, how do we integrate more of the family or the social structure into to therapy, um, because we're not going to cure depression or anxiety, or a lot of these things in a single shot, uh, intervention, just working with the individual person.

We can often be much more effective when we work with systems .

Meghan Beier, PhD: Yeah. The environment is so important, including everyone who's living in the household.

Is there any final thoughts that you have about, uh, how community mental health providers or other mental health providers who are listening to this might integrate support partners into therapy, or maybe even help with interventions for support partners?

Abbey Hughes, PhD: Sure. Um, going back just one step to, of other aspects of our study and when ways that my practice has changed and this may be relevant to other providers, um, is how much that validation of emotion is such a key component to that, that every emotion we have is valid. Um, our thoughts are not always accurate about those emotions, our assumptions and beliefs around those emotions are not always accurate, but the, the fact that we experienced some emotion is valid.

And, and I think just reminding and recentering within that to say that it's okay to be angry and it's okay to feel sad and it's okay to feel, um, mixed emotions at any given time. So that, I mean, it seems so obvious being a psychologist that we validate, and there are some therapies that. Do more or less of that validation depending on what the goal of the therapy is.

So I think that's going, moving toward that validation and, um, helps people be more accepting of their emotions and then, and then cope more effectively beyond that. And they can focus more on their behaviors, um, in terms of community providers of how to engage support partners. Um, it's gonna depend a little bit on your practice structure and how you do billing and how, um, you do diagnosis.

So, um, w we have a problem sometimes where an insurance company might not reimburse for psychotherapy if there's not a diagnosis. So a support partner might not have a formal diagnosis of anxiety, depression, MS. Um, or, or another chronic health condition. But that doesn't mean that they wouldn't necessarily still benefit from the therapy.

So it may take some creativity of working with the person with MS, to have some joint sessions with the family, um, where the focus of the therapy is still on the person with MS. But you involve the family in the goal of supporting the person with MS. If you're in a private pay situation where, um, you, you can really focus on either partner that gives you a lot more latitude and there's a lot of advocacy work.

So for, for those of us who are involved in advocacy work, um, for private practitioners who are involved, um, in legislation and other types of work, this is where we can really use our voice .

Meghan Beier, PhD: Absolutely. What are some resources for support partners? Do you know of any resources where support partners, family members can go for mental health care?

Abbey Hughes, PhD: Absolutely. My number one recommendation for support partners is usually Can Do MS. Um, it's a non-profit organization that you've probably talked about on other podcasts before. And I should have also mentioned this in the last podcast about

sleep. Um, but Can Do MS has a wealth of webinars and programs, not just for people with MS, but their support partners as well, where you can choose your own adventure of attended hour long webinar attend a two day program where you actually connected meet with other support partners. And there there's a five day program.

Meghan Beier, PhD: Yeah. And I think that the National MS Society also has some, uh, support groups that focus on support partners and there was a recently launched support group called eSupport Health that also has groups that are primarily for family members of a person with [00:50:00] MS. And I'm sure there's more out there through other organizations like the MS Association of America and others.

Abbey Hughes, PhD: Absolutely. And for providers who are maybe learning more about MS for the first time and working with a support partner, it can be a lot of really overwhelming information.

The MS Society has some beautiful brochures and handouts and educational materials that can be incredibly helpful and it can also be overwhelming. So I'll often have a conversation with the support partner about, what is your goal? What are you trying to understand more about, um, if six months from now, what would you like to know more about that you didn't know today?

And usually the goal would not be, I want to know everything about it's more effectively. I want to learn some skills for better supporting my person. And I think that's our breaking it down and helping someone navigate the MS Society website to find the resources that might be most helpful for them .

Meghan Beier, PhD: Absolutely. Well, thank you again for joining and talking about support partners today. If people want to follow your work where can they find you online?

Abbey Hughes, PhD: Sure. You can find me on Twitter. I'm Abbey J Hughes, PhD.

Meghan Beier, PhD: Wonderful. And I will also link to your Johns Hopkins website as well so that people can see the work that you're doing there. Again, thank you so much for being here and I, I truly appreciate your time and energy.

