

Severe ME/CFS: Caregiving Webinar Transcript

October 9, 2024

[Access the webinar recording here.](#)

[Access the resource guide here.](#)

Tahlia Ruschioni

Good morning, everyone, and welcome to the first in our series of four webinars focused on severe ME/CFS, presented in collaboration with the Bateman Horne Center and Solve ME. I'm Tahlia Ruschioni education and deputy executive director of the Bateman Horne Center, and I will be your moderator today. We're so glad that you've joined us. This first webinar is focused on caregiving, where we will hear from four incredible caregivers who will share their personal stories, practical strategies, and ways to navigate the medical system when supporting a loved one with Severe and ME/CFS.

This is the start of our series, and we encourage you to join us for all four sessions. On November 13th. We will cover legal rights and protections. December 4th medical treatment approaches for severe ME/CFS and on January 15th, the latest research on ME/CFS and infection associated chronic conditions. All of these webinars will be recorded and made available on the Bateman Horne Center and Solve ME websites as well as on our YouTube channels.

You will receive an email in the days following the session, with the recording link and a resource guide that will include tools and insights shared by our panelist. As a reminder, this webinar is for informational purposes only and does not constitute legal or medical advice. Viewers are always encouraged to consult with qualified legal or medical professionals for specific advice tailored to their individual needs.

If time permits, a Q&A will follow the presentation. Please enter your questions in the box at the bottom of the screen and upvote your favorite questions. Closed captioning is

available on the Zoom control setting as shown on the PowerPoint slide. On the screen. Each of the panelists will start by briefly introducing themselves and their connection to the illness.

We will then follow with three questions for each panelist focused on one of the following daily care and relationship maintenance, navigating systems and trusting your instincts, selfcare and relationship navigation, and caregiving and mental wellness. I'd like to take a moment to express deep appreciation to our panelists for being here and sharing their experiences. We're grateful for your vulnerability and willingness to share your caregiving journeys and insights with us.

Caregiving for someone with severe ME/CFS can be a complex and evolving role. It's not just about providing care. It's about maintaining connection, managing uncertainty, and supporting the wellbeing of a loved one whose daily life is deeply affected by the disease. We are here today to honor the importance of that role, and to provide support and share strategies that may help caregivers navigate this path.

I'd like to begin by hearing from Kyle Kitzmiller, who will speak on daily caregiving and the impact on personal relationships. Kyle, please take a moment to introduce yourself and share your connection to Long COVID and ME/CFS, and then follow up with what practical strategies you have implemented to help manage daily care tasks for your wife.

Kyle Kitzmiller

Absolutely. And thanks so much for hosting us. I'm really honored to be a part of this. It's so important to talk about caregiving and it's such a central role in a person's recovery, as is the system around them.

So my name is Kyle Kitzmiller. I'm a mechanical engineer. I was a producer at the YouTube channel Physics Girl. My wife, Diana Cowern is the post curator of that YouTube channel. And she fell ill with Covid in the summer of 2022, and it rapidly progressed to the severe ME/CFS style of long Covid. And I am now her primary caretaker. And so that is my connection to the illness.

Tahlia Ruschioni

What practical strategies have helped to manage daily care tasks and activities of daily living for your wife?

Kyle Kitzmiller

Absolutely. Yeah. The practical stuff is just sort of the straightforward organization. Make a schedule so that every day you know exactly what's going to happen. Create a symptom log so you know exactly how your partner is doing. Over time, you can see changes whether they're good or bad. And lastly, employ help, meaning get family, getting friends. When Diana first got sick, I had a friend, you know, at that point, my life was just exploding. When she first became very severe, I had a friend organize meal drop offs, that made a very huge difference, because I. It's just one more thing I didn't have to think about. And then I slowly onboarded scheduling symptom logging. And then also creating treatment plans is another key one, because even if you don't end up following those, which you almost never do exactly, you have like the security and you know what's going to happen in the future. So those are all really important things. And the last thing I would say on that is to try and enjoy the day to day. It's one of those things where, you know, when I'm making food, I'm always listening to music and I'm just trying to, like, enjoy the ride. You know, there's the, you know, the driving freeway analogy. If you're stuck in traffic on a highway, like you're going to be there whether you want to or not, you might as well try to enjoy it. So it's not what you want to be doing. It's not what you would prefer, but you have to make the most of it. You have to try to enjoy your life every day. So that's my advice in terms of activities of daily living and staying organized.

Tahlia Ruschioni

I imagine having some of that routine and consistency allows a little bit more flexibility when something does come up or, or a baseline changes. Would you say that that's true?

Kyle Kitzmiller

I haven't had a problem sort of changing or being flexible either way. But for me, what it really does is it opens up my mind to focus on other things. I can focus on our relationship because I'm not focused, I'm not worried about what I'm going to do today. It's just background noise at that point. Once you have a schedule, I need to implement it for a few months. It's autopilot. You can just look at a sheet of paper and know what you're going to do, and then you can take time to be present in the moments with your

partner that are going to be more meaningful, rather than focusing your energy on worrying about what medications or food or something is happening that day.

Tahlia Ruschioni

That makes sense and I'm glad that you brought that up. How have you and your wife managed to maintain your relationship despite the challenges of severe long Covid? Do you have any tips that you can offer to other caregivers on preserving intimacy and connection?

