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### **Episode 9: Combating the Stress of the Holidays** **December 3, 2021**

(Music playing)

Mindy Henderson:

Welcome to the Quest podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest family of content. I'm your host, Mindy Henderson. Our mission with this podcast is to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities, and those who love them. And this month, we'd like to acknowledge International Day of Persons with Disabilities, [00:00:30] which we join you in celebrating this December. We at MDA are here for you to educate and inform, to demystify, to inspire and to entertain. We are here shining a light on all that makes you you. Whether you're one of us, love someone who is, or are on another journey altogether, thanks for joining.

And now, let's take a moment to recognize our sponsors. Wishing you a very happy holiday season from our sponsor [00:01:00] Cytokinetics. Cytokinetics is dedicated to supporting the MDA community and to advancing potential medicines for families impacted by neuromuscular diseases. And thank you to our sponsor, Amylyx Pharmaceuticals, a Cambridge-based company focused on the development of therapeutics for the treatment of ALS and other neurodegenerative disorders. The people and families facing the challenges of serious neurological conditions [00:01:30] is at the heart of everything we do. To find out more, please visit [Amylyx.com](https://www.amylyx.com).

Today, we're talking about the holidays. We all know that the holidays can be a fun, festive time of year. There are fun decorations, music, parties, food; but for many, the holidays can be an incredibly stressful time. And when dealing with an illness or a disability like a neuromuscular disease, while the holidays can still be lots of fun, there are also additional circumstances [00:02:00] that can increase our stress. So with me today to tackle some of these more difficult topics and to

provide some suggestions for how to handle holiday stress, I have Dr. Paige Lembeck. Dr. Lembeck, I'm so excited to have you with me today, thank you for being here.

Dr. Paige Lembeck: Thank you so much for having me.

Mindy Henderson: Absolutely. So I know your credentials, you've got lots of great experience, and lots of impressive credentials. I think I'd love for you just [00:02:30] to introduce yourself for us, tell us a bit about your background and your work and expertise with the community of individuals with disabilities or neuromuscular disease.

Dr. Paige Lembeck: Absolutely. I'm happy to give a big portion of my back story. As many people know, if you want to be a psychologist, you go to school forever. So that's where it began for me. I'm a school psychologist by training, but over the past many years, I've been working as what's called a pediatric psychologist. [00:03:00] And what that refers to is, you specialize in working with children who are affected by acute or chronic illnesses, and their families. So that's my main area of focus. I do have a bit of an oncology background, but importantly, and most relevant to this talk, I've been working with the muscular dystrophy community over the past four years at the Yale Child Study Center in Yale New Haven [00:03:30] Hospital, up in New Haven, Connecticut. So that's where I've really gotten to know the muscular dystrophy population.

Mindy Henderson: Perfect. Well, thank you for all of that information. It sounds like you've been doing some fantastic work over the years, and I know that you've got a great reputation with a lot of the people that I work with at MDA, so...

Dr. Paige Lembeck: Thank you.

Mindy Henderson: Let's jump into the heart of the matter. Like I said in the introduction, the holidays can be a really, really fun time, but for [00:04:00] a lot of people it can also be a difficult time. Do you want to talk a little bit about this?

Dr. Paige Lembeck: Sure, of course. And what immediately comes to my mind that I think a lot of people can relate to is, even if you are not affected by a chronic medical condition, the holidays at baseline, as fun as they can be, are very stressful for many. So I think you hit the nail on the head that if you're affected by a form of muscular dystrophy, or really any kind of illness, [00:04:30] something that is intended to be quite fun and celebratory, like the holidays, can take on a very different meaning and it can be stressful.

I think what immediately comes to mind with stress with the holidays is that the holidays can come with some reminders of things that have happened in the past in relation to illnesses, and they can also serve as a trigger for thinking about what the future could look like.

Mindy Henderson: Uh-huh (affirmative).

Dr. Paige Lembeck: And [00:05:00] I know we'll really get into more conversation about the details of this, but the holidays can be complicated with family and traditions that can really put a strain on those with muscular dystrophy.

Mindy Henderson: Yeah. Is there also an element maybe of, a little bit of anger or resentment maybe, because what dealing with might be so challenging at a time when everyone else is having such a good time?

Dr. Paige Lembeck: Of course. I think anger, resentment. [00:05:30] I think there's lots of emotions that could be triggered here. I just think of the fact that it's ripe for opportunity for people to be asking questions, or we all have those nosy relatives, for example. So sometimes it could even set the stage for some conversations that trigger those negative emotions. Some people might feel more depressed or more anxious. And I think, [00:06:00] again, the holidays can be stressful, period, and this can really escalate around this time.