Abbey Hughes, PhD: Thanks so much for having me.

Rosalind Kalb, PhD - MS Psychologist, Educator, Clinician, & Author

Meghan Beier, PhD: And finally, we're going to hear from Dr. Rosalind or Roz Kalb one of the country's most specialized MS psychologists. She's a clinician, educator and author who has dedicated the majority of her career to supporting the families of individuals living with multiple sclerosis.

I'm thinking of somebody that I recently worked with and I turned to her spouse during one of the appointments and just said, and how are you doing? And he burst into tears. You

know, I'm not sure that he's ever been asked that before. And, um, I think you've shared similar stories. And so I'm just wondering if you can talk a little bit about the invisibility of somebody. Who is a family member of somebody living with MS.

Roz Kalb, PhD: Absolutely. I think this is not just true in MS. I think it's true. A lot of disease states that the focus of healthcare team families, friends, whatever is, is on the patient. Right. Um, how is this person doing what's happening with his or her MS or cancer or whatever?

Um, when I meet with groups of support partners, which is a very powerful experience. If I say to the group, how long have you been asked how you're doing maybe one or two hands out of 15, 16, people will go up. If I say, how about within your own family? How often are you asked? How are you doing? Um, it's just not happening.

They're not really upset about that until I pointed it out because many support partners don't feel that the attention should be on them or don't feel that they deserve help because they're not the one who's sick. They're not the one who's needy. So they make sort of stuff their own needs and feelings down until, someone like you did with your patient, somebody says, well, okay, so how are you doing?

And then in the support group, one person starts and shares and talks about a challenge or fear or worry. And then the next person, and I've had groups where suddenly 14 or 15 people were all passing the Kleenex box around. Crying. And it's the relief of having some of their own feelings made, normally made acceptable.

If they hear other people talking about healing, grief, stricken, resentful, guilt ridden, um, overwhelmed their own feelings, come into focus, and they're just overloaded.

Meghan Beier, PhD: You know, and so you're highlighting some of those feelings that people are bringing up, but beyond those feelings, where are those feelings coming from? Where some of the challenges that are, what are some of the challenges that you hear from people, family members of people with MS.

Roz Kalb, PhD: So I think that several come to mind, but we have to bear in mind that the majority of people with [00:55:00] MS are women.

So many support partners in these groups, are men, not all, but many are men. And in one support group I had there, when that, uh, this was at an in-person Can Do MS program and we met five times over four days. And I noticed that there was a group of guys who chose to sit together at each group. And when I finally commented on that and.

Got to know them a little better. It turned out they were all engineers. They were different types of engineers, but they gravitated towards each other in this group because their mindset and their whole beings were around fixing things could be fixing cars could be fixing buildings could be fixing, but they, they needed to fix things and they couldn't fix this.

And their feelings of failure of inadequacy of guilt were around not fulfilling what they saw as their role as a partner. So I think that's part of it. That's one thing. The second thing is that

the disease itself is out of people's control and show support partners, as well as their loved ones with MS.

Are always waiting for the next shoe to drop. Um, we just about get a handle on what's happening today and strategies to manage it. And then it all shifts. It shifts later the same day or the next week or the same month, and we have to start problem solving all over again. We have to grieve all over again of the changes.

Um, so that's another. The third one I think is, and this covers a lot, but the partnership for, particularly couples, right? The partnership changes as MS symptoms interfere. So we could be, uh, the more obvious physical symptoms, which make it harder for them to do things together or carry out their household activities or take care of their children.

Um, or it could be the, the, the less visible, but really more impactful mood and cognitive changes, which subtly, or perhaps not so subtly alter, um, communication, shared decision making, uh, shared planning and problem solving where suddenly the person who's been your help mate is not fulfilling that role for you. And you feel as a support partner abandoned or like you're having to go it alone. Um, Or you just miss the person's smarts or humor or, um, general ability to share a life with you. It gets pretty lonely for some support partners.

And I think for parents who are support partners, it's like throwing your hands in air, right? You, you have adult children who have left home, launched their own families and careers, and suddenly they're faced with really significant challenges sometimes. So significant. They come back home! And aging parents, they will wait a second. How am I, how do I parent this child? I adore who is now an adult when I'm feeling my own age and my own limitations.

