>> Hello! And thank you for joining CADRE’s webinar titled “Self-Care Strategies for Families with Children with Disabilities,” presented by Missy Longman. Today’s presentation is one in our continuing series of valuable CADRE webinars. A few technical notes. Phone lines have been muted to minimize interruptions. At any point during the presentation, you can enter any questions or comments into the question box — not the chat box, please — and you would enter those on your control panel. CADRE staff will be monitoring comments and questions throughout the webinar. The PowerPoint for the webinar is available in the Handout section of the control panel and on the CADRE web site. We are so extremely fortunate to have Missy Longman with us here today. Missy is a mother, advocate, and co-founder of the SMS Research Foundation. Her 12-year-old daughter, Sienna, lives with a rare genetic disorder called Smith-Magenis Syndrome, SMS, which causes global developmental delay, challenging behaviors, and chronic sleep issues. Missy co-founded the SMS Research Foundation nine years ago to help direct much-needed funding to the study of SMS in order to develop treatment options to improve the lives for those living with SMS and their caregivers. In addition, Missy authors the blog Rarely Perfect, and her posts have been featured frequently on The Mighty. Thank you for joining us, Missy.

>> Thank you so much for having me. I really appreciate you, Amanda, Noella, Melanie, Diana, and everybody with CADRE for this tremendous opportunity to speak on a topic that I’m really passionate about. So, good morning to everyone on the West Coast, good afternoon to those of you who join me down on the East Coast. I’m coming from sunny South Florida. It’s about 68 degrees and sunny, not to rub it in. I promise you we definitely get our payback in September when you all are feeling nice fall weather and we are suffering in the height of hurricane season, sweat, and humidity. So as we begin, I think it’s really important, first of all, to discuss… Before we can talk about self-care, we need to talk about what self-care is not. We need to be able to define it. And our culture, our current culture, will have us believe self-care is something that has a price tag. Something that we have to pay for. It’s a bubble bath, it’s the bottles of champagne, it’s the chocolate, the shopping sprees, the pedicures, the indulgences in life, not the stuff that we need but the stuff that’s extra. And for those of us who are caregivers of children with special needs, we automatically disqualify ourselves as candidates of anything extra because we’re already super-overwhelmed by the obligations and the challenges that we face on a daily basis. So I would argue that self-care is not only not self-indulgent, it is absolutely an act of survival, especially for those of us who are caregivers of people with challenging needs. So in my quest to redefine self-care, I think that self-care for us has actually a lot of different definitions, and I co-moderate a self-care group for SMS diagnosis with parents from all over the world that join it, and we are constantly kind of trying to reframe our day in the context of self-care. Self-care can be many, many different things throughout our day. But overall, I would say that self-care essentially is about, it’s about reclaiming our joy. So many of us have lost that joy. It’s about rebuilding our health, because we are putting other people’s needs ahead of our own. We’re not paying attention to our own health. Rediscovering ourselves, what we love, who we are. Our definition of ourselves becomes “a caregiver” and there’s very little room for other things, so who are we, aside from a caregiver? And redefining what a meaningful life is going to look like for us. Rescripting. You know, letting go of some of the things that we’ve lost on the journey and redefining a new definition of what it’s going to look like. And most of all, self-care is about strengthening our core. And I use this term because if you look at people in fitness and coaches and trainers, they talk a lot about the importance of having a strong core. Your core is what gives you good form. Your core is what keeps you balanced. It stabilizes you. And we really need to have a strong core in order to be stabile throughout the rough storms and the day-to-day challenges that we face. So I really hope at the end of this discussion and this conversation that you’re able to take away a few things. Number one, I hope you get, find some tools for managing anxiety and depression. These are two really prevalent mental health issues that I think caregivers of children and adults, children with special needs, face. And I do have some tools to help manage that. Some ideas for how to begin building your core or increasing the strength of your core. Some reassurance and encouragement that you are not alone. There is a whole world of people out there, a community of people, who are dealing with a lot of the same issues that you are dealing with and struggling, just like you are, trying to figure out your own path to self-care. It is really an ongoing discussion. This is not like a, there’s not really an end to it. I can tell you, I’ve been on a self-care journey for 12 years and I still don’t have it all figured out. I still have more questions than answers, sometimes. So it’s just kind of adding to the toolbox every time we get a chance. And then, I hope that you walk away with some questions to begin asking yourself. This could be the beginning of some self-exploration for you and the changes and things that you can realistically do in your life to achieve some goals. And I set a few goals for us. I’m a big believer in setting attainable goals. I don’t like to fail, so I like to pick goals that I can actually achieve. And I think that these three goals are achievable. I think that we can increase our endurance. We are in this for the long haul. My daughter will be under my care for the rest of her life and mine, so I need to build on that endurance. Resilience. And I’m going to talk a lot about resilience a little later in the presentation. And just an overall improved quality and outlook on life. I’m not expecting you to walk away from this singing and twirling in the hills, Sound of Music-style. Like, that’s not the goal of this. This is really just to move ourselves in the direction of an overall improved and better feeling, quality of life, and better