Mindy Henderson: Definitely. So if you're a person with neuromuscular disease or some other medical illness or a family member, there can be additional issues, like you've said, that bring about additional stress and challenging emotions. Can you talk a little bit more about those special circumstances, and what some of the issues are that are wrapped up in this [00:06:30] topic?

Dr. Paige Lembeck: Absolutely. So for those with neuromuscular disease, we think of, first and foremost, what's involved in the day-to-day routine for that. So for not all, but many people have some mobility restrictions, some people are wheelchair bound. Oftentimes, for example, there's financial stressors related to medical care that make the holidays more difficult. So immediately what I'm thinking of is transportation, [00:07:00] financial stress. And I think what can be really disheartening is the holidays are supposed to be a time where we let loose a little bit, and some things that are typically stressful in our life we let go to the wayside. And for the neuromuscular dystrophy community, that's harder to do because aspects of medical care can't always be pushed to the side in that way.

Mindy Henderson: Absolutely. So what are some of the best ways then to combat [00:07:30] stress and distress around those issues? How can they be mitigated, exactly?

Dr. Paige Lembeck: What a great question. And I think probably one of the more important questions that we'll talk about today is...

Mindy Henderson: Definitely.

Dr. Paige Lembeck: Okay, we've named all the tough parts, and now how can we help? Which is a little bit of an uphill battle, but certainly one that we can work through. I think from working with the patients that I've encountered in the past, it seems like [00:08:00] those who are most successful with this challenge are the ones who are able to be creative and create a new normal in some ways.

Mindy Henderson: No, no, no.

Dr. Paige Lembeck: And it's certainly not a matter of being selfish, I would never say that, but it's tapping into, how can I access the best self care and really know the limits of celebrating or participating in the holidays? Knowing what's most important, and also knowing when not to give into [00:08:30] the pressure of certain traditions or gatherings that might add to the stress, if that makes sense?

Mindy Henderson: Yeah, absolutely. For sure. So one thing that you just said about creating a new normal, it brought to mind that there could be a few different scenarios that people are dealing with around this issue. It could be a time where you are maybe an adult person who's just been diagnosed [00:09:00] with a condition and you're dealing with the loss and the grieving of your abilities, and like you said, trying to figure out what your new normal is, and then going through all of those complicated emotions that come along with that loss. But then, there are other scenarios where maybe you're a parent who has a child with a disability.

Dr. Paige Lembeck: Sure.

Mindy Henderson: And you're trying to make the holidays fun [00:09:30] and special for them. Do you see those as two terribly different scenarios in terms of how you might want to approach or address what you're going through?

Dr. Paige Lembeck: I think there's common threads between the two of them. What's coming to mind as you're describing those two distinct scenarios is that I think for both, it's important also to acknowledge the stress and what's going on. I think as human beings, we [00:10:00] have such a strong pull to escape or to avoid the emotional distress or whatever's bothering us, and we're especially vulnerable to that during the holiday season, when it's easy to get busy and focus on other things. I would encourage anybody listening to this, regardless of whether you're a parent or somebody who's facing the holiday season themselves with a muscular dystrophy or other type of neuromuscular disease, I would encourage you to lean [00:10:30] into some of those tough emotions.

And what that might look like in real life is just taking a few minutes to acknowledge that, yeah, there are aspects of this that really stink and are difficult, and it's okay to take a few moments to allow yourself to be sad, or whatever emotion, almost like a narrator for a movie. You could just name it. Like, oh, I'm feeling really bummed that I can't go to that person's house tonight because it's hard for me to get my wheelchair into their house, or whatever. And [00:11:00] in fact, by doing that, it's a healthy coping mechanism because it allows you to acknowledge what's happening and then identify what you can do next to cope more effectively. So I think being a realist can help.

Mindy Henderson: Yeah. That's very true, because I know that we need to give space to those emotions.

Dr. Paige Lembeck: Right.

Mindy Henderson: And I know that to bury them is not healthy, because they're going to come out one way or the other, right?

Dr. Paige Lembeck: Oh, right. And especially, [00:11:30] you mentioned parents and I'm a pediatric psychologist, so we see this all the time across different disease conditions is, of course, as a parent, you are anxious and upset when your child is anxious and upset.

Mindy Henderson: Mm-hmm (affirmative).

