

Severe ME/CFS: Medical Panel Webinar Transcript

December 4, 2024

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Dr. Hoppers

Good morning, everyone, and welcome to the third webinar in our series focused on severe ME/CFS, presented in collaboration with the Bateman Horne Center and Solve M.E. I'm Melanie Hoppers, a physician at the Bateman Horne Center and I'll be your moderator today. So, we are very glad you've joined us for this important conversation about overcoming barriers and providing medical care for severe ME/CFS patients. This series is part of our ongoing commitment to address the unique needs of those living with severe ME/CFS, their caregivers, and the clinicians that are striving to improve their quality of life.

Today's discussion brings together three leading experts in the field. Dr. Lucinda Bateman, she is the founder and chief medical officer of the Bateman Horne Center. Theresa Dowell, nurse practitioner, physical therapist and owner of Four Peaks Health Care. She is also a member of the US Clinician Coalition and Dr. Nina Muirhead, an international advocate and clinician specializing in ME/CFS. This session will delve into the challenges faced by both patients and clinicians, offering insights into strategies, systemic needs, and potential solutions for improving care accessibility.

So, we're going to start with Theresa Dowell and Theresa one of the first questions I want to ask you is just simply, could you define what severe ME/CFS is for us?

Theresa Dowell

I guess the best way to define it is by giving you a sense of what this patient looks like. Okay. So typically, in my practice they're about in the 30 to 40 year old range. I'm sure they go from teenagers up until their 60s or 70s. But that's typical. You're going to see a middle-aged person. They'll live with a family member. Some of them don't though I have several that depend on family, friends or neighbors to come in and help them. On a good day, this patient may be able to walk to the bathroom. They may be able to read a text or pantomime messages to their family. But typically, that would be for like a minute and they may be able to do it 2 to 3 times that day. On a bad day they typically are unable to perform any physical activity. They'll typically lie in the dark in silence trying to cope with these symptoms and they may have an eye mask and some earplugs. So, some of them are and most of them, I would say, are 100% bedbound. Right. They can't lift their heads so they can't sit up. They can't lift their legs. Post exertional malaise may be triggered by just reaching for something. And there are some in my practice that are unable to drink or feed or even stool independently. So, the goal for this population of course, is not a cure though we all want a cure, but basically it's a win. So, it might be to be able to brush their teeth independently, or to be able to sit up for a minute or two. So that's basically what this patient population looks like.

Dr. Hoppers

Wow. That's truly descriptive. Very helpful. So how do you adapt your clinical approach to meet the needs of these patients? What practical strategies can you share with other clinicians? What can they do?

Theresa Dowell

Okay, so first of all I run a practice that's mainly telehealth. So that's really helpful for this population because they don't have to go anywhere. Right. I allow family members or caregivers to participate in the consultation. And in this population, they're usually the ones that are speaking to me. So, I may have them bring the laptop in. So, I see what this patient looks like and then come on out. And of course they have to have power of attorney to do that. I try to meet the patient where they're at. Right. So, I look at, you know, what are they able to do? Where can we go from there? We record the visits, and then I give them written instructions. This is super important for our patient population because the caregiver may feel under a lot of pressure to try to remember everything I said. So, I'll give them a summary where these were the key notes that they should relay

to this patient when they can. And then lastly is collaborating with their care providers. So, in my practice, I require that patients need to have a primary care provider that's going to be managing things on a local basis and ideally home health. But we'll talk about that later. So those are the adaptations that I make for them.

Dr. Hoppers

Great. Thank you. Dr. Bateman so what diagnostic and treatment barriers do you see is most pronounced for the severely ill patient? And what have you done to overcome those challenges?

