“Coffee” with a Clinician: Special Session — Severe ME/CFS

Clayton Powers, DPT

Welcome to this special “Coffee” with a Clinician. I'm Clayton Powers, and I'll be facilitating today's discussion. I'm a Doctor of Physical Therapy and Director of Education at Bateman Horne Center. But before we begin, we want to thank the donors whose support and donations make our community programs like this possible. Today's session is centered on people living with severe ME/CFS and for this session we’ll define severe ME/CFS, discuss advocacy, clinical care, research and caregiving and we'd like to acknowledge that most of those with severe ME/CFS are not able to attend this session due to the severity of their illness, and we remember those who are no longer with us because of this devastating illness as well. Individuals with severe ME/CFS are often not included in health care, education, research studies or clinical care. We want to change that. This session is one hour, so if you start to experience symptoms or can't attend the full session, please don't feel pressure to stay for the full time. The session is recorded and will be posted on YouTube so you can watch it later if you when you have the capacity. As usual, we'll try to answer the questions the participants have written in the Q&A feature, but unfortunately we can't provide any medical advice. In the chat feature you can use it for comments or conversation between participants. So thank you to our wonderful panelists who are here today from the different organizations to share their thoughts and efforts on behalf of those with severe ME/CFS. I'd like to start by introducing my friend Amy Mooney. She's an occupational therapist and owner of OT4ME, as well as our professional affiliate of Bateman Horne Center. Next we have Danielle Meadows, who's the Vice President of Research Programs and Operations at Open Medicine Foundation. Jessica Maya, Vice President of Scientific Programs that Solve M.E., Jamie Seltzer, Scientific Director of #MEAction and Stoo Brown and Lisa Geissler from the “What Is M.E. Like” book? Thank you all for joining today. So we'll start by defining severe ME/CFS. And then, I have some questions for you. And we'll start a discussion. So there's a spectrum of severity for myalgic encephalomyelitis from mild to extremely severe. the severe ME/CFS is an advanced stage characterized by extreme physical and cognitive impairments that substantially limit a person's ability to engage in activity and exertion. People with severe ME/CFS are typically housebound or bed bound, and may be unable to perform basic daily self-care without assistance. And those with severe ME/CFS suffer from intense post-exertional malaise, sensory sensitivities unrefreshing sleep and other debilitating symptoms. So I want to start by grounding today's discussion in the lived experience of severe ME/CFS. And so we'll begin with a reading from the “What Is M.E. Like” book by the author of this essay, Lisa Geisler. Go ahead Lisa, we'd love to hear your essay.

Lisa Geiszler

The title of this is When My Myalgic Encephalomyelitis Was Severe. My life with severe ME was small, very small, a bedroom, a bed, a commode next to it. The bathroom 12 steps away, too far. The blinds down. Sunglasses or eye guard on, and earplugs in. All the time. Light hurt, sound hurt. Everything hurt. I experience deep cellular exhaustion and extreme weakness. Too

weak to sit up straight, I slumped for the short time I sat up to eat. I could stand, but only for 1 to 2 minutes. Then I sank to the floor. When I walked to the kitchen, I had to sit down to take breathers on my way there. Sometimes I crawled. My spouse bathed me, but not often. I frequently didn't have the strength to brush my teeth. My gums went bad. Perhaps you've felt this sick when you've experienced severe flu. Your body felt too weak and heavy to get out of bed. You got better, but I and millions like me did not. I had to move in with my parents because I couldn't complete the basic activities of living and for financial reasons, because I could no longer work. My mother cooked, did all the shopping. My father cleaned. I couldn't tolerate screens. My spouse monitored my email, composing any necessary communications. Too weak to speak. My brain forgot how to compose sentences. I spoke in fragments. Once in the morning. Once at night. Communication was difficult because words became sounds without meaning. I did not have the strength to think. I could not tolerate visitors. I lost all communication with friends. I lost my ability to read. I was often too weak to pet my small dog, Hoovie, whom I adored. I missed the funerals of beloved family members. I missed weddings. I missed birthday parties and reunions. Too weak to sit upright. I lay in bed all day. All night. I experienced deep cellular exhaustion. I had frequent severe migraines and hollowing nausea. I developed bedsores on my right ear, the only side I could lay on due to nerve pain and my left arm and back. Sometimes I was too weak to move my limbs. I lay in bed alone for hours, days, months, years. My life was small, very small. Weak and in pain, I lay in the dark, in the quiet... for years.