outlook overall on what direction our life is headed in. So, a little bit about myself. Amanda covered a lot of my background already, but this is my family: my husband, Dan; my daughter, Sienna, who we’ve already mentioned, she’s 12 years old; then in the red shirt is my son Sean, he’s 11; and then the little guy in the middle is my 4-year-old Ben, and he is my little bubble and ball of energy and excitement, and he keeps us all on our toes. In addition to co-founding the SMS Research Foundation, I also have a background in social work. I have a Master’s in social work. This was pre-children. I worked in the field of hospice, crisis care unit social work. And I also have a little bit of a background in pharmaceutical sales. I spent some time with selling and marketing, so I have that as well. So, Sienna’s story: she was my first-born child. And her pregnancy, my pregnancy with her was unremarkable to me at the time, but that’s because I had nothing to compare it to. And, you know, looking back, there was definitely some red flags. When I was 36 weeks pregnant, the doctors, in one of her routine ultrasounds, noticed that her ventricles were enlarged, and they were concerned about that so they sent me to the hospital to get a fetal MRI, which at the time, I didn’t think was a big deal, but now, looking back, I realize that it’s not routine at all and it should have been cause for alarm for me but it really wasn’t. I was so focused on having a baby and having a little girl, I wasn’t really paying attention to what the severity of that probably meant, and coupled with the results of that were that they were in the upper limits of normal and she actually looked really good on the MRI. So there really wasn’t a big concern until around 38 weeks. They determined that she, I was having intrauterine growth restriction, IUGR, and they wanted to induce because she had stopped growing, essentially. So she was induced, but her Apgar scores were great. We were sent home after two days. Everything else, like I said, was really unremarkable. It wasn’t ‘til about her two-week check-up when the doctor noticed a heart murmur and sent us to a pediatric cardiologist, who diagnosed her with two very large holes in her heart. And we understood that she was going to need surgery, but the intention was… She was very small when she was born. She was five pounds. She was still very tiny at the time of the heart diagnosis, and the intention was to allow her to gain some weight before she could have the surgery because the cardiac surgeon didn’t want to do a surgery on such a tiny baby. He would prefer to hold off. However, she was going into congestive heart failure. She was actually losing weight. She was about four pounds, ten ounces. And at one point, we were feeding her one day and she turned blue and stopped breathing and we called 911. And at that point, we checked into the children’s hospital down here in Miami and waited our turn for the surgery. So she had the surgery, and the surgery was successful. This picture that you see to the right is me holding her for the first time three days after she was removed from the ventilator. My first time holding my brand-new baby girl after she just had open heart surgery, and the geneticist walks in and tells us that she has Smith-Magenis Syndrome, and she completely altered the trajectory of our lives forever with that information. So of course the geneticist tells us not to look it up, that we should just go home and love her, but, you know, we did look it up. We needed to know what we were dealing with, and this is what we found. Smith-Magenis Syndrome, also known as SMS, is a microdeletion of the 17th chromosome. It has many, many characteristics. I’ve limited them here but I’ve only listed the really major ones. Global developmental delays, cognitive impairment. There is a severe behavioral phenotype associated with it, including attention-seeking behaviors, self-injury, aggression, meltdowns through adulthood. A significant sleep disorder, they call it an inverted circadian rhythm. It basically means that her melatonin spikes during the day and drops at night, which is the opposite of our normal circadian rhythm, which means that she inevitably has some daytime sleepiness and nighttime waking. And also a whole slew of medical and health issues, which, unfortunately for Sienna, in the first three years of her life, she had several surgeries, things like a tethered spinal cord, torticollis. She had two eye surgeries for strabismus. Tons of ear issues, ear infections we still battle to this day at age 12. We’ve had, I can’t even tell you how many ear tubes we’ve gone through. She had to wear orthotics. She had, she’s been through the gamut. So the doctor tells us to take her home and love her. However, after reading all of this, we felt instantly a profound sense of loss. We were in the throes of grief. It was physical, painful grief, and what I find so interesting, especially looking back, is that, and especially having a bereavement background, you know, when somebody dies, when you actually physically lose a loved one, grief and the grieving, there’s a process to grief and grief is expected. And, of course, very normal. However, it gets complicated when you are grieving somebody who is still alive, and it is incredibly normal but it is not quite so acceptable. And we learned that almost instantaneously. We were not given, at the hospital, any resources, contact person, any professional to help us process that grief. Nobody was there to help us, to help normalize or validate the grief that we were feeling. And even outside of the hospital on our return home, we found really that nobody was really able to help us work through it. So, what did we do? Well, I think we did what probably all of you have done, and that’s because we are incredible advocates and parents for our children, and we threw ourselves into making things okay. That became our number one job, right? We have to make everything look okay, feel okay. We have to give them the best shot that they have at a good life. So we started with the therapies, the OT, the PT, the speech therapy, the behavioral therapy. We’ve done hippotherapy. Every kind of therapy under the sun. You name it, we did it. And then, of course, all of the medical issues on top of that, trying to fix all of the things that internally and externally were going on there. And then, in the meantime, really trying to normalize and build