Dr. Bateman

Yeah. I mean, I wanted to kind of preface it by saying that there are a lot of factors to consider because there's so many differences in patients, and it really depends on their age, whether they're pediatric or adult, what their resources are, especially, as Theresa mentioned, family, caretakers, what their financial resources are, what their insurance coverage is, and of course, their illness severity, which can vary over time and just tolerance for the visit itself. Because just the visit itself can cause people to relapse. And also I always try to consider the patient's state of mind because some people go through really down periods and hopeless grieving periods and other times they're kind of ready to try new things. So, some of the things I do, I'm sure we all do a little bit, but I try to do telemedicine visits as much as possible. I also text with my patients because sometimes they are too weak, to get on a computer, or sign in to the electronic health record. And that allows them to do very brief messages back and forth with me. And I engage the caregivers as much as possible to be energy conserving for the patient. But it depends on how sick the patient is. I try to have them in the same room together, if possible, so that the caregivers can speak for the patient, but the patient can speak up if they don't agree and I often direct the questions to the patient and let them defer just so they don't feel overlooked. I try to really be sensitive to cognitive impairment and post exertional malaise and we try to be really available with our electronic health messaging as well. I engage a close staff member so that we can answer questions quickly. Sometimes people think of things after the appointment because they were anxious or not thinking straight. And when I really need to have more eyes on sometimes I'll engage a home health team, a multidisciplinary team to go in and be my eyes and ears, right, and draw blood and give IVs or do things that might be difficult,

but it's hard because you have to really train any staff that go into the home how to be around someone who's so severely ill.

Dr. Hoppers

That's so true, right? I'm always hesitant when I think of some sort of intervention perhaps that someone needs or really, you know, really requires. I'm always so worried about what they're going to encounter when they go to that other aspect of health care that I have no control over. So, speaking of that, Dr. Muirhead, do you have any limitations that affect what you do? Are there any emerging models or resources that you see as promising in addressing the gaps in our patients' care?

Dr. Muirhead

So, from an international perspective. So, I'm based in the UK, our guidelines, the NICE 2021 guidelines, are in practice in some areas but not in others. So, it's a lot of luck for each patient as to what care they can actually access. However, having said that, the idea is that each patient is treated as an individual and in an ideal world, a care plan is documented in advance with the involvement of their carers if possible, and done over a period of time when the patient is in a slightly more able phase, such that if there is a flare up or increased severity, or they need to be admitted to hospital for any reason, it's all written and documented and that includes everything from mobility aids, nutrition requirements, pressure mattresses, whether they have a catheter or not. Nurses doing research, visiting patients in their own homes know to have a very quiet approach, low lighting, calm, maybe even contact the family in the days beforehand to make sure it is an appropriate week or day in their ability level to be able to have the capacity to have a visitor and then work very closely with the patient and their carers to ensure that things are kept short. Like Dr. Bateman said, maybe write things down. Have a responsible adult there to take in the information that's being told. And from my own personal experience of being a patient, my GP called me and I could only manage a few minutes on the telephone and that was exhausting. And it took about a week to plan that very short conversation. So, it's about understanding the capacity of each patient and how to work around it in a practical way. A text or tele medicine is a really good way of accessing patients because traveling and transport and the post exertional malaise that that can trigger can often make things worse.

Dr. Hoppers

So, I'm really curious how often does it go in that manner? I think it's amazing you have nurses in home health that understand the disease. That's incredible. Is that something that happens like 100% of the time?

Dr. Muirhead

No. This is rare. This is the ideal. I think that there are areas where people are striving to provide this care and certainly the Cure ME Team who are doing research and collecting specimens for the biobank fully embracing these care methods. But I think it's very variable for patients in parts of England and Scotland and Wales, there are no specialist centers. So, patients have to either travel a very long way or they often rely on charity help to try and access a clinician. And it's usually a remote consultation.