Who's taking care of whom. I think those are all big themes in what I see.

Meghan Beier, PhD: Okay. How about children of people living with MS?

Roz Kalb, PhD: It depends on their ages, of course, but I think, um, many parents struggle with when to tell your children about MS. Um, and yeah. Um, my, my two very favorite short stories about that, where one parent came to me at an in-person meeting and said, she really, really wanted her son to understand where I'm asking.

She wasn't sure when to start talking to him about it, but she didn't want it to take over his life or smile his life. And they said, how old is your son? And she said, 18 months. And I said, well, I think we first need to wait until we can really talk and understand. And then it's a little bit like sex education.

We'll start simple where their questions are and you gradually give them information, but we can give him a little time, yet. And then another mother who said know, now my son's not taking his medication. I'm just frantic with worry. I don't know what to [01:00:00] do. I don't know how to be the best child to him. So how old is your son?

And she said 35, so, well, you know, he's 35, she's a man. And he is making decisions. You may not agree with, or I may not agree with, but he's a 35 year old man who gets to make

his own choices. So parents struggle at whatever age and, um, I think when I have worked with families the most around this, it was when, uh, um, an adult child with MS was trying to figure out how to be as independent as possible, make choices, go to parents for emotional support when needed, but not returned to the helicopter parenting of their young, young lives or their teenage lives. And if like an adult with MS does have to move home, then it's helping parent and child, renegotiate a relationship they've essentially grown out of.

So you're living in my house again. This is how our household runs. This is what our rules are. You need to respect our needs we need to respect yours. Let's talk with them, how we can do that.

Meghan Beier, PhD: I wanted to ask you another question. You were, you were highlighting sort of the fixer type person before. I think there's the fixer, both with the, with people that have MS as well as family members, um, And I think a lot of that is trying, at least from my experience is trying to push away the grief of this situation, trying to make it better. Um, but I wondered if you had any thoughts about that, you know, what, what advice do you give people when they are in fix it mode? And this is something that can't be fixed.

Roz Kalb, PhD: That's a great question. And I, I have always said that I worry the most about. People with MS who get the diagnosis and decide that they are going to be the ones to beat this. They are going to fix it . It's not going to get them because these are individuals that I know are setting themselves up for failure rather than success, because we don't know how to beat this disease yet.

So what I try to help those individuals with MS. And also their support partners to recognize is that there's a difference between trying to fight the war on MS, which we're all working on, but we're not there yet. And how to pick individual battles or individual challenges that we can do something about.

And so identify individually and together. What are your biggest challenges today? And what are the strategies you can use to improve those who are the right healthcare professionals? What are the right community resources? What, what can you do on those? And then when they get wound up with their, what ifs.

What if I can't walk, what if I can't do my job? What if we can't live in this house anymore and they're ruminating and then sort of unproductive and very uncomfortable way. I'm likely to say, okay, let's talk about, what's the biggest worry right now? Well, what if I can't walk? Okay. What could you do today that would help you feel less vulnerable and more prepared if the disease were to go that direction? Would you have to think about different work? Would you have to think about a different place to live? What could you start to think about and plan? So you have that in your back pocket and you can stop worrying about it.

Um, and, and I think that really helps fixers because they're. They're reframing what "fixing it" means. And they're coming up with strategies that help them feel a little bit more in control,

Meghan Beier, PhD: puts them back in the driver's seat,

Roz Kalb, PhD: put them back in the driver's seat to the extent that we can do that with MS.

Meghan Beier, PhD: Right, right. I'm wondering if I also see. Two ends of a spectrum for family members. And I wonder if you can talk about this more or tell me if you agree with the spectrum. I sometimes see family members that say, they're fine. I can't see anything there. There's, there's nothing going on here. Why aren't they doing more things around the house?

I also see sometimes family members who want to do everything for the person. I mean, they don't even want them to get out of the seat. Right? Like they want [01:05:00] to. Make everything for them, almost take over and there's, there's certainly people all throughout that spectrum. Um, but can you talk a little bit more about that and maybe different strategies for managing those challenges?