our family and our lives and, you know, adding to it. I had, gave birth to my son Sean 16 months after Sienna was born. Six years later, had Ben. And also really trying to build a sense of hope for ourselves and contribute, you know, to the population by starting the SMS Research Foundation. So we’re doing all of these things, and on top of it, in the midst of all of that, we are learning how to manage these intense behaviors. And with Sienna, the way that SMS manifests in her life really hasn’t changed much since the age of three. She’s matured, for sure. There’s been a lot of growth and a lot of progress, and I would never try to minimize that. However, her needs have not really changed. She requires constant supervision. When she’s left to her own devices, she can be quite destructive. She can rip up books that she loves. Things that belong to her brothers, she can tear apart. She can… The kitchen, now that she has access to things like the stove and the refrigerator, you know, that’s problematic for us. And she’s also a lot smarter now, so she can figure things out a lot quicker, so it makes the destruction actually a little bit worse as she gets older. But, and then in public, we battle with, she has no stranger danger. She will walk up to people that she doesn’t know and everybody is her best friend and it’s actually really sweet and really endearing and I’m always so thankful that the majority of people are super kind and receptive to her and I appreciate that. However, I have to be on constant guard because as she’s hugging somebody, she’s also pulling off their glasses, taking off their hat. She’s a total pocket-picker. Like, she will pull a wallet out of somebody’s purse, or a phone. She’s obsessed with phones and she will take people’s phones right out of their hands. So where that puts us is in a constant state of hyper vigilance, right? I mean, we cannot leave her alone for a second. And you learn to stay three steps ahead, but you’re always on alert and it is mentally and physically exhausting. And my body let me know that. So, about three months after my son Ben was born, I was coming out of my newborn kind of, you know, breastfeeding-around-the-clock coma, and I was having lunch in a deli with two of my girlfriends and I remember just feeling elated that day because I was finally out among the living. Ben, I mean Sean and Sienna were at school. I just fed my baby. He was sleeping in my arms. And I had just finished nursing him and my friend was telling a story and there we were at the deli, just having a nice time, and in the middle of her story, all of a sudden I just felt this weird tingling in my left arm. And it wouldn’t go away, it just kept kind of building, to the point where I stood up because it was kind of alarming. My first thought was “I think I might be having a heart attack.” And almost immediately, as soon as I stood up, my chest got super, super tight and it felt like somebody was covering my mouth. I couldn’t breathe. I was trying to grab breaths and I just wasn’t getting oxygen. And at the very same time, it was like my system was shutting down. My hands and my feet got completely numb and I had, my heart was racing and pounding so loud that I couldn’t even hear the other sounds in the deli. I could only hear the blood flowing through my brain. And I felt really dizzy, like I was going to pass out. So I handed Ben to one of my friends and said to the other one to call 911 because there’s something really wrong. So 911 came, the ambulance came, and they brought me out to the car, well, to the, you know, ambulance and they started taking all of my vitals, and in the meantime I’m still going, I’m still experiencing all of these physical symptoms. And they start taking my vitals, and he says, “Your oxygen is at 100 percent, 95 percent,” whatever. Super high. Totally normal. “Your blood pressure is perfect. Your heart rate is perfect. You are physically okay.” And I said, “No way. You are missing something. I need to go to the ER immediately. I am definitely dying.” So I went. I had them take me to the ER. I left my baby with my friend. I called my husband, called my parents. They all met me at the hospital. And within ten minutes, the nurse administered a shot and seconds later, I felt totally fine. And I looked at her and I said, “What was that?” And she said, “That was Ativan.” Being in the health care field… Well, you probably don’t even need to be in the health care field to know that Ativan is for anxiety. And I just could not get over it. I couldn’t understand why a shot for anxiety would help me. And when we spoke to the doctor during my discharge process, when he was explaining what was going on, he said, you know, “You had a massive panic attack.” And my mom — this is actually kind of funny — my mom was in there with us, in the room with us, and she looks at him, she goes, “What? She’s handling everything totally fine. What do you mean, she’s had a panic attack?” and he said, he looked at her and he goes, “Excuse me, ma’am, with all due respect, but your daughter is in the ER for a panic attack. She is not handling everything okay.” So sure enough, I had all of the symptoms, and if you’ve had a panic attack, you know exactly what I’m talking about. I had all of the symptoms of a panic attack and with no prior history of anxiety, no prior history of panic. I did not see this coming and I was completely astounded and actually still didn’t even believe it. I went to a cardiologist to get a full work-up. I did everything I could to try to figure out what was really going on, because there was no way it could be that. So in the midst of all of that, actually… Sorry, I’m going to go back for one second. In the midst of all of that, months, throughout several months later, I had what I would call aftershocks, where I would be in a store and all of a sudden, I would feel the symptoms coming on, and I would have to leave the store because I was so worried that I was going to freak out and have another panic attack there. It became so debilitating that, you know, I would call my husband and have him come home from work sometimes because I didn’t want to be left home alone with the baby. I would call my mom and ask her to come stay with me. I did not want to be alone and I really didn’t want to go out in public, so it was becoming very, very debilitating for me. And I couldn’t figure out what was going on with my body, why my body was so out of control. So