Kyle Kitzmiller

Yes, and it's like, you know, this could be a half hour or hour answer of itself. But I think a relationship is always going to start with trust. And in order to develop that trust with your partner in this like crazy, their life is just changed so drastically. Their body is out of control. You have to connect with them. You have to ask questions and really try and understand what they're going through, in a way that no one else is going to be able to understand, not their doctors, not even other patients. Right? You have to just ask questions and really try and understand. And that builds a trust from which the rest of your relationship can then develop.

The second point, and I could go off on this because I'm very passionate about it, is that you have to view your relationship outside of the context of societal norms. I call this, defining your relationship. We have, you know, relationship escalators in life. That's like, this is what you're supposed to do next. And these are the things you're supposed to do, and you're supposed to get value out of the relationship, and your partner provides some value, and you're supposed to both get the same amount of value according to, you know, some external judgments of what's valuable. And when someone becomes sick, the way that the things that they're able to bring to a relationship are very different. And so you have to start by saying, well, do I love this person? And if I love them, how can we, you know, each get things that we need and not worry about judging the value of those by some external metrics? But it's like, you know, if Diana wants to, you know, like she loves making puns. And that's just like a thing I love is, like, leaning in to, like, all right, let's talk jokes today or whatever. We're just going to make a bunch of puns and, like, I find that very valuable. But it's not like an external metric of, like, what is a relationship? You know? And I don't know, you just have to sort of release a lot of the expectation that have been put on what relationships

are supposed to be, and it takes a long time to do. But I think at the end you're going to have a relationship that's just so much more beautiful than even it was before. If you can do that.

Tahlia Ruschioni

I love that. Really just giving yourself permission to redefine what that means, right? For you two and for that relationship. That's beautiful. And thank you.

So what practical steps have you taken to maintain your own selfcare and to nourish your own mental and emotional wellbeing as a caregiver?

Kyle Kitzmiller

The main things I've done is around friends and community. I think for me personally and, you know, it changes for different people. But for me, having active friendships and things to do with friends is how I am revitalized. So in terms of the psychology I have, I schedule regular hangouts with friends. I think this is important because it means that if I don't want to see somebody, I have to cancel it right. Whereas if you want to see somebody and you don't have anything scheduled, you have to go through all these steps to schedule something. So, I just have like with a few different friends, it's every other week we hang out, love a board game night. I'll go to a friend's house another night, whatever it is. And so those are things that are scheduled, and they just happen. And then I get Diana's friends involved to come and, you know, visit her when it's appropriate, when she can feel up to it. They'll just come and visit me sometimes, you know, these are, you know, involving as much community and family as you can is, I think, really important. Another key point is to maintain your, like, levelness in this, because this disease is full of ups and downs and it's just it's designed to create anxiety is avoid projecting how you're feeling now on to the future. Your partner might be healing, and you might then say, I feel good. And I think that next week I'm going to feel better. And then next week comes along and your partner is crashed, and they feel worse than they have in six months. And you just flipping between those two things, it's just devastating. And on the same token, if your partner is feeling ill and you're projecting that sort of despair into the future, you're just going to feel really bad. You're going to be frantically trying to change things, and you can't change things quickly in this disease. So, avoid projecting what you're feeling now onto the future. That's really been key for me to just kind of level out the day to day and stay mentally healthy.

Tahlia Ruschioni

Really good advice. And I mean, there's a couple of quotes in there that I think we need to just pull out and keep on sticky notes for all of us. I really appreciate your time today, Kyle, and for sharing you and your wife's journey with us. I hope that we will have a little bit of time, after we speak to some of the other panelists to get back to some questions. Thank you so much.

Next, we have Amy Mooney, an occupational therapist and mother who has navigated both health care and education systems for her daughter with severe ME/CFS. Amy, please start by sharing a bit about your background and then follow up with how you've relied on your instincts to navigate these complex systems, ensuring that your daughter receives the support she needs and deserves.

Amy Mooney

I thank you so much for this opportunity. I'm an occupational therapist, and I'm also a mother for three medium sized kids, that are in the throes of developing who they are and becoming. They're just figuring out where they want to go with their lives and throughout my daughter, my middle child's almost years of having ME, she's now had ME for a long period of her time.

I have been told countless times that it's my understanding that's wrong and I'm exaggerating her symptoms, or I'm catastrophizing the situation. But I'm there to witness the heartbreak of her not being able to go to school or attend a sleepover, or even eat a meal at the dining room table. And these are things that parents will just take for granted.

It didn't take long for me to recognize that it was the medical experts in the school who were misunderstanding the consequences of my daughter's illness, not necessarily me. I was witnessing it and picking up the pieces as she experienced the devastating symptoms of ME. I remember the exact moment my perspective actually shifted from me trying to pull my daughter along to keep up with me and the rest of the family, to actually following her lead and listening to her needs. My instincts had radically shifted, and it was at that point that I realized I was the advocate for my daughter's new voice, and she had been telling me and the doctors and the caregivers or the teachers all along what she needed, but no one was really listening. She was a child. How do you how do you really take for granted?