Roz Kalb, PhD: Well, I'm going to start with the answer, which is communication, because I think that's at the root of everything, but I think the spectrum is absolutely real. Um, and it's motivated by different things for different people. Sometimes support partners, hover, and overprotect, and step in to do everything for their loved ones, with MS, without regard to whether the person with MS wants it, needs it, or has indicated any wish for it. And I think for them sometimes that's, um, Trying to exert control over a situation that feels out of control. Sometimes it's, it's like, um, a mother hen. I'm so worried about you and I'm so anxious that you're going to fall and hurt yourself, or you're going to make your MS worse, or something bad is going to happen that I'm going to kind of wrap you in a cotton ball and try to keep you safe. Uh, sometimes I think support partners are looking just to feel better about themselves. And so they do things that make them feel better, but may at the same time, make the person with MS feel worse.

I think the other piece of this is that folks with MS sometimes give very, very mixed messages. And our work with them has to be around helping them recognize when they're giving mixed messages and try to clarify. So if on one day your family member with MS, um, says to you, stop hovering. I'm fine. I want to do this myself, and you're just, you're just in my way, could you just back off? I'm not sick. Support partner says, got it. I'm backing off. Um, you're you handle what you can handle then on Tuesday or even late in the afternoon on Monday the person with MS says can't you see that? I feel awful. That I'm exhausted.

Why aren't you helping? Why aren't you doing more? What's wrong with you? Well, support partners can feel pretty bad. Um, not knowing when's the right time to step in. When's the right time to step back and feeling like they're guessing all the time and walking on eggshells. And that's when our work as therapists is really to help the two people communicate in a clear, more effective way.

Right. So it can be as simple as. Um, you as a person with MS. Need to take responsibility for giving clear signals, no matter how so much, no matter how much somebody loves you, they can't read your mind. They can't read your body and you can't expect them to, that's not fair. So you have to say, today I'm feeling really pretty good, and I'd like to go it alone, but I will let you know if things go south and I need, I need some help. Right? Even with mood, I worked with one couple, her moods were all over the place, irritable, angry, jumpy. He was

always walking on a minefield. They worked out a system. Where they put up a little chart in the bathroom because that's the room. They were both in, early in the morning. Right.

And if she woke up and it was a pretty good day and she was feeling pretty calm and whatever, she'd put up a green dot. And if it was the day that she was loaded for bear and knew, she was just. Wired, she'd put up a red light and he knew to kind of back off, give her some space until she felt better. So whether it's in words or in a code of some sort or signal, the two members of the couple have to be able to understand what's going on.

We want people who love us to be able to read our minds, but it just.

Meghan Beier, PhD: It doesn't happen. [01:10:00] I wish that I wish it worked, but it doesn't work,

Roz Kalb, PhD: but it doesn't.

Meghan Beier, PhD: No, and I hear that a lot from people actually that they think their family members should just know what to do, what they're thinking, how they're feeling and it's it's surprising when I come back and say, no, no, you have to be very clear and ask for what you need. Even if that's in a conversation where you say, I want you just to listen and not problem solve right now, or, you know, you give them what you're looking for before you start talking.

Roz Kalb, PhD: I think that's a really important piece of advice that sometimes support partners really need to be told you don't have to do anything. Just be here with me, just listen. First of all, it's a great relief to some support partners, but it also lays the kind of ground rules for the, for the conversation. You know, I also had, uh, a support partner who said, I wish my wife had a gas tank and the top of her head, a little meter on it.

And then I could see when her energy was running out. I wouldn't have to, I wouldn't have to guess, and I wouldn't have to step in it and get in trouble when I ask her to do something that's just beyond what she's able to do right then.

Meghan Beier, PhD: You know, and I think some of the things that you're bringing up, uh, have to do with MS.

And some of them are normal, couple things, you know? Um, so as a person who works with family members or couples living with MS, how do you figure out what is MS. That's bringing these problems to the table. And when it is, this is just a normal couple relationship that if you went to see any marriage therapist, they would work through it with you.