it turns out there’s a really good biological, physiological reason for that. It stems from my role as a full-time caregiver of somebody with, of an individual with special needs. And if you get a chance, I highly recommend reading the full article from the Journal of Autism and Developmental Disorders. They measured levels of maternal cortisol in mothers of children with autism, and I’d like to add, it was mothers of children with autism who demonstrated clinically significant behaviors on a regular basis. I think the behavioral component is really important to remember and keep in mind because that, for sure, is the thing that throws the stress levels over the edge. Cortisol is the stress hormone that’s released in our bodies during, it’s the stress hormone that’s released in our bodies in reaction to crisis, and it triggers our fight-or-flight instinct. Cortisol is… We basically have like a built-in alarm system in our body, so it’s like a, it’s like the red emergency pull that’s behind the glass that you’re not supposed to touch unless there’s absolutely an emergency. When it’s used chronically, over and over and over again, and it’s not supposed to be, it wreaks havoc on our bodies. And it causes a lot of health issues, including — ding, ding, ding — anxiety and depression. Also things like weight gain, which I know many of us struggle with, and memory loss, concentration problems. There’s a whole list of stuff that comes with this chronic stress. In this article, the maternal cortisol levels were significantly lower than normal, yielding profiles similar to those of combat soldiers and others who experience constant psychological stress. So we are like in combat. And we are losing our buffer. We are losing our resilience. Really, the longer that we do this job, I think, the more we get, our resilience gets blunted. So the first thing that I wanted to do was really kind of reset my nervous system, because I was so out of whack, I wasn’t even functioning. And I needed to be able to function for my family, and I needed to be able to function just in my daily life. So what I needed to do is get everything on the surface sort of figured out first. And I explored a lot of options. I want to say this list is all natural ways to cope with immediate anxiety, with any anxieties that you’re feeling now. I didn’t put medication on there because I am not a candidate for medication. I actually tried two antidepressants, but the first line, which is therapy, immediately they wanted to put me on antidepressant. I tried two of them and unfortunately, I am in like the one percent that gets side effects from any types of pharmaceutical drugs. So I wasn’t a candidate for it, but this in no way discounts the importance of medication and the benefits that you can get from being on a medication to treat your anxiety or depression. So it’s just not on this list because it wasn’t for me. But if it’s for you, absolutely please use it. So the first thing I did was I actually eliminated caffeine and alcohol. Caffeine for obvious reasons. The heart, you know, your heart rate goes up when you have caffeine. Alcohol because alcohol is a depressant, and anxiety and depression really go hand in hand. They’re like bride and groom. So, and I did notice that when I was having a panic episode or periods of some anxiety that it was usually followed or coupled with some depression. So I cut both of those out. Breaking a sweat daily is still a go-to for me. It’s huge. I need some place to put all of that adrenaline that’s constantly pumping through my system, and I highly recommend getting some kind of exercise routine into your day, whether it’s walking, running, you know, biking, swimming. Anything that gets your heart rate up in a healthy way will be good. Essential oils, I love essential oils. They’re really grounding. And what happens in anxiety is it’s disorienting, you sort of disassociate from yourself for a little bit, and anything that can ground you and keep you really in the present and away from the stuff, the dread that kind of overwhelms you with a panic attack, is really good. And you have to experiment with scents, because some scents can kind of do the opposite and kind of throw you out of whack even more or they can just turn you off or put you in a bad mood. I love wild orange and peppermint. Other people prefer more calming scents like lavender and cedarwood. But I just encourage you to kind of explore essential oils if you get a chance because the benefits of them are amazing. Supplements, I tried so many supplements. GABA Calm is 100 percent my favorite. It’s not on here but CBD oil is another one that I am a strong advocate of. I didn’t put it on here because at the time it wasn’t accessible to me but now I find it very, very helpful. There’s other things, like passionflower, lemon balm, a ton of different adaptogens that are helpful. There’s a product called Serodyn that’s also a supplement, and kava tea I love, I drink almost daily. Really calming. Breathing exercises. Brene Brown teaches something called “square breath” and she teaches it to children, so it’s really easy to remember. And what we need is we need tools that we can latch onto when we’re in the throes of a panic or anxiety attack that we can, that are easy to remember, because otherwise we won’t use them. And the square breath is super easy. You just inhale four breaths, hold for four breaths, exhale four breaths, hold for four breaths. And that really helps to kind of calm and center you. And again, it’s that grounding, that putting you back in the present moment and away from those feelings of dread. I love the Calm… There’s so many meditation apps, but I love, the Calm app is my favorite. They offer, like, anywhere from 5-, 10-, 15-, 20-minute meditations, and so just depending on how much time you have, you just pick one of those. The 10% Happier app is really good. I think both of those apps cost money. There’s tons of apps out there that don’t. And also, by the way, just sitting in peace for five minutes, like, by a tree or a body of water or something is the same thing, and you don’t have to pay anything for it. And sleep and nutrition are last because I do think that those are probably our biggest struggles but the ones that we know the most that we need to do. Sleep was a nonnegotiable for me from the beginning. Actually, when I read all of the characteristics of SMS and I saw that sleep was an issue, I totally freaked out