How do you understand what a child is going through? But once I believed in my ability to be a caregiver, I began to listen to her actual needs, her story, rather than imposing what I thought they should be. So, like I said before I've been a medical provider for many years but I never really truly understood what it meant to be a caregiver. It is completely different. And to me, being a caregiver is about active listening. It's about respecting another person's needs and supporting their goals. And with this new perspective, after years of listening and learning from the awesome ME community, I began to reflect on how my profession fails to understand ME and I took a closer look at understanding how the rehab specialists were going about it wrong. This was really uncomfortable. This is not a pleasant experience, but it pushed me to rethink how occupational therapy specifically should really be supporting people with me and what the proper care should look like, what should be involved. And I was able to take some of that and kind of adjust it to our life. So what did my daughter actually need? So, you asked about instincts. And I think that's a major component is trusting my instincts. And that meant focusing on my daughter's goals. These weren't society's goals. Like Kyle was saying, these weren't even family goals. These were her goals specifically. And I found that, you know, you really can't compare them to other kids with ME even or, you know, even to siblings, even the kids in the same house here. That didn't seem that didn't help. So, she was she was grieving, I was grieving, there was a lot of loss, and my priority had to be to help her find the small ways to find some control and predictability in her new daily life. And also, this was also involving trusting my instincts to recognize her limitations and the limitations in general of this disease. I had to accept that no matter how much we wanted school to be part of her life and part of the plan it wasn't going to benefit her health right now. So when she was healthier or when she is healthier, the plan is that she return to learning and actually be a better learner. But at this point in the illness process, it was not the right time. So, I needed to trust that education is a life long journey and it can take many, many forms beyond the traditional settings of a school. And for a child with severe ME education just wasn't part of the current goal. And it just simply was beyond the capacities for that moment. So how can caregivers really trust their instincts? It's essential. My husband and I know our daughter better than anyone else, and we also needed to protect ourselves from being misunderstood. And whether that means being seen by outside

professionals as being controlling or even falsely accused of situations that were possibly abuse or neglect, which were completely false. We need to do things that would protect us as being her caregivers. She was a minor just last year.

And so these are my three takeaways that I think for those people that have children with ME may be able to benefit. The first one is to invite as many professionals as you possibly can into your home. That can be a school nurse or, you know, even a nurse at your child's pediatrician's office, the social workers, even your clergy. Invite them into your home so they can start to witness firsthand. It's no longer you retelling the story and recounting the situation, but they now have firsthand knowledge. And number two is whenever you can let your loved one express for themselves. And it's so hard as a parent, you want to speak, you want to take control and do things for your child. But I've learned you have to let your child speak and let others witness the struggle that for them to find the right words, for them to share their thoughts.

The medical team and the education team needs to witness this. So, the impairment needs to be witnessed beyond just the parents or the caregivers. And finally, documentation is essential. And like Kyle was saying that, you know, writing things down and documenting symptoms and just the overall functional performance is very important because you need to show that six months ago, things were different.

And sometimes we forget that we, you know, we block out things that were really uncomfortable and painful, but we need to be able to document it. And this can be used for disability applications and also just helps in general to monitor progress and decline. And I'm going to make my worksheets available for you all to have access to just give examples and you can cut and paste and design it yourselves, but at least it gives some background of how to start documenting functional performance.

Tahlia Ruschioni

We have just another minute here but I really want you to touch on how can caregivers validate their own loved one's experiences and ensure that the voices of that loved one are heard?

Amy Mooney

I think recognizing those lived experiences. That is their truth. That is your truth. As a caregiver you witness things that nobody else is experiencing and that alone is chronic

traumatic stress disorder. It is deep. Loved one's experiences and ensure that the voices of that loved one have are heard. In my world it is one of the toughest challenges of caregiving, and the constant need to have to explain the disease outside of our walls of our home, is really exhausting. So, we meet that experience or we meet that resistance most with those that are trying to force the narrative that we aren't living up to their expectations. But I think when we flip it around and start looking outside, there are a lot of people that are in the ME community that share those same experiences. We might not have the same dynamic. We might not have the same age. There are age gaps, but those people have what we don't find in the general population. They have that lived experience. If they understand the kind of code words and they recognize how big crashes can be but they also can understand how very minute improvements mean the world. So, I think that not looking to necessarily getting the validation from the professional medical community, I think looking at who your peers are in the ME community is where validation and lived experiences can be exchanged.

Tahlia Ruschioni

Amy, your unwavering support in advocating for your daughter and bringing awareness to the community's needs, it runs deep and it's felt. Thank you. I've personally learned so much from you, and I hope that we can continue to share that with many others. Our next panelist is Kim Moy, who has developed the Thrive as a Caregiver Course. Throughout her caregiving journey, Kim has focused on maintaining a strong relationship with her husband, ensuring he remains central in their lives while also recognizing the importance of selfcare.

Kim, could you please introduce yourself and share some of the strategies from your Thrive as a Caregiver Course that have helped caregivers build resilience and prevent burnout? And how do you suggest caregivers can balance selfcare with the demands of caregiving?

Kim Moy

Hi. My name is Kim Moy, and my husband has had ME/CFS for over 30 years. When we first met, his ME/CFS was not that bad. Meaning that we could still go salsa dancing, but we just couldn't dance every song that we wanted to, and we could have a career. We had two kids. However, his ME/CFS unfortunately took a nosedive about a dozen years ago. And he's been, I would say, in severe, kind of classification now. He spends

most of his time in bed at this time. I started the ME/CFS partner caregiver support group affiliated with #MEAction about six years ago and became so rewarding for me to meet other fellow caregivers like myself. That I actually left my job about two years ago. And I am now spending most of my time with Caregiver Wisdom, which I launched with the intention of helping support other caregivers.