Clayton Powers, DPT

Thank you. Lisa. That really helps us to grow in this session and be able to recognize the debilitating nature of this illness. Stoo, you were a part of the process of writing, “What Is M.E. Like” book. And can you tell us a little bit about what inspired the book?

Stoo Brown

Sure. Thank you. I was a patient volunteer with my local medical school, and I was telling students about my lived experience with M.E.. I realized that not only did the students have no clear understanding of what M.E. is like, but neither did the doctors and the professors who were running the class. It dawned on me, if the healthcare professionals don't understand what M.E. is like, how could we hope for them to offer appropriate services and care? I'm part of Pillow Writers, a group of creative writers who all have a M.E. or a related illness, and I thought we are just the right people to tell health care professionals just exactly what M.E. is like.

Clayton Powers, DPT

Thank you. And so, since your audience is mostly healthcare professionals and legislators or decision makers, what do you hope they understand after hearing the stories in the book?

Stoo Brown

Yeah, sure. There's lots of things I'd like readers to understand. But there are two central messages. The first is that M.E. is a common disease, more common than, say, multiple sclerosis or even rheumatoid arthritis. The second message, as everyone in today's audience will understand, is that M.E. is a very serious disease. Its impact on quality of life is worse than that of chronic renal failure, colon cancer, or even schizophrenia. It's a dreadful disease. It's common and it's serious.

Clayton Powers, DPT

Thank you. I think that's a great if we can help health care providers and decision makers understand those two messages. And yeah, I think we'll make a big difference in being able to improve care and legislation. For those who are joining, who have severe ME/CFS, who may feel invisible or forgotten. What message would you like them to hear today or from the WIMEL book?

Stoo Brown

Yeah, I appreciate that question. It's a good question because our book isn't really intended for people with severe M.E.. I mean, people with severe M.E. already know what it's like. They don't need a book to tell them. Our message is to such people that we hear you, we're on your side. We're trying to put your accounts into the public domain and bring your experiences to the attention of influencers, decision makers, and health care professionals. They're there for you.

Clayton Powers, DPT

I love it, it was such a great experience to be able to work with you and the WIMEL group on the chapters, and we're super grateful at Bateman Horne Center to be able to have contributed and get that message out.

Stoo Brown

I'm very grateful to you.

Clayton Powers, DPT

Oh, yeah. Absolutely. We, it's a team effort. And reading those essays was really powerful. And so we hope to be able to distribute that and help health care providers and others, have access to that. Jessica, how does Solve M.E. ensure that the voices of people living with severe ME/CFS are represented in research and advocacy and policy discussions.

Jessica Maya, PhD

So in terms of research, and Clayton, you kind of touched on this earlier. The patients most affected by ME/CFS are often the least able to travel and the most easily left out of research studies. Now, Solve is trying to prioritize funding for projects that will adopt decentralized approaches. This would remove travel and have remote visits where home health nurses can come to them, and that can improve retention rates while also letting researchers capture that important data across the full spectrum of the severity of this illness. Now, as for advocacy, our Advocacy Week this past year was fully remote, which allowed for accessibility from home. And we always have a digital component, even during in-person Advocacy Week events. For example, we hosted a special Empower M.E. roundtable devoted to the topic of pacing, where we specifically included information for those with severe M.E. and videos from one of our severely ill lived experience task force members. Now Solve's lived experience task force is, community of advisors. That includes people with severe M.E. And it's been involved in many of Solve's decision making processes from conception, implementation and even just evaluating how we're doing. Now in terms of current advocacy actions at the federal level, the Office of Management and Budget, the OMB recently proposed this new rule that would change how the federal government awards and manages research grants in the United States. And this includes the federal grants for ME/CFS, and Long COVID research. This rule would specifically make it harder for researchers to get funding for accessible ways to recruit for trials, and able to communicate or travel to people with severe M.E.. So barriers to access would actually increase in people with severe M.E. to be able to participate in these studies. And so Solve's led this advocacy campaign opposing the proposed federal grant rule to voice their concerns from the community. Recently, I think the committee has introduced this continuing resolution with language that would pause implementing this until December of this year, which prevents it from taking effect while Congress continues to evaluate the impact. So the work is not done, but things still need to move so that this doesn't become a reality for researchers when designing studies and considering the need to include severe M.E. individuals. And then lastly, in terms of our educational efforts, we share information about severe ME/CFS on our research page and include information in our free webinars. And for example, we actually co-hosted with the Bateman Horne Center a four-part webinar series devoted to severe M.E. caregiving, research, clinical care, and legal rights.