because I love my sleep, I need my sleep, and I knew I needed to figure out a way to make sure that at least I got sleep in order to be able to function. And so we did the best thing for our family ever. When my daughter transitioned out of the crib, we got a Safety Sleeper. And if you are not familiar with the Safety Sleeper, I would encourage you to look up the company. The owner is amazing, the product is amazing, and it is absolutely life-changing. I do not sell the Safety Sleeper but I promote it and advocate it for it as much as I, every chance I get because it really changes your life. It first of all keeps your child safe and free from wandering the house, free from eating, free from getting into trouble in the middle of the night. For elopers, keeps them free from escaping the house. And for the rest of the family, it keeps all of us rested. Even if the child is not sleeping well, at least we are, and we need to be able to function and keep doing what we’re doing every single day, so that sleep is really essential. And actually, what I have found with Sienna is that the Safety Sleeper has really created some excellent sleep habits in her. She sleeps, for the most part, every night from 8 to I would say about to 6 a.m., sometimes earlier, sometimes later, but I know without the Safety Sleeper, her sleep would not look like that. So the sleep hygiene that’s created and that one I think is really important, too. Nutrition does not have to be complicated. Most of your plate should have greens, some protein, some complex carbohydrates. You don’t need to spend a lot of time, you know, counting things or measuring things or weighing. Good lord, we have enough going on. But, you know, decrease sugar and things that come in a box. So after I finally got all of my nervous system sort of calm and relaxed with those things, I began to dig a little bit deeper into what was really kind of maybe behind some of what was going on that led up to that panic attack, aside from, of course, the obvious, the constant hypervigilance, what else I was looking at. And I did this with therapy. And what I found is that a lot of us, our stress reactions, our negative stress reactions, manifest themselves in some of these ways: exhaustion, resentment, regret and guilt, anger, a short fuse, impatience, isolation, comparison. And all of these things are associated in some way, especially when we act on them, with shame. And shame is really toxic. So when you peel back, though, when you peel back the layers of these stress reactions, what you also may end up finding is an underlying connection called grief. And so now we’re back to where we were in the beginning. And what happens, interestingly enough, I think, especially when you are caring for somebody who is still alive — this is grief, again, not when somebody has passed but when you are grieving over a life-altering diagnosis — is that you revisit grief again and again. It comes up in waves and there are a lot of triggers out there that trigger grief. There are milestones. Sienna is, you know, hitting that middle school puberty time right now and there’s a whole new sense of loss at this age, things that I know that her peers are doing that she’s not doing. And grief, once again, that unresolved grief from the very beginning, can become unresolved grief throughout our life if we don’t stop and figure out how to process it. So it’s a really, really an essential part of the self-care that we do is processing our grief, talking about it when we feel like we’re in the throes of it, having somebody that can help us normalize it and also help us connect some of these outward emotions to the grief that we’re actually experiencing. So in addition to that, when we’re talking, we’re going to go back to building our core with radical self-care. And so now, this is about trying to add to that resiliency that we’ve lost. That study that I shared with you, really important point that I don’t want to forget to mention in that study is that the author made a point at the end of the, during the discussion section, you know, when they talk about other things, the future research that should be looked at, the author suggested that there should be a study done, a follow-up study, with mothers only of children, of young children, so mothers in new, early stages of special-needs parenting, to measure their cortisol levels and see where they’re at. And his hypothesis was that their cortisol levels are probably going to be normal or much closer to normal than the mothers that were previously studied. And I find that so interesting, because what that tells me is that mothers — or not just mothers, I’m sorry I keep saying “mothers,” it’s really caregivers — caregivers of adult children with special needs really require much more support and resources, first of all than they’re getting, but possibly even more than caregivers of younger children. And if you look at our culture and what’s currently offered right now in our country, it looks quite different. There’s a lot of resources poured into early intervention and there’s a lot of support in those younger, elementary years but once the child ages out of the school system, those resources significantly diminish. And I think that if you are a professional on this call and you’re looking into this, I hope that, you know, there are people out there who are willing to change that and to do something about that, because caregivers of adult children with special needs really, really require a lot more support than we are providing them at this time. So what we can do for ourselves is we can try to help to build that core with radical self-care and we can increase our resiliency through many different things. We’ve already talked about a lot of these: therapy, medication, essential oils. Decreasing and eliminating social media, especially if we’re feeling particularly vulnerable or fragile. Social media is a wonderful way to connect and feel less isolated, especially if you are homebound most of the time. It’s a great way to find people who are going through your similar situation. But it becomes unhealthy when we start comparing our real lives to other people’s Facebook life, and even within the world of special needs and comparing our own children to somebody else’s child who has the same disorder but maybe we think looks like they are higher functioning or doing more or able to do more, and then we start to add that guilt, that feeling