Dr. Paige Lembeck: So there's this pull to be in fix-it mode, and I'm going to problem solve through everything, and oh, here's how we can make it better for you. And for some people, that can feel actually pretty minimizing and invalidating. [00:12:00] And I, again, want to encourage people listening, it's okay to say, "I can tell you're really sad. I'm bummed too that we can't do that thing." And I think that's really a powerful validation.

Mindy Henderson: That's good advice. What about the other scenario that I haven't mentioned yet is, there may be people listening who have lost a loved one to one of these conditions or to some other condition, and the holidays are maybe [00:12:30] a painful reminder. What's your advice for approaching the holidays under those circumstances?

Dr. Paige Lembeck: That's another great question, and one that's not totally easily answered, I think, because the way that people grieve and remember loved ones will vary so differently. But some broad considerations are, I'm trying to think in advance, what are going to be the reminders that might come up? [00:13:00] When I work with families, it's almost like playing detective a little bit, and it could be such a simple thing. It could be a food that that person enjoyed, or a color of a sweater they would wear around the holidays, or there's countless examples that could serve as a reminder. So being aware of those things, not because the goal is to avoid all of those reminders, but it can help us know what is more likely to trigger us.

And I think another [00:13:30] area that comes to mind is usually, if we've lost a loved one, usually there's things that we did with that person around the holidays that we really did enjoy. So this is an opportunity also to remember that person in a meaningful way and continue their legacy, if you will, if there's parts of that that you would want to continue. But it can be very painful, absolutely.

Mindy Henderson: Right, and you kind of read my mind because, and I don't want this to sound [00:14:00] insensitive, but what I'm wondering is if there's a way, if you are maybe dealing with a new diagnosis or a loss or a decline in function, you have a child who is maybe newly diagnosed with something or even the loss of a person, I'm wondering if there are almost things that we can do that are positive? Kind of like what you just said, to almost celebrate in a different way that acknowledges [00:14:30] what's going on, but still allows you to find some joy. Does that make sense?

Dr. Paige Lembeck: Absolutely. And I think that's a really realistic goal, and I think this is where we want to move away from that black and white expectation that either the holidays are going to be totally perfect or they're going to be totally awful. It's probably going to be some good and some bad in any scenario. So I think a

couple additional, very broad recommendations [00:15:00] are practicing things that we know help with mental health and stress in general, for both people who are healthy and people who are affected by chronic disease.

And those things could be things like mindfulness. Just to put a plug in, there's a psychologist at Yale who runs the Happiness Lab there, her name's Lori Santos, and she talks a lot about just savoring the moment. So this is something that could be easily done, to be in the present. [00:15:30] An example of this is, even driving around the streets looking at Christmas lights, for those who celebrate Christmas, just tapping into those moments where you can just soak in with all of your senses something that gives you pleasure and joy.

Mindy Henderson: Wow.

Dr. Paige Lembeck: And this could be done even if you have a very advanced, progressive form of muscular dystrophy that doesn't allow you to move very much, or it doesn't allow your child or loved one to move. [00:16:00] Usually there's some availability of senses to be accessed, and that's a simple recommendation that comes to mind.

Mindy Henderson: I really like that. That's really good.

Dr. Paige Lembeck: Yeah.

Mindy Henderson: The holidays are also a time when we typically spend a lot of time with family and friends.

Dr. Paige Lembeck: Right.

Mindy Henderson: It may less so during a pandemic, but [crosstalk 00:16:21].

Dr. Paige Lembeck: Yes.

Mindy Henderson: Not everyone may understand what you're going through or why you're not in as best of a mood as they are. How [00:16:30] do you recommend individuals navigate those conversations?

Dr. Paige Lembeck: This is another one where I think it will look different depending on personality type and how people are built. For example, I know some who would feel very comfortable using a bit of snarky humor to shut down certain conversations or change the topic. Others are less comfortable with things like that. I think what's important here is to, again, be proactive, and try [00:17:00] to anticipate, as much as one can because, of course, life is unpredictable, try to anticipate what are the comments that you're likely to receive?

For example, it may be, be ready for the question of, well, why do you look so miserable if it's insert holiday here. So almost creating, not a canned script, but some ideas for how you might respond. And this is where it goes back to self care too. It's totally... I think there's a lot of pressure with the holidays to [00:17:30] join things, and there's invitations, and there's sometimes stuff that

people feel obligated to go to that they don't necessarily want to. And it's okay to step back from things that contribute to less happiness sometimes. And that's not being selfish; that's engaging in self care.