Dr. Hoppers

Thank you. So, Theresa, what are the barriers for you with your patients when they're seeking care outside of you? You know, you can do all the things correctly or as best that you can. What about what happens when someone needs, you know, an IV or what have you, and they have to access or go to the ER, heavens forbid. What's that like? Is there anything you have in place to help with those barriers

Theresa Dowell

Oh, yeah. So those are probably the biggest barriers to overcome. Right. So, when a patient has to go to the ER, often they don't they will try to ride it out. If they have to then they generally will have to call an ambulance to come and transport them. The problem is that can usually cause a very severe crash because of the lights and the sounds and they're expected to interact at the hospital. And then there's also the stigma of ME/CFS or long COVID that they can't possibly be this affected. Right. So, they go in now they're dealing with a handful of medical providers, some of which may or may not be into this condition. And so, I try to prepare them with a list of medications that they may react to. I try to educate them all along the way as they are my patients that they'll be able to explain what mast cell activation is, what post exertional malaise is, but I don't expect the patients themselves will be doing that. I expect the caregiver would be doing it. Some of the other barriers in those conditions I think that's all like I mean, the big one is, stating that and then the other one is perhaps inadequate

caregiving. You know, we assume that caregivers are medically literate but now they come into a situation where perhaps they're not able to explain what the condition is and what the patient can and cannot do. And so, they don't get the help they need. And often, it comes down to who's your provider. Why are they doing this? You know, and so I allow them to contact me. So, then I can perhaps explain to them what's going on.

Dr. Hoppers

Do you find that when you do explain it, are they receptive?

Theresa Dowell

Sometimes. So, in my community, yes. When it's outside the community, no. It really comes down to that primary care provider in that area. If they're on board then they'll support me and what I'll be saying. But if they're not on board, it can be a difficult situation.

Dr. Hoppers

Dr. Bateman, you said something about this recently and this is just a random thought you know, nursing needs to be educated as well because, you know, that's a lot of the patient contact. They'll see their doctor for 3 or 4 minutes, but they're with the nurse all day long.

Dr. Bateman

We have so much to do in terms of educating medical providers. But and it can be very discouraging. But if one of my patients goes to the emergency room, you know, I call the ER doctor. I mean, I call and talk to the person who's going to assess the patient before they see the patient. And because they don't know what to do with the complicated patient, right. So, I try to make their job easier, right. And say, here's what our main question is, right? And here are the things to watch out for with this patient. And oh, by the way it would help them a lot to give them IV fluids and keep the lights low and things like that. Bateman Horne Center also has a handout that we made at the beginning of the pandemic. We really made it for our patients who went into the emergency room or got diagnosed with COVID, and we'll try to get that resource for you. But it's on our website and it is in a quick two page description of the illness and the basic presentation and the things that might help patients in the ER. I also wanted to

add that patients in the ER sometimes it doesn't go well. I had a patient that was admitted to the hospital. I did everything I could. I called the gastroenterologist before the admission so it would be a direct admission and didn't have to go through the emergency room. I sent handouts to the nursing staff on the station. I called in advance to the admitting physician wasn't the GI person he wanted to consult, and the whole thing was just horrible. They treated him horrible. He was not happy. They left me out of the equation. And so sometimes the very best effort we make is met with skepticism, or people are just too busy. So, for that reason, you know, I try to keep patients out of the hospital as much as possible and do as much as we can without that. I also wanted to add that there are things that you can do if you have an elective procedure, the patient has to go for, in terms of like, let's say they have to go get a pick line put in or they have to go get a CAT scan or something and try to pave the way beforehand. But there are things they can do. They can be transported supine, they can wear sunglasses, they can, you know, there are instructions you can give. Sometimes I'll pre medicate, depending on the patient with IV fluids or with low dose benzodiazepines and in some cases even stress doses of hydrocortisone just to help their stamina through that day. Don't put them on a chronic basis, but just kind of a little extra hydrocortisone to help with the stress of the travel and coming back.

Dr. Hoppers

So, you've sort of already answered this. But just in case you have other suggestions as well. What about and you mentioned this before and I love what you said about having the interview. I understand that sometimes the patient can't be in the room, but having the patient be in the room to be heard. So, if they're able to contribute. I know, one of my family members has ME/CFS and she now wants me out of the room so that people will talk to her instead of me, you know, and she has expressed feeling overlooked, and no one ever means to. I mean, her caregivers are amazing, but, you know, I got kicked out. But I love that you do that because I think that's respectful and a wonderful thing. Are there any other things that you can think of for us, you know to think about when we're caring for our patients, to provide them that respect and dignity with this condition.