that maybe we should be, we’re not doing enough, and it can become a really negative spiral for ourselves. So if you find yourself in that situation, I would definitely encourage you to at least drop it for a little while and see how you feel and see if that helps lift your mood a little bit. Support groups are essential. If you can find one that is specific to your child’s disorder, I strongly suggest that. I think the more specific it is, the more relatable the people in the group are, but any kind of group that you feel like you are heard and can share and open up about what’s going on internally is very beneficial. The physical aspect, the physical piece, is the exercise, it’s the gardening, it’s the nutrition, the hydration, the proper sleep, playing with your pet, the snuggles and the cuddles. Your emotional and spiritual piece is journaling, it’s prayer and meditation, it’s mindfulness, paying attention to our thoughts, and I’m going to get back to that in a little bit because it’s really, really, really important component of self-care is what we’re saying to ourselves. Gratitude. My family and I this year just started, I got one of those really giant water bottles and I put it in the kitchen with a notepad and some pens next to it and everybody has to write something every day, something that happened in their day that they’re thankful for, somebody or something, so that we can fill it up and by the end of the year, take a look at all of the things in our life that we have to be thankful for. Hope. The SMS Research Foundation is an incredible source of hope for me personally. When I can look toward the possibility of things rather than feeling stuck in what is, that definitely gives me a better outlook on life. And then my relationship with my friends, my spouse, my family. You know, we kind of isolate ourselves sometimes. It’s important to really maintain those connections to the people who really love us and care about us. And then any time you’re in nature or any chance that you get to interact with nature can add to your toolbox. Okay, so we talk a lot about lack of time and lack of resources. So first of all, when you look at this group, I really tried to only pull out things that don’t really cost any money. Therapy is probably the most expensive thing on there. Everything else is essentially free. So it’s not really a financial issue, and in terms of time, some of these things can be done speckled throughout your day. It can be done in chunks of five minutes even. It doesn’t even have to require a ton of your time, either. So, I think, a lot of times, how, the roadblocks that we face and how we end up sabotaging our ability to practice self-care is one of two things. And I’m bad at both. So I can admit that. Number one, saying no to the stuff that we don’t want to do or the stuff that doesn’t serve us. We have to prioritize ourselves. We don’t want to disappoint people. I understand that. I’m the same way. I don’t like to hurt people’s feelings or disappoint. And I also want to get that invitation again. So I hate saying no, because I’m afraid that that’s going to discourage somebody from asking me again. But at the same time, if I’m going to, you know, make these other things a priority and I want to engage in some of these things in order to feel good, then I’m going to have to say no sometimes to people. And then my really, really hard one is asking for help. There are people who are willing to help, willing to give us a break, willing to take on some tasks for us, and we’ve got to be able to tell people what our needs are. They can’t guess, and sometimes that’s my expectation is that people can figure it out on their own, but we need to give people some guidance. The people who love us in our lives, we’ve got to give them a little bit of guidance in terms of what would be helpful for us. So back to self-talk. And I made this as one slide because to me, this is number one. To me, this is the most important thing, the most important act of self-care that we can give ourselves and we can start it immediately. Therapy does actually really help in this department, and again, I would encourage, if you’re able to do it, I would, especially if you find that your self-talk is extremely negative. But we narrate our life story every single day. If you stop and listen to your thoughts, you are telling a story of everything you see, interact with, experience. And the way that we tell that story to ourselves is going to determine the way we see and perceive our lives. Self-talk is going to determine our self-worth and how much we value ourselves. Our self-talk is going to determine our level of self-compassion. When we mess up, when things don’t work out perfect, when we lose our temper, how much grace are we offering to ourselves? Are we talking to ourselves like a friend or are we putting ourselves down constantly about all the things that we are, all the ways that we are falling short. Self-talk also really dictates how empowered we are. There’s so much about this life that we cannot control. It’s out of our control and we’ve got to find the areas where we have some autonomy and where we can feel empowered and we, it starts by what we tell ourselves we have control over. Problem solving starts with the way that we talk to ourselves. So it’s our life script. Sometimes we need some help reframing and rewriting that life script, and again, like I said, therapy helps, support networks help. But sometimes even just sitting in meditation and listening to your thoughts and starting to get a sense of where thoughts are going, you can just really start to learn how to reframe what you’re saying to yourself about your life. So another tool that I think is really important to use when it comes to self-care is rediscovering ourselves by finding joy in things that nourish us and nourish our spirit and our soul. And these are often things that used to, we used to find pleasurable but then somehow lost touch with that along the way. And so it’s hard sometimes to reconnect with the things that bring us joy. So I just listed a few questions to help kind of prompt or spark maybe some thoughts in your own self-exploration for what might be the thing that helps you find your joy again. So things like what makes you feel the most alive and in the moment? What activity have you participated in in the past where you actually lost track of time? You know, you hear about people who paint and, like, six