Clayton Powers, DPT

Thank you. That's great. Yeah, so often, individuals with M.E. who can't, tolerate going into clinics or being part of research are left out and then decisions are made without their input or experience. So thank you. Jamie, MEAction is also involved in advocacy, art and community engagement activities. How do you see these efforts help create meaningful change for those with severe ME/CFS?

Jaime Seltzer, MS

Thanks. So as Jessica mentioned, it's very hard for people with severe M.E. to advocate. People with severe M.E. are bed bound and light hurts and sound hurts. They can't, necessarily show

up in person the same way that we can, or even via zoom like this. So they often get left out of conversations about their own disease. And we've been working on that from a number of different directions. One of them is, advocacy. We met this year with six Senate offices on the labor HHS appropriations subcommittee about funding the ME/CFS Research Roadmap this past year. Two of those meetings went especially well, and we came away with solid commitments to show our language to the entire subcommittee. We're also working with the Surgeon General's Office on Communications to clinicians across the country. Getting good information to a doctor, can change someone's whole life. And in addition to that, we're running the emergency department survey, which is showing severe presentations of M.E. and developing, clinical guidelines to address those with partners from all of the different advocacy organizations and experts in many clinical fields. In addition, we do, There's art. We partnered with the Writers Guild Institute, which is a nonprofit arm of WGA East. We support artists like the WIMEL Group and the Pillow Writers Group. People who make art from bed in the dark, sometimes ten minutes at a time. This past weekend, we hosted our severe M.E. Artist Salon. And the community piece is what holds people together while the rest of it our scientific progress. Our clinical progress, is sometimes slow. And it's worth saying that isolation isn't just an effective severe M.E., it is the hallmark of it. So the salons, the peer support, all of that says the same thing to people. However you show up, or if you can't show, you are still a part of this community and we care what happens to you. In all of our advocacy work, centering stories of the most severe is what we do whenever it is possible. At this year's Millions Missing, which brought on one of the most successful relationships we've ever had. The acting surgeon General was reading the WIMEL book and hearing from severely ill individuals with M.E. directly.

Clayton Powers, DPT

I love that I had heard about that, that, the attorney general was reading the “What Is M.E. Like” book. And that's a huge win for this community, being able to share those stories. Are there, Jamie, are there any ways that patients and caregivers can be or get involved, even if they have limited energy or ability to be involved?

Jaime Seltzer, MS

Absolutely. So we have a Wednesday advocacy group, and we would love for folks to come as able. It's a thoughtful and understanding group of people that meet virtually. There are many actions like our artist salon, support groups like Living with Me Facebook group, where people can contribute as they're able, at intervals that make the most sense for their energy. And, we have a monthly zoom support call for caregivers, which is run by two amazing people. And we believe that taking care of yourself is also a form of advocacy, and that you can't do one without the other. You must look after yourself to be able to advocate today and tomorrow. And last but not least, all of the studies that we have at MEAction are all online and all at your own pace. So even people who are at every position except the very most severe end of M.E. can contribute information that can help ensure that patients in the future are better cared for and have a better experience than we have. That's great. I see a lot of research studies that completely exclude

people with severe M.E. like there's a recent one I saw for POTS where they have to do an exercise test and they have to do all this other all these other forms of exertion to understand exercise and tolerance. But then it's excluding a bunch of people and their experience. So it's good to hear that there are research studies being done that include the perspectives and experiences of those who maybe don't, aren't able to tolerate the traditional studies.

Clayton Powers, DPT

Amy Mooney, from your experience, you've treated, a lot of patients with severe ME/CFS. What do you wish health care providers understood about caring for someone with severe illness?