Happy to be here today with all of you. I've been asked to answer the question about how do we avoid burnout? How do we strengthen our resilience? And we're in it for a marathon. And with this particular illness for better or for worse. So, I believe there are three steps a three strategies to strengthen your resilience as caregivers. The first is to really make sure that you're taking care of yourself. If you burn out, you're no good to anyone. And I've been there. Actually, I have been burnt out, and I was no fun to be around, and I couldn't really solve problems very well. So that's the first strategy. Make sure that you are taking care of yourself. As caregivers, we oftentimes feel guilty for taking time for ourselves. But I actually I believe it's part of your job description as a caregiver to make sure that you can sustain yourself. And so, you can actually be a good caregiver.

And so, the second strategy is to empower yourself. And what I mean by empowering yourself. Well, I'll go into a little bit more detail what that means, but it can mean several things. And the third strategy is to connect with the community. So, we'll go a little bit in some more detail about selfcare and give you some real life examples in hopes that, that, you can take a few tactics and techniques that I've, I've learned over the years. The first sort of thing I wanted to share with you is a concept of a morning ritual. And that's where my coach has taught me to take ten minutes every morning before you do stuff for other people, ten minutes for yourself. And so may be just waking up in the morning. And then doing a few yoga stretches, maybe for ten minutes or meditating or enjoying a quiet cup of tea, going out for a quick walk, getting a breath of fresh air before you do any household chores or caregiving chores. Once you set that intention, it really gives you the fuel for the rest of the day and sets a really nice tone.

The second tip that I love to share with you is doing a good jobs list at night. So, you have your morning ritual, then you have your evening kind of before you go to sleep. Ritual. And that is, again, to do a good jobs list. The good jobs list is you writing down maybe five things that you're proud of doing for that day. A lot of caregiving work is invisible work. It's behind the scenes work. It's calling the doctor's office, getting

prescriptions, all of those things. And lots of times it's invisible. And lots of times it's not acknowledged by your loved one or other people. You're just doing it as part of your job as a caregiver. Well, the way you can make it visible and the way you can have some acknowledgment is to acknowledge it yourself. In the Good Jobs Journal. I found that practice, quite frankly, very transformational for my own journey. So, I just wanted to make sure to share that with you here today.

And then the second strategy, again, is empowering yourself and empowering yourself can mean a lot of different things. For me, it can mean everything from getting more help and not you taking everything on yourself. We talk about really. You know, it takes a village to raise a child. Well it certainly takes a village to also be a caregiver to someone with such a debilitating illness. It should not be just you. Okay. Even though you feel like you're fully capable and you, I know you all are. It's just a lot to do for one person. So, get a team of people. It could be family members, friends, volunteers, paid help. So, if you need help with that, that's something that I'm working on. Putting together a blog post on, for, caregiver wisdom, my website. I would also mention it can also mean things like setting boundaries, setting boundaries with yourself as well as with your loved one or coworkers or family members. That is also a part of empowering yourself. I would also say learning how to navigate different kinds of systems, whether it's a medical system, the legal system, applying for disability, you need to power yourself with a lot of information, quite frankly, a lot of information you never thought you would have to learn. And you don't really want to learn. But here you are. So, the more you can empower yourself with this stuff, you don't need to reinvent the wheel. There are other people who have walked this path before you. That's part of the reason why I started Caregiver Wisdom to share what I've learned over the past 20 plus years I've been a caregiver for my husband and also my elderly parents. You don't need to walk this path alone. Please do not. It is a lonely path, and we are here to support you.

The third thing I wanted to mention as a strategy, again, is connecting with community again. I've been leading one of two support groups with #MEAction that is focused on caregivers. And we're here for you. We would love to have you come and attend one of our, zoom meetings just to connect and not feel so lonely and perhaps get some words of advice. Or just being there with each other is really powerful. You know, there's also other Facebook groups out there as well as, I believe some on discord. So, there's a lot of support out there that I really encourage you to seek out. I have heard from other caregivers who said they were not comfortable being on social media or had no desire

to join social media. So, I actually launched my own online community for chronic illness caregivers. That's not on social media. So, if you're interested in joining that, please reach out to me as well.

One of the topics I've been also asked to speak about is ambiguous loss. This is a really important topic to me. When I discovered this concept, it just resonated so deeply with me. I felt like, oh, that's what I've been feeling this whole entire time. And so what is ambiguous loss? It's basically a unique type of grief where the person that you love is still alive. They're still physically there, but there's something else about them that has changed. So they may be psychologically absent or they've been altered by in this case, a chronic illness. So it really results in a profound sense of loss and grief for both the person who is ill as well as their family members and you as a caregiver. So really, what do you do once you know about this concept? Okay. It's great to feel like, oh, now I know how I've been feeling. What do you do? How do you deal and cope with this? What Pauline boss, who actually coined this term what she recommends doing is to one acknowledge the loss, acknowledge the grief, and two to really carry on and live the best life you can and enjoy the life you have that still remains. It's critical to be able to do both, and you may need to fluctuate between the two, in any given day. I kind of switch back and forth. And that's fine. That is really normal. So you may ask, well, how do I do that? Easier said than done, right. Well, there are about a dozen strategies that you can take on to deal with this. I'd like to share a few. My favorite ones. Maybe my top three.