hours later they, you know, they weren’t even thinking and all of a sudden the time just goes by and they have this painting in front of them. What about an activity that you participated in in high school or college that you loved but didn’t pursue later because life got in the way? So anything that we were passionate about in our younger years, chances are we still have that passion there, we just didn’t get a chance to follow through with it or pursue it. And then, also, what about somebody that you admire and is there something about them that you admire the most? Because it’s possibly and probably something that needs to be birthed in you. And if you look towards other people that you tend to follow maybe on social media or feel inspired by, what are those qualities and those traits in them that you aspire to have and what are the types of things that you can do in your life to help you manifest those qualities in your own life? So again, self-care doesn’t have to cost you anything. If I were to name my four top, most important things that you could walk away from today and do, number one would be to please, please give yourself permission to grieve whenever and wherever you need to. And understand that grief is a process and it’s an ongoing process and it’s not something, you don’t just arrive at acceptance and then it’s over and done. That was something I believed early on and I would get frustrated every time I found myself spiraling into grief again, that I thought, “Why am I going around this now and again? I thought I got over that part already.” Well, it doesn’t work that way, and grief really needs to be processed. So figuring that part out about where you can process your grief, contacting people that you have in your life that can help you validate and normalize your grief, identify your grief, that’s really, really important. Strengthening your core with all of those, the things that we discussed. Monitoring your self-talk and the scripts that you’re writing about your life. Engaging in activities that really help to heal your adrenal system and your nervous system. Calming your body down as much as you can in the time periods that you have to be able to relax and allow that part of you to heal. So we get asked a lot how others can help, and it’s so much simpler, I think, than we’re led to, than people think. I really think that we kind of complicate these things. First and foremost, I think caregivers of individuals with special needs really are looking for empathy and encouragement. We’re looking for somebody to help us normalize and validate our grief as well. Grace. You know, we develop this sixth sense when it comes to judgment. I think we’re so in tune with the way people perceive our children and how they’re responding, how the world is reacting to our children, that we develop like this sixth sense of judgment, and we can smell it a mile away. And it, we also know when somebody is truly offering us grace. And I would just say that if there’s a mom who isn’t coming to all of the, you know, school events or doesn’t want to be room mom or the kid comes with messy hair or disheveled, you know, clothes or, you know, put yourself in that parent’s shoes of how difficult it might be, you know, at home to take care of this child, to put a brush through their hair, to… They might be so exhausted and school, when their kid is at school, is the one time where they have a break. And so really just try, especially if you’re a professional, to offer grace wherever you can and just give that parent the benefit of the doubt that they are actually doing really the best that they can and that this job is so hard and it is, it doesn’t ever end. And there really is very little time away. There’s very little breaks. So if you can, offer to keep the child for an hour or so to get an ice cream or smoothie. You know, if you don’t feel comfortable with that, offer to help in other ways. Make a meal for the family. Pick up a sibling from school and take them out. You know, oftentimes the siblings are not given a certain level of attention because all of the attention is on the child with special needs. And keep inviting. Don’t stop. Like I said before, we may say no but that doesn’t mean we don’t want to join and it doesn’t mean that next time we will say no again, and just to know that people are thinking of you, this… It is very isolating to be a caregiver, a full-time caregiver, and just knowing that somebody is thinking of you is enough to make you feel like you’re still part of the community in some way sometimes. In terms of the community and what I think the community can do, I think making available weekend and holiday respite or camps is huge. I actually have access here in South Florida, our local JCC offers a winter camp that my daughter attended a few days of the winter break. Not the whole time, because we did go away, but she went for a few days and they did, you know, activities and the center and then they did field trips. It was just like summer camp except in the winter. And that kind of break for families is really huge. I find that weekends and holidays are the hardest for us because the schedules are all out of sorts and our children often really thrive on structure and it’s very difficult to properly structure a weekend or the holidays, especially when you have other siblings involved, so I really think that the community at large should have more resources available that allow for parents to get, or caregivers to get a break during this difficult time. So one thing I hope that you take away from this, too, is that you remember that healing is not linear. I wish that my rollercoaster was as pretty and colorful as this one. Mine looks a lot messier and lot sloppier and I guarantee my drops are a lot steeper than the ones in this picture. But with every, you know, drop, there is a comeback, and I always seem to find new tools and new ways to cope that I didn’t know before. And I think that you learn a little something different every time you take a slide, and we are going to be able to do this, but you just have to keep in mind that sometimes you’re going to take a hit. But you will get back up again. And these are my contact information and some more resources, the link to my organization, the SMS Research Foundation, the organization that I co-founded, as well as my blog. I just want to thank you again so much for having me on this webinar and thank you to CADRE.