Mindy Henderson: Very true. That's a great point. I think that's something, particularly at the holidays, I don't know if it's because it's a condensed period of time [00:18:00] that these things and events and social gatherings are happening, but I think we all feel a lot of pressure to accept all of the invitations, and to say yes, when that might not really be what we need.

Dr. Paige Lembeck: Mm-hmm (affirmative). And I think, too... I'm still pondering your previous question. I think, too, in terms of not feeling as joyful or as happy as others might expect you to feel, it's also okay to use just [00:18:30] a little bit of assertiveness here too. I think that can be a tough thing. And knowing that less can be more when you're sharing with people. Sometimes I've had some families say it's helpful to even bring in a little bit of an ally, if there's a family member who can head off something triggering. I think thinking as a unit about how people can feel better and be protected in these scenarios

Mindy Henderson: Yeah, and [00:19:00] to that point also, I'm wondering if it might be a good idea... Obviously, all of this is going to depend on the individual person and the family members they may be dealing with, and all of it is circumstantial, but I wonder, too, if in some cases it might be helpful just to say to the people that you'll be spending the holidays with, maybe even giving them a heads up, that this is what we're dealing with [crosstalk 00:19:27] this holiday season.

Dr. Paige Lembeck: Mm-hmm (affirmative).

Mindy Henderson: And [00:19:30] so, this is going to be a hard time for me, please respect that; almost a preemptive conversation, so that it can maybe head off some of that discomfort.

Dr. Paige Lembeck: I think that has the potential to be a really effective plan. And I think most of us try to surround ourselves with people who are nice and respectful and, no, not everybody is that way, but I think certainly that raises the likelihood that they [00:20:00] would respect that. And now with technology and email and text, there's so many different ways to communicate that upfront, that that opens your options.

And again, let's say hypothetically, there was a recent hospitalization. Maybe ahead of time, you can anticipate, all right, if people are going to be nosy about this or ask lots of questions, that's a time, just as you said, Mindy, to set some ground rules [crosstalk 00:20:25], and maybe hit on the big picture of, we [00:20:30] just went through this big thing, we're really looking forward to just having a break from thinking about that.

Mindy Henderson: Right.

Dr. Paige Lembeck: Or, if you notice that I look a little down, it's probably because I just went through X, Y, and Z.

Mindy Henderson: Right.

Dr. Paige Lembeck: Thanks for... Or, this is how you can help me in that moment.

Mindy Henderson: Right, right. [crosstalk 00:20:47] I like that.

Dr. Paige Lembeck: Yeah.

Mindy Henderson: I like that. I love the language that you just used of, this is how you can help me.

Dr. Paige Lembeck: Mm-hmm (affirmative).

Mindy Henderson: There's something really empowering about that, I think.

Dr. Paige Lembeck: I think on both sides there's something empowering about that [00:21:00] because, I'm certainly the type of person that wants to give people the benefit of the doubt that they're trying to help, even if it looks very clumsy and does not end up being helpful. So this is a chance for us to really guide people on how to support. And I think when we do that and we make it clearer in a direct but respectful way of, here's what I'd like you to do to support me, people most of the time honor that.

Mindy Henderson: Yes, I would agree with that. And also, [00:21:30] I think that sometimes people just don't know what to do. They don't know-

Dr. Paige Lembeck: Yeah.

Mindy Henderson: ... How to act or how to respond. And so, I think if you almost take the bull by the horns and tell them what you need, what you're going through, all of that, that can be doing them a service as well, because then they can respond accordingly, and have the conversations that are going to be more comfortable, and interact in a way that is going [00:22:00] to be the least amount of stress and pressure and all of that.

Dr. Paige Lembeck: Mm-hmm (affirmative).

Mindy Henderson: Yeah.

Dr. Paige Lembeck: Definitely. Definitely.

Mindy Henderson: Yeah. So what resources would you recommend for people who are working through these sorts of situations?

Dr. Paige Lembeck: So there are ample resources out there and some have to do with the holidays [crosstalk 00:22:22] specifically. And the good news is, a lot of the resources that exist for just managing stress and [00:22:30] mental health promotion in general can also be very relevant here. I know in my current job, working with families, we rely a lot on apps that have been helpful to people that teach what we call cognitive behavioral strategies. So they teach relaxation techniques, thinking techniques, and other tips and tricks that save you formal therapy appointments, which is a whole different thing that you could always access. So I



[00:23:00] think things like that that are pretty simple, that you can have very accessible to you.