Amy Mooney, MS OTR/L

So my very first, the basic kind of the, the lowest bar is do no harm. It is your job to provide care for somebody in this population. And that is recognizing that health care itself can be a source of exertion and physiologic stress. So being sick is actually a full time job. So I think we need to recognize as health care professionals that more treatment, more activity or more intervention is not the best care for a person with severe or even mild M.E. Sometimes good care means just reducing the demand. It means protecting rest and creating stability. That together can down the road, prevent deterioration. So building care around what the body or what the patient's body can tolerate. Not a not about exactly what we traditionally as health care professionals, expect a patient to tolerate. We need to shift our view of that. So the first piece that I think a lot of patients have told me is they just want to be heard. So listen, that's your job is just to listen to what this patient's lived experience is. And they're telling you their story. They're telling you how they want to be, helped and supported. So it's your job just to hear them hear their lived experience. Don't judge capacity. This is not a piece of, not only asking, you know, what can I, as a health professional, do, but it's also understanding what happens when you do an activity. What are the consequences? And those are the bigger pieces is just being an active listener. For how the environment influences a patient's, functional performance. Listening to caregivers, caregivers know what that patient needs. And they are helping that patient express their needs. So I think the first piece is just be an active listener. The second is believe. This is moving from listening to action. So actually, you know, believing is actually is a way to act. It is witnessing what is happening and then acting upon that. So if you are, you know, asking the patient to, to move through their body, role in bed experience, sensory, stimulation, I want of health care professional to understand that those systems of the body are being activated by those interventions or those stressors. And I need to believe that person's response so that I can provide better accommodations and supports for that event. I'm not witness or I'm not experiencing it, but I need to witness it and be an active learner from that person. And the other piece is really being an advocate and documenting this experience. So it is my job as a health care provider to write good notes and document it and tell other medical team members what is being experienced behind closed doors. I need to be, an active participant in documenting that so that it goes into disability documentation. It goes into their lived experience written path. So that is my job. And I have the skills to be able to help interpret these experiences into more

medical terminology. So that is the final piece is respect. By giving good documentation, believing a person, understanding what they are going through. I am respecting them. And as a holistic, kind of piece of their snapshot of their life and being able to give them the respect that they need, even though they are going through very hard times. Thank you so much. I agree with what you said about listening, witnessing that suffering and being able to be there to support and validate.

Clayton Powers, DPT

Last month I gave a presentation at the Dysautonomia International conference about caring for patients who are homebound or bed bound. And in the presentation, I frequently quoted your research paper. Caring for patients with severe or very severe ME/CFS. And it's just it's surprising how few, providers actually are there able to help or understand it. And so, that paper was especially helpful to provide tips for providing good care. So do you have any tips or, practical ways clinicians can improve quality of life? You touched on some of those. But any practical things you recommend when a healthcare provider goes into a situation where they're going to be helping someone with who's homebound or bed bound?

Amy Mooney, MS OTR/L

Yeah. So one of the one of the main pieces that I was trying to add to that paper and it's written by, you know, some amazing coauthors, my piece was adding my skills as an occupational therapist. I wanted to be able to give back to the patients and the caregivers. Ways to practical ways, that we can adjust and analyze activities of daily living so that we can see where barriers kind of intersect and interrupt the ability to act upon, meaningful and purposeful activities of daily living. Occupation is the roles of your life. It's not your profession. It's not, you know your degree. It's actually your activities of your daily living. And so I want to be able to and from this paper, I wanted to be able to break down those activities of your occupation, of being a family member as being a, you know, a person within this home setting to be able to do self-care tasks or communicate with your loved ones. How do you break those down when symptoms are so functionally limiting? Every aspect of functional performance is impaired in this disease. And it's different than other diseases. You know, somebody that has you know, say a stroke or they have diabetes or they have other types of illnesses, they don't necessarily span the entire, domain of your life. And, and I kind of see this as, you know, an onion. And so many people with M.E. have peeled back the layers of that onion and I want to be able to give them that core. What is it that is so incredibly meaningful in your life? Is it communicating with a loved one? Is it feeling just a tiny bit, you know, clean, you know, what is it about your day that you want to achieve? And and this is in the paper where once we understand what the meaning and the purpose for this particular activity is, or what your choice is, you start getting more control back and with more control, you get in slightly a tiny, tiny bit more, improvement in your quality of life. And so if I can go through and kind of pull apart what, you know, feeding is like, you know, the goal of feeding the golden nugget of, of feeding is actually nutrition. So how can we get food in your body so that you are able to digest nutrition the most effectively? You know,

it's not necessarily feeding with a utensil if you just need to get food into your mouth. Or do we need to have softer food so that you are able to not chew as much and you just kind of swallow it down? So those are the pieces that especially for people that have severe M.E., if we can pull back the barriers for your most meaningful activities, that is how I hope that your quality of life starts to improve, and that this paper just kind of gives concrete options or concrete ideas that patients and caregivers can kind of play with and see what would best suit them.