Roz Kalb, PhD: I think the starting point for that really important conversation is to you ask them, um, and get the little history. So sometimes it's as simple as pointing out, you know, this might have to do with MS and it might not. And for some couples, that's, that's surprising thought, what do you mean it doesn't have to do with my MS.

Well, let's explore. Did some of these same issues or conflicts happen before I'm asking him into the picture. Do you ever have similar types of challenges or disagreements about other

aspects of your life that don't have anything to do with them as MS? MS becomes a very easy target for blame because it's there.

But I think over the years, what I've learned, um, particularly for couples who were together before MS came into the picture. That MS tends not to bring a lot of brand new couples issues with it. It tends to highlight or exacerbate some issues that were already there. Right. But this was kind of a tipping point in terms of those areas of conflict or disagreement.

And the kinds of regular couples issues might be simple communication. How was your communication before, but it could also be styles, you know, people. In couples aren't always the same and their preferences or their likes or their, uh, feelings about, um, do we do everything together or do we do something separately?

Do we like very, very active things or do we also like activities together that are not so active? How do we manage disagreement when that happens? Do we fight fair? Right with respect and tolerance and good listening skills, or do we go for the jugular? What's the style? They have to discover for themselves, I think, with our help, oh, some of this doesn't have anything to do with MS. Right. And what happens if we just set MS aside for a minute? Can we. Can we problem solve a little bit about how to handle, um, what's going on? Does that sound right to you?

Meghan Beier, PhD: Absolutely. Yeah, that definitely sounds right. Um, you know, as you're talking a few other things that are, are coming to mind for me is, um, you know, how did you tackle problems before MS.

You know, did you. Attack them together as a team or did one of you try to solve it. And the other person sat [01:15:00] back. And, um, I see that coming up with MS. A lot where if people or couples are, are tackling that problem, the problem of MS, whatever that brings to the table as a team, they tend to do better than if one person is relying on the other person to manage it.

And I don't know if you had any other thoughts about that?

Roz Kalb, PhD: Well, one that just came to mind is that sometimes there has to be some real role changes, right? Um, some of the obvious ones person with MS becomes less able to, um, bring in financial resources, less able to manage household responsibilities, whatever, less able to do it, but sometimes they have to swap roles around things that are a little less clear. So let's say one person in the couple was the problem solver. Was the more organized manager of things, um, and the other person executed tasks. Well, maybe was fabulous with the kids and planned fundings. And suddenly that organizer has I'm asked and cognitive issues and the skills that they brought are compromised.

And then you have a support partner who is really out of his or her depth. I didn't have to keep the bills organized and the children's activities and the household and the taxes. And, uh, because that, wasn't what I was so good at. My partner, used to do those things.. Then suddenly they each have to learn how to play a different role and those couples need a lot of help.

They're doing things that don't come naturally.

Meghan Beier, PhD: Now we're bringing up a lot of different topics, but I'm wondering if you could summarize for me. When you first meet a couple or a family, or maybe you're working one-on-one with just a support partner, what are the primary things that you're asking, looking for? What's what's the jumping off point for your work with that person?

Roz Kalb, PhD: So if it's a couple that comes to me. You know, it starts with that obvious mental health professional question. Why are you here today? What's changed? What are you struggling with? And what are, what are the biggest challenges and what are the strengths you think you each bring to this right now that you want to talk about with me?

Because something has changed that is challenging their usual way of doing things. And so I have to start with that. And if they're at loggerheads, if there's a lot of tension and whatever built up, I have to go back and ask them what got them together in the first place, because sometimes they've, they've lost sight of what connected them so deeply at the beginning.

And it helps to remind them what, what those things were that made them feel good as a couple. When it's just a support partner, I really try to focus on all aspects of that person's wellness. How are you emotionally? Are you taking care of your physical health? Are you taking care of your spiritual wellbeing?

Do you still have time for your friends and activities? That mean a lot to you? Uh, how are you balancing work and home? And so it's sort of a series of things to check how they're doing and chances are they look at me like I'm out of my mind. What do you mean I am? This takes all of my time. I come home from work.