Dr. Bateman

I think it's our demeanor, right. And for me, I like to really, not feel rushed. I, you know, schedule plenty of time so I can do a lot of listening and reflecting because I think severely ill patients are very, very isolated and they feel disrespected and they don't feel like they have a voice. So even if I talk to their caregiver outside the room to spare them energy, we always go in the room together and I'll say, here's what I was told, right? Short and sweet. And do you want to add anything? So that they and I make eye contact with the patient as much as I can so they know I can see them.

Dr. Hoppers

That's beautiful. I love that. Okay. So, I'm just curious if anybody has anything to add about that anything additional because I think that's such an important topic. Yes, Theresa.

Theresa Dowell

I've been writing in the chat, so I'm not sure I, I might have missed this, but I just wanted to say it is important that the patient in the end decides what their care plan is. So, you discuss it with the caregiver and then a lot of times we end the visit. They are in the caregiver approaches. It says these are the things that we talked about. These are some of the choices that you might want to make, what sounds good to you. And they're generally very capable of doing that.

Dr. Hoppers

Okay. That's very helpful Nina. Speaking of caregivers. So, the unsung hero right. The caregivers are so important. And you know, I'm so thankful for our caregivers. But what do you do to involve the caregivers in the care process while also respecting the patient's limits? How do you balance that dynamic yourself?

Dr. Muirhead

I've spoken to so many families of patients and what I've found is there is such a variety of capacity. Some of it is medical knowledge. Some is ability to cope with their loved one being ill. And, sometimes it means that, a marriage breaks down. Sometimes the caregivers end up being the parents who are sometimes very elderly. Occasionally, a patient will lose all of their network of support, and then they're relying on friends and social services for caregiving. But I think the key is open communication. And also, if

the caregiver can understand the mechanism of the patient being completely exhausted they can start to look for signs. So, some patients might actually seem more energetic when they're really, really quite exhausted. And it's because they're pushing through with adrenaline. Sometimes their eyes will flicker, sometimes they'll get very pale or start to shake. And I think it's really important that the caregivers are told that these are signs and symptoms. The person is not coping. They might be trying to get their feet higher or compensate in other ways. They may be breathing more labored, sighing. And it's about documenting all of these things and explaining that these are not the patient or the person with ME creating symptoms, but that they are linked to how they express that they're getting exhausted and if that can be communicated, then if the carer does need some respite then this can all be documented and handed over. So, that the carers can maintain some sort of quality of life. Because some of the research that I've done shows that it's hugely impactful, for friends and family of those affected.

Dr. Hoppers

That's such great information. That's so true. I'm a slow learner sometimes, but I have finally learned, you know, I can look and go, oh, I need to back off. I need to just, you know, it's not that I'm upset, but I, I've learned when to talk and when not to talk, you know, and it took me a minute to figure that out. So that's really good information. Does anybody have anything to add about that? Have we covered that?

Dr. Bateman

Well, I'd like to add just a little bit. And, in preparation for this, I made my own personal list of just my patients from memory, you know, listed about 8 or 10 patients just to think about these individual cases. And one of my observations was that the people who had very supported loving family around them did the best. And those are people who the carers had a lot of support from me, from other sources and other family members. And in some cases there were multiple members sick. One of the people who had a supportive partner that partner got such bad caretakers' exhaustion that they split up. And it was so sad and traumatic. I thought the patient would never make it, but, that person had to rejuvenate and that person has been involved, run errands, pick stuff up, come over, help with visits. They're there but I just have a lot of respect for how caretaking can become really depleting and exhausting if the caretakers don't have support as well. And on my list were poor single people, people who had to

hire outside caregivers to come in and take care of them. And the three of them one has a lot of money and can get whatever she needs. And, you know, she's still totally impaired and discouraged by her illness because money can't buy everything. And another patient who, fortunately, has a doctor who will come to his house for his primary care, will do home visits. And then I have a person who her illness led to divorce and she lives by herself. And in her case actually this was just my own decision. I do a very short call once a week with that patient simply because it's scary for her. She lives alone. She worries about things and we just. She's pretty stable. But I just touch base so she has a friendly face to talk to.