Clayton Powers, DPT

Yeah. It's, so true that I love how it breaks down the different activities. We've still got a lot of work to do to educate clinicians. I recently got invited to present about, they said about bed bound patients, and they said, we'll give you a 20 minutes. And I thought, oh my goodness. It's like, no, we can't do it justice in that amount of time. And so we still have a lot of work ahead. But one of the main objections I hear when we try to educate clinicians is what research is there to support the treatments that we're recommending. And so, I want to go into the topic of research, because so often health care providers don't, won't accept our advice or recommendations unless there's research to back it. Danielle at Open Medicine Foundation, what research projects have have focused on people with severe ME/CFS and what have you learned from them?

Danielle Meadows, PhD

Yeah. Thanks. Clayton. You know, we've had a couple research projects that have been very targeted, very specific for the severely ill patients. We have, a few years ago, had the severely ill patients study that was, out of Stanford University and, in collaboration with our computation team that really looked in-depth at 20 severely ill patients and compared them to ten healthy controls. And we have a really extensive data set that includes genomics and metabolomics, cytokines, clinical labs, and a lot more from those patients. They were very generous, to give us, you know, the effort that it took to really get that extensive data set. And, you know, we have put out a few papers on what we've learned from that, and we continue to learn from that data set. Over time, we also, have conducted, a home visit study, in Sweden through our Uppsala center, including another 25 severely ill patients and comparing those to healthy controls, but actually also elite athletes to kind of get the full spectrum. When looking at longitudinal metabolomics in response to, different activities. And when I see activities, I'll say like eating a meal, or performing a social task or doing some cognitive or physical exertion. We've looked at the reaction in the metabolomics for each of those groups. And that was done completely in the home. And so, you know, I think what is really great to see is that some of the learnings that we have from the severely ill patients study and some of the initial things that we've seen with the home visits study that's still being analyzed now, are that the themes that are pulling out of those are things that are recurring in the field. Right? So we've seen things that, implicate oxidative stress and immune dysregulation and altered metabolism. And we saw some significant findings with cortisol and estrogen. And, you know, of course, there's the connection to, the female predisposition to having ME/CFS. And I think it's really encouraging that the

things that we learned from these, you know, studies that have focused on the severely ill patients are not isolated findings. So that and we're able to build off of that in future studies. And, you know, we have some ongoing studies right now, you know, in Australia and Canada, all across our centers that are bringing nurses into the home so that people can participate, who are house bound or bed bound. And I think we're trying to continually improve how we include people with more severe ME/CFS as well. So continually having conversations with, severe people who are able to communicate with us or, their caregivers if they're able to provide us any perspective to really understand what it is that it would really, actually take to safely include severe patients within our studies, I love that. I love that you take that into consideration and how to do it safely, because I there's not very many groups out there who would do it safely, I would assume.

Clayton Powers, DPT

So you kind of covered this, this ability to include people in research who maybe it wouldn't normally be included. So we have a better understanding of how we can provide better care and treatments for people with severe M.E. Can you tell us about the new decentralized clinical trial network and how that helps?

Danielle Meadows, PhD

Yeah, absolutely. Yeah, I think Jessica alluded to this earlier, actually, the nature of decentralization being really important for including severe, the, our severe population. And so we've recently launched, new decentralized clinical trials network, that we are specifically designing to include severe and very severe patients. And, you know, we're trying to be as thoughtful as we can about how we approach this and keeping, our community, our patients at the center of it all. Really? Yeah, we know we're collaborating with patient led organizations and people in the community to, really think through how we design these trials and the ecosystem that they sit within so that, they can be done fully remotely. So anybody who is housebound or bed bound could participate. You know, we started this whole, network with, launch of a survey for the community to really understand their priorities and how we go about treatment research for ME/CFS and Long COVID. Really trying to make sure that the research that we do is addressing what the community actually needs and wants to happen. And then we're doing, you know, deep dive follow ups in certain symptom areas and looking at specific symptoms and trying to take this precision medicine approach so that we can, hopefully have the best chance for success and have the some of this rigorous scientific evidence that clinicians can use to then, you know, translate to actual clinical management of the disease. And, you know, we're taking, I hope, what is seen as a really thoughtful approach to engaging with the community to understand trial design considerations, understand what's most important, how we approach things, and really trying to make sure that we are doing this for patients, but with patients also.