The first is to let go of what you cannot control, and to focus on what you can control. So, I can't control that. My husband is in bed and in constant pain and is constantly just fatigued, cannot sleep, and even if he sleeps, he is not well rested. I can't personally control that. What can I control? I can control you know, being there for him. I can control, you know, finding doctors, right? I can control how I react. I can control, you know, my mindset and like, yes, I'm going to help support him as much as possible. But I can't control some other things. So, focus on what you can control. Let go of what you can't. The second strategy is to redefine your identity. So, I actually practice Zen Buddhism and my Zen teachers talk about non attachment. And the idea is if you attach to something that you can't have or attach to something that you, that used to be, you can't move forward, you're frozen and you're just stuck. So really the idea is to redefine yourself and don't be so attached to, oh, the way how things used to be.

The third strategy is to practice both and or thinking, I'm sorry, both and thinking, so this means balancing two different ideas at the same time. So, the example might be, I am a caregiver and I need care as well. I can take care of both him and myself. I am both sad at my loved ones illness, and I could be really happy that we get to enjoy a sunset together today. So those are some examples.

There's a lot more to say about ambiguous loss. You know, I talk about it in, you know, hour and a half long support group meetings that I lead. I've also written a blog post on it. So, if you'd like to read a little bit more about that, I invite you to come to Caregiver Wisdom Dot net. And you can check out my blog post there.

Another question I've been asked is how do we maintain hope in light of all of the, difficulties and the challenge that our loved ones and we as caregivers face? And in the light of not knowing if there will ever be a cure or not knowing, you know, how, how they're going to be, you know how few answers there are really. You know, first off, I want to say that there's a lot more research being done than ever before. So, I'm really encouraged by that. And thanks to groups like Bateman Horne doing the research. So really, so hopeful there. And also say that, you know, Solve ME and #MEAAction is they're both, really wonderful organizations who are doing a lot of advocacy work to help fund research. So, I encourage you to participate, and volunteer. And it's really not that hard. I was a little intimidated to do it myself, but I ended up doing it, and I was so happy to do so. To contribute your voice. And if you can at all possible have the financial means to donate, I encourage you to donate as well to help with those causes. There's a lot of more movement afoot right now than ever before.

In addition, I wanted to share a few things that my Zen teachers have taught me because, over the past few years, I've learned more about these concepts that really help me as a caregiver to navigate these really big challenges. And again, one of those concepts is nonattachment to not get attached to what used to be what you hoped it would be, what you thought your life would be like. You know all of life is constantly changing. So the thing is, if we then attach something to how things used to be or how we want them to be it's not reality, right? It's very human. But it's not. It's going to create suffering on your part when you can't have the thing that you want or how you thought it would be. So, you know, letting go and being able to accept things how they really are and then still moving forward and living the best life you can given the current situation is something that I've embraced myself and has helped me quite a bit.

You know, after all, hopefully we can all feel that we can experience beauty, hope, connection and love.

And I just briefly, in closing want to say that I don't wish this illness on anyone or having to be put in this situation of caregiving for someone with this really terrible illness. That said, I do appreciate, that I learned a lot, and I feel like I have been going on a personal development journey, and I really do appreciate those learnings, those lessons I'm learning, and I feel so much stronger for it. And really, just right now, I really want to support others who are going through this horrible situation and we can get it through it better together.

So, if you're interested in attending a support group, reading blog post, being part of my course, any of that kind of stuff, would really welcome you to come to visit my website and can sign up for the newsletter. So, thanks very much.

Tahlia Ruschioni

Thank you. I'm going to go ahead and move on to Galen. So, Galen, thanks for coming on. Galen Warden is a mother whose son is living with severe ME/CFS. Galen's journey through the emotional stages of grief and loss, both for her own life and her son's has been deeply inspiring. Galen, could you please begin by sharing the key turning points or tools that have helped you sustain your caregiving role, and give us a little bit of insight into your journey through this illness?

Galen Warden

Thanks Talia, I am really thrilled to be here. It's good to see everybody and to join, you know, these amazing caregivers are telling our story.

I really resonated with so many things others have said. My journey began with my complete denial that my son was as sick as he was. He was getting worse and worse for ten years, in which doctors said nothing was wrong with him and suggested, you know, the standard cognitive behavioral therapy and things like this, until finally he was not being able to care for himself, not being able to prepare food, do his laundry, you know, bring the cat litter into the house to feed his cat. And during that time I was I was just in denial. And, I sold the house he was living in and he had to get into an apartment and at that point he was already, you know, like at the latter end of moderate because my personal, you know, issue was I'm flight, I'm not fight. And when I saw the horrible