I'm exhausted. I start my second full-time job. I don't have time to breathe. I don't have time to exercise. I don't have time to do anything. And oh, by the way, um, when I come home, instead of having a partner, an emotional partner, a sexual partner, a recreation partner, a helpmate, I have somebody who needs to be taken care of.

So all those other parts of my life feel gone feel robbed. Right. And so [01:20:00] then we focus again on, okay. What are the areas that we can tackle? One, one by one. Um, I look to see if they're depressed, which many support partners are. Many of them are self-medicating with alcohol or drugs or other ways of sort of drowning out painful feelings.

Um, I look to see if they have any support system at all, that is their own. So I try to identify the areas of challenge while building up a support system for them. So they don't feel so isolated. Right. And to answer your question.

Meghan Beier, PhD: Yeah, definitely. I think that gives a really good jumping off point. One other question is and maybe this gets back to the fixer question in the beginning, that one person is always bringing up solutions and the other person is sort of shooting it down. You know, a family member who wants to go out to a restaurant with the person that has MS. And the person says, well, I can't go there. There's no bathrooms. Or why don't we get a scooter so that we can go on this trip to Disney world? Well, I don't want to take a scooter.

Those are too expensive. And that can be very frustrating for a family member; support partner. How do you manage those types of situations?

Roz Kalb, PhD: So that's a big question. It is a big question. So I'm going to focus in on the mobility aids and other tools first, because when I work with couples, I always try to frame those as family tools. It's not, you're a person with MS. You shouldn't be using a scooter so we can do things.

It's. If we had a scooter, we could go and do a lot of the things that we always enjoy doing together, taking our walks, going to museums, traveling to fun places. I really think it would be wonderful if we had one and you don't have to use it all the time, but when it came in handy, it would help a full fee.

So it can be a mobility device. It can be any other kind of tool that makes life better. And then each day the family looks at what they're going to be doing and they decide what tools in the tool chest. Will make it possible for them to do the things that they all want to do, whether it's going to soccer practice with the kids or, you know, going to a park or whatever.

And I think that that same model applies to other aspects of problem-solving. Do we agree that we like going to our friend's house to see people particularly now that we're able to do more? Do we want to do that? Yes. Okay. Then what are challenges we might encounter there that we can problem solve before we go?

Is it accessible to get into the house? Is the bathroom comfortable enough for you to use? Is there anything we could do to make it more comfortable? Um, do we have to plan it earlier? So you're not as tired. Hmm. Do we always have to have a plan B. In case at the last minute, it just doesn't work because MS symptoms have flared up, so that we have arrangements with friends who know that we do want to see them, but sometimes we have to go to plan B, like you come to our house and we order a pizza. So you problem solve together based around what your priorities are as a couple. And then assume that it's a joint responsibility to figure out how to make those desired outcomes happen.

Meghan Beier, PhD: So it gets back to that piece of communication, making sure that you're communicating effectively and both problem solving the issue together.

Roz Kalb, PhD: Which as you know, from Can Do MS. We, we started doing, um, communication workshops because at some point during an in-person programming, a support partner raised his hand and said, you guys talk about the importance of communication all the time.

Please tell us how to do it. Yeah. Um, and because of that, a whole new area of focus was born, but we now start with communication and all the things that can interfere with it, like mood changes, [01:25:00] cognitive changes, um, and other aspects of MS, which is sometimes make it hard for people to communicate.

Meghan Beier, PhD: Absolutely. I want to switch gears towards, what do you see as couples, family members doing well? What are some of the best coping strategies? You've seen the people who are really. Working together successfully. What does that look like?

Roz Kalb, PhD: I think first and foremost, they see it as a we disease, not a me disease.

They approach it as a team and they assume that they each bring skills to the table, knowledge and resources, and they share all of that to problem solve. I think a second, they are people who tend have a pretty good foundation in their relationship or have solved challenges and problems in the past. And so they can look to past successes to build strategies for working now. I think they are people who grieve together over the losses and changes as opposed to having a contest over who has it worse. Um, they really see these changes in their lives as a shared, um, as a shared grief and they support each other through that.