Dr. Hoppers

When I first came to the Bateman Horne Center and saw how y'all took care of patients I wanted to be just like you. And listening to that just makes me want to be just like you again. So that's amazing. That's really wonderful. And all three of you do such wonderful things. It's very inspiring. I hope that there are clinicians that don't see severe patients that hear this and can. It's so rewarding. You know, people deserve care. Everyone deserves care. And they deserve good care for sure. Do any of you have any special things or any comments about pediatric patients?

Dr. Muirhead

Before we move on to pediatrics, I do have another point about the system for social care here in the UK. And that is that often patients need to be struggling with all their activities of daily living or have rehabilitation target to start to engage carers. And unfortunately, that model doesn't fit at all for ME. So, patients shouldn't be challenged to be more independent or do more or reach further because they could be made more ill from that. But secondly, sometimes we have to list whether patients need care with a shower or dressing. Well, often patients won't be able to have a shower or dress but they need to have an individual in the house so they're not completely isolated. And that individual sometimes won't even be able to have conversation with them. But just knowing that someone is present can reduce anxiety so much that that the person can feel a little bit of relief from being so ill and on their own. So, I think it's worth just mentioning that just having a person there not even necessarily in the same room can be a real comfort for patients if they're in pain and suffering.

Dr. Hoppers

That's a good point. Do any of you have anything special or different? It may all be the same. There may not be anything really different, but I'm curious if there's anything you do differently with you know juggling the caregiver and just the fact that they have more, I guess, I don't know what the word for this is but maybe more control over what the person does. Do you try to educate the parents as well about the disease? You know, because kids are kind of pushed sometimes you need to go to school you need to continue this activity or you need to go with us. You know, you need to come down for dinner when maybe what they actually need to do is rest. Do you find that difficult to kind of navigate that?

Dr. Bateman

Because I'm internal medicine and I don't see young kids. But I've certainly seen a lot of teenagers you know through the years and they're just like a different animal than an adult for me being an adult doctor. But I've learned to be much more patient and allow them to be a teenager and to be oppositional and not want to believe what their parents say and not want to do what I tell them, and I try to gradually and gently teach them but also a big effort to educate the parents so they understand what's going on. And most parents get pretty desperate for answers and so they're easy to teach in that way. I mean, it takes a while for them to understand. But yeah, I'm always so happy when they kind of round over that age 20 and start to take an interest in managing their own health, right. And taking initiative because it's just really different and challenging.

Dr. Hoppers

They do have to grow up fast for sure. You know, and learn the repercussions when, you know, if they push and that's hard, right? Because when you're that age, you're right, you're oppositional. I was oppositional for sure. Theresa, do you have anything different to add or anything?

Theresa Dowell

Yeah, I do, in that in the severe and very severe, not as many. But, yeah, sometimes I actually have to sometimes, I want to say, convince is not really a good word, but convince the patient, the parent that this is real. So sometimes they'll say all he does is lay around all day. And my son has ME/CFS. He's very functional now. But when I

didn't understand it before I got ME/CFS I used to say those same things. So, I'm sort of embarrassed that I used to say, well if you would just maybe get up a little bit then maybe you would feel better and did the same thing. So, I definitely learned my lesson there. The other thing that I find is especially as they're getting towards graduation, where they would have graduated and they have their friends is grief, you know, is sort of helping them work through what grief is and then also kind of showing them that life is, you know, it's a movie. It's not a snapshot. And, I guess selling hope, you know, to give them a sense of this is just a moment in time we don't know what the future will bring.

Dr. Hoppers

Do you attempt any sort of school? I guess with severe you're really not. Do you have any barriers convincing the school system that they can't do it?