Clayton Powers, DPT

Yeah, absolutely. That makes so much sense. And it's so needed because I whenever clinicians ask for research, we need research that really is grounded in the patient experience and being able to share, what it's happening in the homes that's not being captured when people go in and go into clinic to do research. Jessica, can you talk about also about how Solve M.E. is helping make that research accessible to patients with severe ME/CFS as well?

Jessica Maya, PhD

For sure. And I mean, I think we all know studying severely ill populations is really important for understanding the full spectrum of ME/CFS, but it's also important in just improving the care pathways, adapting the research methods for vulnerable populations, and then also making sure that research priorities reflect the realities of the ones that are most affected by the illness. And since people with ME/CFS that are severe are the largest yet least studied subgroup of the ME/CFS population, or actively working to help change that. And I can point to a few examples. There was a recent catalyst award that we gave to Doctor Jay Chang that's investigating this molecule called IVO 21 and this targets mitochondrial dysfunction and chronic inflammation. These are both believed to be central drivers of a lot of the persistent symptoms that we see in a ME/CFS. And what's great about this drug is that it actually has the ability to act as this inexpensive small molecule therapy, taken as a simple oral pill, which can be critical for severely ill patients where many of the treatments can become inaccessible simply because of how they are delivered. But then another example speaks to what Danielle was talking about in prioritizing decentralized trial funding. For example, the Cimarron Group, they're currently doing a decentralized trial for low dose rapamycin, and this allows for severe patients to participate in this trial. The study team adjusts the blood drum volumes. They'll provide additional assistance with patient surveys, which can, you know, if you have a participant in one of these studies, you know, they can be long and can go on for hours just filling things out. And so they help with that. They'll also conduct surveys via the phone for severe participants to be able to still participate. And then another example that I want to talk about is one that we recently funded just last month, Solve selected Renegade Research as the latest recipient of our Catalyst award. And it's funding this study called signal, it's going to basically act as a decentralized discovery platform for emerging therapeutic devices. in ME/CFS and Long COVID. And the signal study was specifically designed to be accessible to this 25% of patients who are housebound and severely ill. And once I started looking at all the devices that exist out there, you start getting like the algorithm telling you, oh, look at this device, look at this other device for vagus nerve stimulation or for red light therapy or all these things. And so the project is built around this idea of trying to understand the landscape, the device landscape, and it's built around this lending library idea through which people diagnosed with ME/CFS and Long COVID can borrow promising therapeutic devices shipped directly to their home at no cost for a three month lending period. And then, while borrowing, the participants will contribute to standardized longitudinal data through the Unhide Solve Together platform. And that's run by the Brain Inflammation Collaborative. So this basically allows each lending cycle to be a real world research opportunity to collect data with these known outcome measurements

that are standardized at this point and understand what devices work, for which subgroups of this illness. So the funding that Solve's giving is going to expand patient participation, accelerate data collection, and then increase the speed with which findings can actually be shared with the community to make it more, able to understand what devices work where and not having to spend the, you know, sometimes thousands of dollars for those devices that you end up thinking, oh, it's a work for me. But then you find out that it doesn't.

Clayton Powers, DPT

That's great. I yeah, I have so many patients who come in and ask about different devices, and it's hard to recommend any because they cost money and and you don't know how or whether they will help. So that's amazing. Thank you. Jamie, sometimes when people are experiencing post-exertional malaise or other severe symptoms, I often hear patients tell me that they go to the ER in those situations to get care, but then they have a terrible experience there. Can you tell us about your emergency department research that you're doing? So you're on mute.

Jaime Seltzer, MS

Sorry. Thank you I clicked it it did not register my click. So that was due to, some generous grants, from individual donors, oftentimes people donating 20 or $25, but also, Grant from Whittemore Peterson, a grant from Mayo Clinic, general internal medicine. And we debuted a survey to ask people about their emergency department experiences, including, what was their chief complaint, what was the main reason that they had come and what were associated ancillary symptoms? So that if somebody says I was there because I was dizzy and also tachycardiac and also nauseated, you can maybe think this is an orthostatis kind of problem, possibly, so that we can look at the major reasons that people with M.E. and Long COVID, in this case, may visit the emergency department. We also, inquired into people's, experiences. What was it like? What kind of care did they receive? What kind of follow up did they get? What, if any, interventions, were proposed or administered? And the goal is to produce, anywhere from 3 to 5 concise clinical guides in terms of how to address the most concerning, issues in the emergency department in these, these patients. So, we and then there will be a Delphi committee. I have to add that because there will be, anywhere from a dozen to 30, depending on how many people give us a final yes, who are going to go through a process of iteratively correcting the emergency department recommendations, making other suggestions. Multiple people in this room right now are on the list, and I've already talked to them and ask them to help. And now that we have all our data, you're going to be hearing from us soon. We opened the survey for about a month. We had to close it after a week because we had that many responses. So obviously this is an area of interest and concern for patients. After we have developed our, our concise little guides, we will be producing a peer reviewed paper with a CME and will be promoting it through, Mayo Clinic channels like we did our last CME. So our hope is that this is going to, result in some consensus based guidelines. That will be broadly helpful far beyond the life of the grant. And thank you to everybody who donated. It was a big deal to all of us. I know, when I say all of us, I don't just mean MEAction. I've had people from