Go on the Internet and do some research on holiday stress and chronic illness or muscular dystrophy. These simple searches, there's a lot out there. There's a lot of blogs, which some people find benefit in just connecting to somebody else who has gone through a very similar experience. There's also another one that I like the APA or the American Psychological [00:23:30] Association. I just learned this, actually. They have a holiday stress resource center-

Mindy Henderson: Wow.

Dr. Paige Lembeck: ... Which is not specific to neuromuscular disease, but it's really nice. They have a lot of different topics and managing stress during the holidays. I think there is actually a section on those affected by medical conditions. So those are some of my favorites, and then of course, I would encourage those listening to also look into, if you're connected to certain organizations [00:24:00] that are specific to your disease or to Muscular Dystrophy Association, I know CureSMA, CureDuchenne, they have resources related to the holidays and navigating that time of year. So [crosstalk 00:24:13] those are just some initial thoughts.

Mindy Henderson: Absolutely.

Yeah, and those are fantastic. And I'll get... If there are links or websites that I can include in our show notes, I would love to do that, to point people to the resources that you're talking about. And of course, [00:24:30] the MBA Family Resource Center, which could be of help to people too, to maybe help you get connected to professional resources that you might need, so we'll post that information as well.

I would be remiss, because you're a pediatric psychologist, I would be remiss if I didn't ask you specifically about maybe resources for kids, for anyone who may be a parent who is listening and have a child [00:25:00] who might be struggling with their condition or with the holidays coming up. Is there anything specific to kids that you would recommend?

Dr. Paige Lembeck: So there's usually within any children's hospital website, there's a ton of resources out there for supporting kids of all different kinds of illnesses, so that's one good place to start and look. I also would really tap in to what's available in your community, and I think schools [00:25:30] are... I know that's such a generic thing to say, but schools often have a ton of resources to support kids' emotional health. I can't even say how many families I've worked with who have felt incredibly supported by their child's special education team, for example, or their rehab team. So I think leaning on those local communities in which your child exists is key. Again, I mentioned those [00:26:00] apps before, and I'm not naming specific ones just because there's so many of them.

Mindy Henderson: Right.

Dr. Paige Lembeck: But if you Google any topic or go onto an Apple app store, for example, and pull up a mental health topic, you'll probably find some options there.

So yeah, those are the initial resources that come to mind. And again, I'm not sure if this is specifically what you were referencing as well, but there's always a consideration [00:26:30] to seek professional services through a therapist if you feel like your child is really affected by this time of year. I think, as a psychologist, my threshold for recommending therapy is extremely low. I think that's how it should be for anybody. It's better to intervene early, especially if you notice that your child's symptoms are starting to affect either their general happiness or other areas of [00:27:00] their life, like their relationships or their performance in school or their medical care or their family life.

Mindy Henderson: Great advice. As we wrap up, any other advice or tips that you would like to leave our listeners with?

Dr. Paige Lembeck: I think one that comes to mind that I began to reference earlier when I was talking about savoring the moment, is there's so much research to support the fact that we cope [00:27:30] better when we try to find the things that we're grateful for. And that sounds potentially cheesy and cliché. I would not say it if there wasn't so much, again, evidence to support that that's true, and I would encourage everybody on this call to keep looking for those silver linings.

I've worked with lots of families with muscular dystrophies and other diseases, and it's amazing what people can come [00:28:00] up with, even in the darkest of scenarios, that gives them a little bit of resilience or a reprieve or a little bit of comfort. So for example, when the world shut down because of COVID, or if we think ahead and for the holidays, you're not able to partake in something that you would've liked to, or your child would've liked to, because of a neuromuscular condition, it sounds strange to say, but think about, what is that allowing [00:28:30] room for, or offering as a positive outcome? And it might be something as simple as, wow, we had a quieter, more peaceful holiday where we really got to enjoy each other's company in a way that we wouldn't have if we had to go to that crazy party that we didn't want to go to, or whatever it is. So I think there's such an opportunity here to get creative about, what is this offering? Even though we didn't ask for it.

Mindy Henderson: Right. That's such good advice, and I think that it's a [00:29:00] perfect note just to leave the conversation on. Such good suggestions and tips. I can't thank you enough for your time, Dr. Lembeck.

Dr. Paige Lembeck: Oh, thank you so much for having me, and I hope this was helpful to everyone.

Mindy Henderson: Absolutely. Thank you.

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