things going on, I was kind of in denial. I was like that ostrich with my head in the sand. So, my journey to caring for him began with the shock of he was bedbound. And that was pretty much when we when we got his diagnosis, he was bedbound. He could get into a wheelchair. He could get to the bathroom, to the toilet, in the wheelchair. But he couldn't walk around anymore. That was when I began to care for him. Brought him to South Carolina, to my home. But it was. It was too late, really. I mean, if I had not been such a chicken. Maybe I could have done more for him and prevented him from becoming this severe. So, he comes to my house. He is completely dependent. He's basically paralyzed. He can't feed himself. I'm spoon feeding him. I'm holding a straw to his mouth, toileting him in the bed. No guidance. No, no conception of what the hell is this. And I fell apart. You know, I was crying every day. I was angry, I was frustrated I would do something for him, and he would have a criticism about it, and I would go cry. And so I got a therapist, and I said, you know, I need help. I'm not managing this. This is not sustainable. They say this is incurable. How can I live like this as this is now? So I went to therapy with the thought that the therapist is going to feel sorry for me and my terrible situation having to do all this work for my son where the reality was my therapist pointed out the fact that, you know, it was my issue. It wasn't my son. Sickness was my issue. I had to go back to my past, where I had a lot of trauma in my childhood that was unresolved. And I was living with this, unaware of this pain in me that was causing me to overreact to everything. And as I went through the therapy and confronted the trauma in my past and said to the little girl my nickname was Gay Gay, said to her, hey, you know, your mom shouldn't talk to you like that. These adults shouldn't treat you that way. You deserve love. You deserve, you know, respect. And as I began to face my past, deal with that trauma and come through it, all of a sudden, it was like, overnight, even though it was weeks and months. It didn't bother me when James criticized something, I did, you know. Oh, you know, the toast is wrong or whatever. Okay, I can remake the toast. It wasn't like, oh my God, I thought I made perfect toast. You know, all of that was gone. And then I became able to take care of business, not be upset and build that routine Kyle was talking about. I couldn't have a routine when I was falling apart. So, this was my mental health journey. And it was very, very important that I take care of me so that I could, you know, rise above those emotions. It wasn't his job to take care of my emotions. He was the one suffering. So, that's how that, you know, resolved itself.

Tahlia Ruschioni

Galen, I really appreciate you're just frank honesty with this, right? I mean, it's hard. And we have to navigate our own grief and loss through this and even our own health. And what we go through just on a on a physical and mental basis. So, I want to touch on a couple of other things here.

What other mental health aspects are crucial for caregivers to focus on beyond preventing burnout? And how can they integrate these into their daily routines or even weekly routines?

Galen Warden

I think Kyle really said some great stuff about this, and I just want to kind of repeat what he said. And that was to, you know, get some earbuds, get some wireless earbuds and listen to music. What your job is not to be a martyr, not to blame the person that your life is miserable and what you've sacrificed, but to find a new path for yourself, to find a new version of the happy you and it might sound cold to say, how can you be happy when your loved one is so miserable? That is not the point. The point is, how does it help them to have a miserable person taking care of them, versus somebody who is content and is able to walk in calm because they've got it together. That's what they need. So, I listen to music in my little wireless earbuds. He doesn't hear it. And I dance in my kitchen while I'm, you know, putting my dishes away and doing things. And these are ways that I have built a normalcy to me, being me and not just a caregiver. I might even use my earbuds to watch something on Netflix I've seen a few times while I'm doing the dishes, and it's not because I'm focusing on it and going to mess up something, but it's something I'm familiar with and it's just to be enjoyable, you know, something that is enjoyable to you. And, you know, I need to emphasize everybody's different. And you may not want to dance while you're putting your dishes away, but you might, you know, have something else. You do once a week, once a month, go out with a friend, whatever you can make happen, you have to have someone you trust to come into your home and help with your person so that you can make your escape and be yourself, do something that is quintessential you. Like I was saying, those evenings with friends, you know, play a game or, you know, whatever it is, it could be, you know, when someone comes to my home, basically sometimes I'm just in my room, I'm writing a book, you know, I'm just alone in my room, but I don't have that hanging over my head up. He's going to need me any minute. That's all gone. So, it's really important to have that support.

Tahlia Ruschioni

I don't know if everyone knows that you did a webinar with us previously, but if you haven't checked out Galen's How to Be a Demanding Diplomat video we will certainly share it in our resource guide, because it's another really amazing tool that you've put together. Galen, that offers so many practical steps. And I think that that's the other thing. When you're caring for someone with severe ME/CFS, sometimes you don't quite know what to do, and you have to be really, really creative in being their best advocate. And that extends into school. As Amy pointed out, it extends into trying to get them the health care or just in-home needs for yourself, for them. So, I do just want to highlight that that's another amazing resource that we've put together. So, thank you.

I want to hit on a couple of questions that have been submitted by the community. One of these questions that keeps surfacing is what suggestions do you have on how to help a loved one who is newly severe? That's kind of a big shift from getting in a routine and trying to figure this out with someone who has been chronic for a long time. We're seeing now a significant number of people becoming newly severe. How do you navigate that? I'd like to start with Kyle on this one.

Kyle Kitzmiller

Yeah. It's so hard and, you know, kind of like what you were saying is patients, you know, they're not always going to know what they need. They know they're in pain. They know they're suffering, but they don't know what the solution is. And you don't know what the solution is, either. I mean, really, nobody knows, right? That's why we're still here. So, my best advice kind of, once again, is just to try and understand their experience. The best thing that you can do for them in the beginning is to make sure that they are seen that they felt seen and understood because they are so lonely and isolated and scared from the disease itself, and building that connection and being open to hearing, you know, what they're saying is hard, but it's necessary. One piece of advice I was given for this is like whether you acknowledge what they're going through or not, they're still going through it. Right? So, your denial you know, your resistance, your internal resistance doesn't change the reality of what's going on. So, the kindest thing that you can do is open yourself up to seeing what they're going through. And so that they felt seen because they're going to go through it whether you're denying it or not. And it's emotionally very difficult. But it is the kindest thing I think you can do for someone who is newly severe.