every patient organization talk to me about how, urgent the need for emergency department guidelines is in this disease. And I've had many people living with M.E. tell me that they would avoid the emergency department because of the care that they've received in the past. And obviously, that's a dangerous situation, and you don't want it to be more dangerous for them to go than for them to stay home. So we need to do the best that we can to improve that.

Clayton Powers, DPT

Yeah. It's so important that this gets addressed because when people are experiencing those symptoms and they go to the E.R., it's often more triggering bright lights and, the they have you come in and tell them what's going on and they don't recognize a lot of the symptoms. And so that's so important to have research and training for E.R. physician. So thank you for doing that. I just want to point out that, each organization has different research projects they're doing to try to find treatments. And also that since COVID there's a lot more hope on the horizon. There's more and more research that's coming out and it's been accelerating. And so there's a lot of exciting potential treatments and options, and we need more research as well as more training for health care providers. So we're all in this together to try to come up with solutions. Well, we also want to touch on caregivers. So, Jamie, with those caregivers who may be joining us today, what support does MEAction offer for caregivers?

Jaime Seltzer, MS

Thank you for asking. So we have two support groups we offer for caregivers specifically. And, the two individuals who run them do so with, a great deal of thought and care. And if Holly is able, we can, drop a link, to that support group in the chat. If not, I will grab it in just a minute.

Clayton Powers, DPT

Sounds good. What have you all learned from listening to caregivers experiences?

Jaime Seltzer, MS

There's so much, I think because, I'm more well known, as a patient and, to some degree as, as a medical, researcher. Not not everyone knows that I was a caregiver as well. My mom was sick before I was, and I was caring for her from a very young age. And what I noted was that, the clinical support was not really there for her. And a lot of things fell on to me that I did not know how to do. And so what I think we've we can learn from the caregiving experience in a general way is that people are being asked to carry out tasks that they are that are very lonely, can be very emotionally draining and can be, extremely challenging and make you feel alone. And I think that that's part of the reason, why caregiver groups are so vital. Even if you are thinking from a purely utilitarian perspective, right, you can't care for anyone unless you're well enough physically, emotionally, to do so. So it's really important that people who are caregivers find community, someone to talk to, who understands their experiences, and who can give them

advice about how to handle the incredibly challenging topic of being a full time caregiver for someone in need who often means the world to them.

Clayton Powers, DPT

Thank you. It's so, yeah, it can be so isolating and difficult, whether as a patient or caregiver to navigate, all of this, Amy, as a caregiver yourself, what advice would you offer other caregivers?