>> Thank you so much, Missy. We do have time for a couple of questions.

>> Okay.

>> First question is: “I’m a middle school special education teacher. What would be helpful in reaching out to caregivers? What would you suggest would be most helpful from that role? I’d like to start a support group of sorts in our area.”

>> I think a support group is wonderful. I think that physical support groups, at least in my experience, are difficult a lot of times for parents to get to because finding childcare can be a challenge. So I do find that online support groups sometimes are a little bit more active, at least, but I wouldn’t want to discourage you from forming a support group. I think having a support group, bringing parents together and caregivers together, is really important and beneficial. But I also, you know, as far as this list goes, I think even just for yourself, don’t minimize your own ability to be able to be a source of support. And really, it comes with a lot of these things that I said earlier in this slide with the empathy and the encouragement, making yourself available, just letting them know that they’re doing a great job and making yourself available to be helpful if you can.

>> Thank you, Missy. Another question. “My question is when, what…” Sorry. “When your daughter started attending school, did you find it harder at any particular age? My son is only three but has a genetic disability called Noonan Syndrome. Can’t see it but it affects his learning and delays but is associated with associated anomalies in his heart and kidneys as well as growth. Doctors say it may be attributed to a chromosome that has not been discovered.”

>> So, I’m sorry, the question…

>> Yeah. Yeah. The question is “When your daughter started attending school, did you find it harder at any particular age?”

>> You know, that’s really hard to say. I think her younger years were harder for me personally, but this is such an individual experience, our kids are all so different, and I can tell you, I’m really connected within the SMS community alone and all of our children have had different struggles at different stages of their life. So I would say school has been really great for Sienna. She tends to thrive in school, so really at no point during her school, her time at school has there been any major issues. It’s more issues that I face at home, really. So I would say I think it varies. I don’t even know that you could go off of my own personal experience because it’s so different from child to child.

>> Okay, next question: “How can we make sure that both mom and dad are getting enough self-care? I feel like as the main breadwinner and main caregiver, medical care, medical case manager, housework person that I resent my husband taking time for hobbies himself. It feels impossible to get as much self-care as I need.”

>> Yeah. Yeah, I totally get it and I think that, you know, you’ve got to prioritize yourself and really demand it. And if there’s ways that you can sneak it in, even throughout your day here and there, before you, you know… It’s, it doesn’t have to require a ton of time. But I also think that absolutely as a full-time caregiver you’ve got to voice your needs and let your husband know that, you know, this is a priority for your health and your ability to care for yourself is really important, because honestly, at the end of the day, if we are not taking care of ourselves, we are not going to be able to take care of our children. And to me, that’s a big wake-up call and that’s scary and that is really what I learned from my issues with my panic attack, is that if I’m not functioning, my home is not functioning. And so there’s nothing selfish about telling your husband or the people who you live with that you need a moment to take care of yourself and to regroup.

>> Time for one more question. “Do you need to have a licensed professional at a support group? Is it mandatory to have a licensed professional available? Does the support group need to be registered via the state?”

>> No, I don’t believe so. I am not a professional and I don’t run professional support groups, but I think support groups… There’s different kinds of support groups. There are support groups that are run by a professional. Personally, when it comes to support groups and talking to other parents of children or adult children with special needs, I prefer to only interact not with a professional but with the other parents. Sometimes professionals get in the way. But I think that, I don’t think, you don’t, you shouldn’t have to register the support group but I wouldn’t want to answer that. I don’t know 100 percent that answer.

>> Thank you so much, Missy. A lot of thank yous on the questions for sharing your story and being so gracious with your time with us. And everybody who listened, thank you for joining us today. Your feedback is very important to us, so please click on the link in the chat box to fill out a very brief SurveyMonkey to evaluate today’s webinar. We would greatly appreciate it here. As a reminder, our next webinar, “Beyond Mediation and Facilitation: Exploring Early Resolution Options,” will be held in March. More information about that webinar will be available on the CADRE web site in coming weeks. We look forward to joining us. I did want to also add that we have some folks asking whether or not this webinar will be archived, and the answer is yes, we will archive this on our web site. Just give us the time to get it up there. And again, thank you, Missy, for your time. We sure appreciate it.

>> Thank you so much. I appreciate it. Take care.

>> Take care, everybody.

>> Thank you, everybody. Bye bye.