Galen Warden

I have something I'd like to add to that, too. As a caregiver, I was in the beginning, feeling like there was some kind of pressure on me to find these answers, to go online, to look for the drugs or the specialist or the something to fix this. And I think one of the hardest things that I had to accept was after a whole lifetime of problem solving, I couldn't solve this. And to accept the fact that there are specialists, you know, there are things you can do. But when they say, you know, this pain is horrible, all I could say was, I'm so sorry I couldn't say here, you know, take this Advil because we learned that Advil didn't do a thing for his pain. So, you know, I would, you know, want to say, can I do this? Can I give you a back rub? Can I whatever, whatever. I had to accept the fact if he wants me to do something, he will say it. I don't have to keep suggesting things, so I don't have to keep trying. I can relax and just listen. I can just say, I'm so sorry that you're going through that and hear his pain and, you know, give that. Just be present for it and not let it burn me that he's on fire. But just take that fire so that was really important for me.

Tahlia Ruschioni

Thank you. Both of those were really excellent answers. Amy, I want to go to you, you know, working in health care, you've learned a lot of different ways to try to both navigate, as we've touched on previously. But what happens when you need someone to come into your house? What sort of resources are there that people should be considering? I know the group here. We talked beforehand about some of the things we want to include on that resource guide, but what are some of those, I guess either apps or you know, state resources or stuff that people should be considering.

Amy Mooney

It is truly the barrier for people with ME to receive health care. I don't I don't know what the answers are, but I think just knowing, that saying it's not an option is not the answer. You know, if you are needing, if somebody has been sick for quite a few years, they are not going to be getting the dental care that they need. They are not going to be getting their eyes checked. They are not going to be getting you know, even skin checks to make sure that they aren't, you know, having some crazy moles or different things that need to be attended to. I mean, these are all things that happen just as life progresses that you need to have just general medical check-ups. And we have set up

our health care system to have to be well enough. You have to be well enough to receive medical care. And it is really scary and sad because these are the patients that are too sick to get medical care and even going to the E.R., it's, you know, it's to the point of like, you know, is this really bad enough or is it almost too bad? I don't want to go. I don't want to take my loved one to the E.R. because they're too sick. I guess my search has always been putting those kind of people in my case on my phone. Just who I know that have connections to the medical community. Who are the nurses that I know you know, who are the people that have a relative who's a doctor who is. Just really searching out in your contact of like, if somebody if my person, my loved one needs an IV, you know, needs IV fluids instead of going to the E.R., is there somebody that I can call? And I know that this is a level of that, you know, people don't have this. You know, this isn't normally in communities. This is, you know, not possible for everybody. But just by putting it out there in you know, Facebook groups in your community, is there somebody that has these skills that can help me and my family or somebody else that's needing home health, you know, what are the companies, you know, what are the people that have set up businesses to do blood draws at home? You know, sometimes people have developed private companies because, you know, kids, pediatric community, they don't want to take their kids, especially during Covid time. They didn't want to take their kids to go get shots. They didn't want to take them to get a blood draw when they needed to so that there are some mobile blood draw companies that are pop up sites that you can you can Google and we'll put some keywords in our resources for how to even Google it for your community. And to find out if there are some mobile phlebotomists out there that would come to your home to do a blood draw or do an IV so you don't have to go to the E.R.? But also, I've had so many conversations with my dental hygienist and my eye doctor to say, hey, who do you know that can come to my house? And, you know, we've had hygienists who just come with an electric toothbrush and they come to our house and clean my daughter's teeth just because she needs that care. She needs somebody to be able to look inside her mouth and see if there's something going on.

An eye doctor. I called up our local hospital, and I just called up their optometry department and said, is there a resident that wants to learn how to do a home visit? Is there somebody that wants to learn how to think about things outside of the actual, you know, medical facility that can go over to our house, you know, just do a visit. I'll pay out of pocket. I just want somebody to come to our house that knows what to look for.

So I think that if you are finding that your loved one is needing certain care, don't stop by some like two people saying, no, it's not possible. Keep pushing. Just that's not the answer I'm looking for. I'm going to keep pushing and I'm going to find somebody that can help me. So I guess, you know, that's my key thing is, you know, if I'm afraid to be told no, then that's on me. I cannot turn to my loved one and say, you know, I'm afraid to ask because they need help. I need to put my own fears aside and go beyond that.

Tahlia Ruschioni

So, I love that, Amy. And, you know, something came to mind the importance of still protecting our loved ones when folks come into our home. You know, Covid is still a very real thing. So are all the other viruses and infections that preceded it. How do you advocate for the safety and protection of your loved one when people are coming into their home and interacting with them? Let's go to let's go to Galen for this one.