Amy Mooney, MS OTR/L

So I'm going to have a theme. Here it is. Witness. Believe yourself as a witness. We talk about a lot about the importance of believing patients. I think caregivers also need to learn to believe ourselves, as witnesses, that what we're seeing is happening. So we do a lot of gaslighting ourselves. I'm a I'm a caregiver. I, I know that it is hard to feel believed. We're kind of straddling that world of isolation, but still have to function in a community. So we leave the isolation to go to the grocery store, or we see somebody on the street and we're asked, you know, how are they doing? How do you even answer that question? You know, how, how, how do I feel like what I just left is, is relatable. And so I think that, you know, that piece that kind of, juxtaposed experience is, is something that we need to be able to come to terms with. And, you know, we feel that from, from other healthcare professionals, we feel it from family and friends that outside world piece is is something that we need to figure out, where that balance is and believe ourselves. And so what we are experiencing also, has value, that my lived experience as a caregiver has value, that it is not the same experience as the person who is ill, which is a horrible experience. But the caregiver also is experiencing trauma. Witnessing your loved one go through pain is trauma. And that piece of it, I think, needs to be put on a perspective of, you know, that that suffering has value. And my importance also is, something that needs to be nurtured. So I think it's giving yourself that permission to acknowledge that this has cost you and it has cost you career decisions. It has cost you financial, family. Just it has cost different things than what a person who has the disease has. But that doesn't make you less important and, and less value. So I think that I think it's to give yourself permission to be able to grieve also, but also find your safe spaces, find those people that do believe that you don't have to explain. That's where the caregiving groups, I think are amazing. I think it's finding those places where you can express your lived experience and not feel judged. So I think that you know it comes as a kind of that bigger picture. I was like, I don't have time to take care of myself. But I think it does give you better tools to be a caregiver when you do take care of yourself. So it's again, find those people, find those places, and give yourself, compassion and grace that you are doing a good job and it is enough. You are doing enough. It's just let's give yourself. And I always talked about this with my patients. Bubble wrap yourself. Give yourself so many more layers of bubble wrap. If you are feeling vulnerable, add more layers. And when you are feeling stronger and more secure, then you can start taking layers of bubble wrap off. But I think that's where I want caregivers to know that this this is an important place that you also belong. And you are also witnessed.

Clayton Powers, DPT

Yeah, absolutely. It can be even dangerous to be a caregiver because of external groups. Saying that that you were facilitating the illness, that you are, not helping that person get better. And so it's so important to find that community and support, so that you're not alone in this. Danielle, how are caregivers helping shape research and advocacy that you you've seen at OMF?

Danielle Meadows, PhD

Yeah. You know, the caregiver perspective is incredibly valuable. And so something that, you know, I'm actually doing actively right now is having a series of conversations with caregivers, specifically, those with severe ME/CFS to talk about what it looks like for, you know, people with severe ME/CFS to participate in trials, but also for what that means for the caregivers of those people. And, you know, there are a couple ways that, you know, we're trying to, to learn from these conversations. But, you know, really trying to to balance the obvious, you know, intense amount of things that caregivers already have to manage. And still wanting to be able to see their loved one participate in a research project, or maybe what concerns they have about their loved one participating in a research project. So really trying to learn from the caregiver experience. And I think, you know, I mentioned, when we launched our, clinical trial network that we did a big, community engagement survey to understand priorities and things. And, and one of the things that we took away from that is, a significant number of people with severe ME/CFS noted that they wouldn't be able to participate in a trial without caregiver assistance being built into a trial protocol. So some of the objectives of these conversations I'm having now is to understand what that really looks like from an operational perspective. What caregivers would be comfortable doing as part of a clinical trial protocol or what they really wouldn't be comfortable doing and how that maybe differs depending on the severity of the patient, but also maybe their relationship to the patient. And, you know, some of the tensions that come with that. So I think we're really trying to, get as much understanding as we can for what that looks like for different people and how we can try to incorporate that into, how we design our studies.

Clayton Powers, DPT

Great. Thank you. Stoo, do you mind, as we close, what gives you hope for the future for people living with severe ME/CFS?

Stoo Brown

Oh, that's a huge question. Do we have another hour? Where do we get hope from? I mean, I guess the plain answer is that we get hope from the prospect of medical breakthroughs. But that's a long way away, and that's a distant hope. I, I think, Amy has touched on being listened to and being believed. I think that gives you hope. Definitely. Our caregivers give us hope. And I value my caregiver, because that's where I get hope from. And then the community that exists

within, M.E.. One thing we say in the book is that people with M.E. don't show psychological weakness. They actually show phenomenal psychological resilience. And in that community, there's a lot of love and there's a lot of hope. And I guess you're just recognizing that. Jamie. Thank you. Yeah, that would be my answer to you, Clayton.

Clayton Powers, DPT

Thank you, thank you. I totally agree that there's so much, resilience in this community. And so I think, there is a lot of hope on the horizon. And as we work together and, join in our efforts, we meet regularly with each organization and we are all in this together. So on behalf of those with severe ME/CFS, so we're going to close. Thank you all for joining us today. We hope to see you again for our next session on Wednesday, September 9th at 10 a.m. Mountain Time, where we will be covering chapter seven of the Clinical Care Guide about assessment of Orthostatic Intolerance and Dysautonomia. And we'll send an email with the recording and other resources at the end of the month. To those who have subscribed to the Bateman Horne Center emails. and we look forward to seeing you next month. Thank you.