Theresa Dowell

It seems like that happens naturally. Right? So, they start doing less and less, and then they eventually get to the point where they're unable to do that. I can't say that I'm very much involved other than a letter, perhaps, but it's usually the parents that are managing that and they just keep slipping behind. But it's also a sign of improvement when they're able to take one class and maybe go back and finish that class or whatever it may be. But yeah, that's a difficult time.

Dr. Hoppers

It is difficult for sure. And, yeah, it is hard with kids just again, sometimes, like you said, convincing parents. And that's where a lot of our resources come into play. You know, I really try to educate. Here's what's happening, here's what's going on. If you understand to some degree, I understand everyone can't, you know, understand all of the medical intricacies but if they can at least get some explanations for why they're feeling the way they feel, I think that it's helpful.

So, I'm kind of switching gears just a little bit. And this is a frustrating question. So, I apologize in advance. But this is for Dr. Bateman, but I want to hear from everyone. What do you think kind of policy changes or systemic health care changes would be helpful for our patients?

Dr. Bateman

You know, it's interesting that I've kind of moved to an angry place about this. And I think it's because we've been working so hard on provider education in the last two years and even with long COVID, right. It seems so slow going. But we really need change. Our medical system is uninformed, inflexible, at all levels and the medical system is designed for acute care not chronic illness and focused on procedures not on care and all of those things create a challenge. So the number one thing that has to happen in terms of policy changes is there has to be some kind of mandated provider education, health care provider education. I think state licensing should require all medical providers who get licensed should have to do continuing medical education hours to get their license. And, you know, we can do it under that broad umbrella of long COVID and infection associated chronic illnesses. But it's going to take something like that kind of a mandate to change things. We need all of our health care providers to even understand this group of people exists. They don't even know they exist. They don't know how to take care of mild to moderate illness and don't want to see patients. And they're just not equipped. We also need to completely eliminate gaslighting and develop collaborative integrative approaches. And our doctors at this point need to learn not just doctors, but all the health care providers. They need to learn about trauma care. I was in a group of clinicians yesterday, and much of the information came up is that doctors should be trained about emotional trauma and what people have been through in their illness. And I think we need to, in our society, demand more in home care options, and we need to fight for the ability to continue to do telemedicine. And we really need to fight because there are so few specialists and some states have nobody to be able to practice across state lines in these fields where there aren't enough specialists and one of the comments made yesterday in our meeting was we need to get Medicare and Medicaid to pay for rehab professionals to do telehealth appointments or to be able to go into the home and to have more leeway to help manage patients. We also need more occupational therapists and physical therapists who understand the illness and nurses, as you said, who interface with the patients more and need to be educated about the fragile suffering of our patients. So, we have a lot to do. But maybe in a state of the political turmoil we could get more done. You never know that.

Dr. Hoppers

After our meeting yesterday, I wrote a letter, and I was like, I gotta do something. And, you know, I just wrote a letter to a representative. You know, just thinking of contacts. Do you have any contacts? Write some letters, you know, make some noise. Be a thorn. Yeah, that's how you get things done. So, anyway I have some questions that have been upvoted that I would like to pose to you guys. And so the first one is, are there any studies that document that repeated post exertional malaise can result in permanent progression of severity of the disease?

Dr. Bateman

I'll start with that and say, I don't think we have any studies to prove it, but I think all clinicians believe it. I'm going to post a special issue of health care that was devoted to severely ill and very severely ill in 2021. And one of the articles in there analyzed a group of people who were severe and very severe, and almost all of them were pushing through it at the beginning of their illness. And one of the things I frequently see when people kind of crash at the beginning of their illness is them trying to work and gradually losing their employment and until they're so sick. And I had another patient that insisted on trying to finish college and she pushed through. And, you know, it's so hard to tell someone, don't do that. You need to let especially young people follow their dream. But by the time she graduated she became homebound and bedridden and couldn't do anything. So, I feel pretty strongly that early diagnosis is very, very, very important. And in that early diagnosis we have to advocate for pacing and avoiding post exertional malaise which is hard because when people aren't as sick they don't want to do that they want to keep trying. But I feel I'd like to see how everyone else feels about that.