Galen Warden

I asked them to wear a mask when they come in my home, and I have them, I have them in the little plastic all ready to go when they need them. But usually if it's some kind of you know, health care person, they say, oh, you know, let me go to my car and they go back to their car and they get one. So, nobody is, by standard, wearing the mask. Actually, the guys who come with the transport they are always masked. I never have to ask them. We do a gurney transport for any visit, but, you know, and I tell my caregivers, they all know I don't care if it's a headache. If anything is wrong, stay home. It could be a headache. It could be a snuffle. It could be allergies. Something is wrong. Stay home. Don't. Don't come. It's okay. We'll be fine. So, those are the two things that I do. And of course, I wear a mask when I'm in public or, you know, CVS or anywhere. You know, whether I'm indoors in a store or whatever. I always wear a mask. And 99% of the time, I'm the only one in the store.

Tahlia Ruschioni

So this has been really insightful and so helpful. We have about three minutes left, and I just want to wrap by going around the horn. We'll start with you, Kyle, and I'd love for you just to have a moment to use this platform to tell other caregivers and those who are living with severe ME, just one last little, little piece of advice, a piece of hope.

Kyly Kitzmiller

Being a caregiver requires holding a lot of opposite ideas in your head at the same time. You have to have the faith that, you know your life, that your lives are going to get better. And you have to also see, just, you know, how brutal the day to day is. And you have to see, you know, your partner in pain and you have to be happy at the same time. And those, you know, I don't want to say, oh, you know, the hope is in recovery. But what I will say is that if you focus your energy on understanding, you know, how to be a caregiver and how to live in this world, that your life is going to improve. My life was a tornado and I was very depressed for about, you know, I don't know, a long time. Well, over a year. And it took a long time to let my partner's journey with pain be their part, be their journey with pain. I can't change that. I, Galen was saying, and, you know, as I learned how to do it, you know, my, my life is so much better now and Diana is happy that my life is better. And, you know, in my personal journey, it so happens that, you know, Diana has seen small improvements. And that could be the case. That could not be the case. It just is how it happens. So sometimes you see some improvements, sometimes you don't. You take the ones when you can but you have to make sure that your life is focused on, you know, expanding and growing and being the person you want to be.

Tahlia Ruschioni

Thank you. Kyle. Amy.

Amy Mooney

And I think we see this as such a marathon. And I think, you know, day to day, it's really hard to not get bogged down in like, you know, the pains of this disease. This is such a painful emotional. I mean, you think, like, all of the stressors, all of the exertions that make this disease horrible. The physical, the cognitive, the social, emotional, every part, you know, this person's soul is changed and it also as caregivers it changes ours. And I think that part can be so overwhelming. But I also feel like there is so much hope, there is so much moving forward. And I know it feels in the moment not to be that the, you know, that shining light, but I think this is a marathon and we have to just keep going forward. We have to put one foot in front of the next and keep moving. And you know, with that we just, you know, there is trust that you know, that today will be, you know, tomorrow will be better than today. And we just keep moving. But if there are bumps in the road and, and pitfalls, we have to believe that that's not necessarily what's going to be a major setback that we just keep moving, putting our head down as

caregivers. And bringing our loved one the hope that they, you know, they don't have the outside resources to really change their immediate environment. So by us just looking a little bit forward, I think is the way that we just keep moving. We just keep going and keep moving. And it's because there is something coming around the corner.

Tahlia Ruschioni

Thank you, Amy. Galen.

Galen Warden

I want to emphasize that for people caring for some with severe ME, there is a tendency to, especially at the very beginning, to panic and to be nervous and stressed, and everything is an emergency and, this kind of thing. And I lost my health. I became sick. I got sarcoidosis in my lungs and in my heart, and I lost my job and all of this because I believe that whole thing I was describing about, you know, how panicked I always was. It killed my health. And I can't be the person that my son needs if I'm, you know, six feet under. So I would like to emphasize turn off the panic button. Don't be constantly on edge. Learn how to, you know, if they need you or if they text. They need something. And, you know, it's not an emergency. Take a sip of water, go to the bathroom. You know, give yourself a moment before you head in there and deal with this so that you are a person. You're not just like an extension of their needs. You're your own person. And it's like, okay, they need me. I'm going to go and do the best I can do, but I'm not going to run unless it's, you know, we have a panic button. He has a call button, and if he doesn't have his phone, but like pushing that button, you know, he urinated on himself or something bad happened, and I do I run, but in general he's saying, can I have a cup of tea? Okay, I can make a cup of tea, but I need to go to the bathroom, you know, and I don't need to say any of that. It's just he learns that, you know, and it does get better eventually he started to say things like, please and thank you. And the next time you're up and when you're in the kitchen, could I do have this or whatever? And, that was a major shift in the way things were from when he was super, super severe. But, I'm going to echo what Kyle said about, you know, you got to be a human being. And if you can be a happy human being, even though your person is suffering, you're going to be better for them.

Tahlia Ruschioni

Thank you. I have really enjoyed this, and I greatly appreciate all of your vulnerability and time today. I want to encourage everyone, both on this call and hopefully those who watch our recording to continue these conversations, be a support for one another. We all are in this together. As a quick reminder, these recordings and the resource guide will be emailed to those who registered in the following days. If you found this resource valuable to you, please consider supporting our free educational webinars. You can do that by making a gift to Solve ME and Bateman Horne today, the donation will be shared between the two nonprofit organizations. Thank you for your time and participation. We look forward to seeing you at our next webinar on Wednesday, November 13th, where we will be discussing legal rights and protections for individuals with severe ME/CFS. Until then, take care and please be kind to yourselves.