Um, and I think couples that look for the positives. Well, this has helped our communication. This has brought us closer together. We've really gotten better at solving problems and they pat themselves on the back and they, they take joy out of their successes. Um, I think those are the kinds of things I seen that the really strong couples just, they just show it all the time.

And I don't know if you would agree with me, but I think when you first meet a couple, you can often tell right away if this couple is going to have a serious challenge to dealing with the unpredictability and challenges of MS or not.

Meghan Beier, PhD: I think that's very accurate, very accurate.

Roz Kalb, PhD: And, and so I guess my advice for mental health professionals thinking about that is to use your experience, know that look for the cues, look for the cues in those early visits that tell you: is this a couple where all you need to do is reinforce their strengths, remind them what they do well, help them see how this is like other things that they managed and problem solved through in the past. Or is this a couple where they're missing some resources, internal resources that will help them do what they need to do? And so you're kind of teaching from the ground up,

Meghan Beier, PhD: So I'm gonna end with this question. What are some key resources for support partners and family members? There's lots of resources out there for people living with MS. Uh, it's harder to find support groups and resources for people that are family members. What, what's your go-to resources?

Roz Kalb, PhD: My go-to resource at this point is to encourage all support partners and the loved ones with MS to tap into Can Do MS resources. And, uh, mostly that's because Can Do has the most resources, whether you choose to come to an in-person program. Where you as a support partner will get just as much attention as the person with MS.

Or you watch a one of many webinars that are archived on the website about, uh, support partners and meeting their needs and building their strengths. Um, or you just read the library articles about support partner needs. However you choose to get your support and information. I think they offer a wide variety.

Um, the National MS Society also, um, is extremely valuable for all members of the family, living with them as any person, whether an individual with MS or support partner, can call the one 800 number 1-800-344-4867 and speak to an MS navigator and say, I need help. I

need a referral. I need information. I need support. And someone on the other end of the line will [01:30:00] help. So I encourage support partners, if they're feeling overwhelmed at the end of their rope. Uh, simply out of ideas for how to manage, they can call that number. And get help. There are also caregiver organizations that help caregivers in all disease states.

Um, but I think it's really helpful, um, to go to, to a resource that is very knowledgeable about MS. Specifically. So that's why I would. Um, and encourage people to go to Can Do MS and the National MS Society and the other MS advocacy groups, groups like MS Association of America and MS Foundation.

Meghan Beier, PhD: Now, if people want to follow the work that you are doing, I know they can find webinars and things that you've done for the National MS Society as well as Can Do Multiple Sclerosis, but you're also an author and you have books out there. Are there other places that people can follow your work?

Roz Kalb, PhD: Thank you. Um, so there is a book it's available. Um, On Amazon at this point, probably for about 25 cents, but it's a book, uh, called Multiple Sclerosis a Guide for Families published by Demos Healthit's out in its third edition. Um, but it has some very good information about families and the ways that MS impacts families and also information specific to support partners, which was, at the time, pretty revolutionary.

And also, the book MS for Dummies, I was the senior author on also has, uh, basic information about all aspects of MS, but they focus on the needs of support reviews as well. So those books are easily inexpensively available these days. So I do, I do recommend those.

Meghan Beier, PhD: Great. Thank you so much again, for all of your advice and expertise and for talking with me today.

Roz Kalb, PhD: Oh, I enjoyed every minute. Thanks Meghan.

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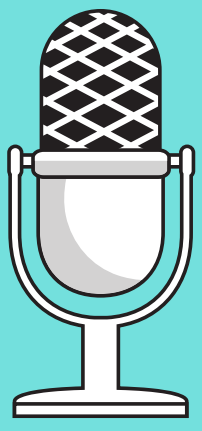

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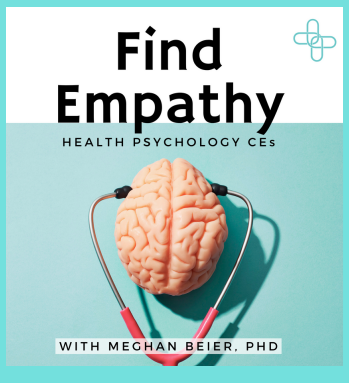

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