Theresa Dowell

So, I agree with Dr. Bateman, and I do think that it is very important to catch them earlier and help them to stabilize at wherever they're at. Though I do think in the past we didn't have an understanding of vascular syndromes or the musculoskeletal involvement in the condition. Right. And so now I think we, we have like more tools. Even mast cell activation is a relatively new thing for us. So now we have more tools where in the past it might have been that we saw worsening of symptoms and or severity. But nowadays we are like, okay let's look at vascular compression. And that may get someone who's bedbound upright again. So those are the considerations. But I,

as always, it's so important to help these patients realize that you can't beat the post exertional malaise game. You know, like there it is. I wish it wasn't there, but it is what it is.

Dr. Hoppers

I so agree with that and I'm like you, Dr. Bateman. I feel like I am the squasher of dreams sometimes, and it's hard because I also sort of second guess sometimes. I'm thinking they're not ready to hear this and so I have to try to gauge when is the right time to bring it up. I don't want to bring it up at the first visit. I do bring up pacing and that sort of thing, but there's some people that I can see very quickly that they're hurting themselves by working and, but you don't want to bring up disability at the first visit, right?

Dr. Bateman

I want to add something for clarity and that is I don't tell people to do nothing. I train them to understand what PEM is and how to avoid severe PEM and make it be less severe and less frequent by really learning to recognize it. And like in a middle aged working person, I will strongly encourage them to take sick leave from their work while we have long enough for them to learn that. And then sometimes we'll try to give them a trial period back where they can learn if they are able to take it on and gradually move forward with options down the road. But yeah, it's tough and it's tough for people who have to support themselves as well. But I think there are lots of alternatives. And so brainstorming, maybe alternate paths or slower or online courses or, you know, a change in job description to work from home. All of those things can sometimes be helpful for people.

Dr. Hoppers

So, another question that we've had is how do you help, or can you, how do you instruct a patient who is severe to pace? Are they already pacing because they're doing so little?

Dr. Muirhead

It's about chunking things down into even smaller parts. Someone who's very severe may actually get post exertional malaise from turning over in bed, from having bowel

motions, digesting a meal, for women during their menstrual cycle. So, knowing what the person can manage and being super sensitive, maybe a carer helping keep a diary to find out what is triggering it would be a very, very helpful, practical way. And then trying to reduce those things or make them into smaller events. Getting someone out of bed to change the bed may be too much. You may have to change one side and then roll them on to the other side. Things like that, that's very helpful.

Dr. Hoppers

I don't have any other questions and I really appreciate everything. All of your wisdom and your experience and your expertise. It's been so helpful. And I have gotten so many good ideas. I imagine that everyone else has gotten so many great ideas and thoughts and has learned so much. And so, I think that there's going to be an email that will be sent out with resources for you guys, but I will turn it over to Karman.

Karman Kregloe

Thank you, Dr. Hoppers, and thanks to all of our panelists. Just want to remind everyone that we have one more event in the series which will be taking place on Wednesday, January 15th. I'm going to pop the registration link into our chat and you can still sign up for that one. And as with all of these events, there will be a recording made available. There will be a transcript and also a resource guide for you to consult. And many of the links mentioned today will be included in the resource guide. I just wanted to remind everyone that we're delighted to be able to offer these free educational webinars to our community, and we know that a lot of you follow both the Bateman Horne webinars and the Solve webinars and we just want to thank you for your support and just ask you to consider maybe if you have ever viewed one of our webinars or you've shared them with someone and you've gotten something out of them to maybe consider making a gift to our partnered organizations here. This [QR code, you see, is specifically linking out to a page](#) that will benefit both of our organizations equally. This sort of support helps us continue to do more of these and we hope we'll be able to offer another one of these series, in the future. So, stay tuned for that. Thanks so much and have a great day, everyone.