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JEN BAVRY:

Welcome to From My Perspective. This is OCALI's Family and Community Outreach Center Podcast. In these podcasts you will hear from people with disabilities, their families, friends, co-workers, and neighbors. You'll hear about everyday life, their passions, their interests, their opinions. You will be inspired. You might laugh or cry. But most importantly, you will better understand what life is like from our perspective.

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I am your host, Jen Bavry, Program Director of the OCALI Family and Community Outreach Center.

During this episode we will focus on the importance of self-care. With me today is Maria, who is a Special Education Transition and Vocational Coordinator with a local school district supporting young adults with a focus on autism. Maria is also a parent of two boys with autism.

Welcome Maria to OCALI's From My Perspective.

MARIA:

Thank you. Thank you for having me.

JEN:

So, Maria, I am sure you know self-care is so important for the physical and mental well-being of any individual. And I'm also sure, you know that it can be a challenge at times to include it in one's regular routine. Sometimes even more so for those with autism in their lives. The experiences and emotions one might feel can make the ability to practice self-care seem somewhat out-of-reach.

Oftentimes the focus, especially for parents and caregivers, is on the needs of the loved one with autism setting aside, you know, his or her own needs while not recognizing the impact it is having on your own self-care.

So as a parent, what are your thoughts about self-care for you and your family?

MARIA:

I think it's those things, like you said, that it's definitely hard to begin to practice, especially in the beginning years when there's a fresh diagnosis or when you're not sure what's going on, though, you know ages of two, three, four. We are kind of in the midst of I don't know what's happening? What do I do? What do I go to? And even for myself -who as I have said "I'm in

the business", even for me that was hard to kind of get to how do I do something that is going to take care of myself, that becomes non-existent. So I think it's just as the years go on you start to realize how difficult life has become. So you start to, you know, seek out different venues.

Everyone's different. I have said people like to do, you know, whether it's walking, it's hiking, it's reading a book. My thing is probably more solitude and quiet because our household can be quite hectic and busy, if you will. Lots of sensory issues, so you're kind of in that heightened state at all times. So I like things that kind of help just bring more quiet to my life.

Probably about five- six years ago, I started acupuncture which really was a very great thing because it was quiet. I was able to feel like I was getting some sort of health benefits with feeling run down all the time. And, I wasn't necessarily doing something extra productive. I was able to just relax and kind of have that quiet time to myself. And I would say that had a real strong impact on just my health and my well-being.

JEN: Yeah. And you're right with the fact that it's - it sometimes is a challenge with all of the stuff that's going on and the busy life with a family, busy life outside of the family. So are you actually able to recognize those moments in your life when self-care is needed and what does that actually look like for you?

MARIA: Yeah, I think you always see that this is a time where you need that quieter, that solitude, or that self-care moment, but because I think mom's in general, but especially moms of children with autism, you're - again that's that caretaker role, so you do tend to put yourself a little bit last so even though you recognize it you might not do things for a long time.

And that's a challenge but I do recognize it pretty quickly. It's just a matter of getting to that place of when can I make time for it? Because I think that's also the challenge between doctors appointments, therapies. You know, I am working a full school day and - and frankly some days I'm just as I say "autism out" and so at the end of the day I'm just wanting to get to the home and just be quiet and have some space to myself.

So a lot of times that's how I will do the day is kind of end it on a quiet note. I think that's the best way for just all our family is to kind of come and be, you know, together and just to be quiet in a way. Whether that, you know in the summer it's a little, you know, easier because there's less hectic to the end of the day and preparing for the next day. That's also a challenge. But I think it's there and you just try to plan for it. You know, we're very planful

because we have a routine, a strong routine. And I think most parents could probably identify with that kind of routine in some way. It's nice because you always know what to expect but then when any little thing kind of becomes different or there's a different change in the school routine, the breaks and so on, you just kind of have to, I think, sometimes make a little bit more effort.

JEN: Right. And I know that that in itself is the challenge but I like how you talk about the fact that it's that quiet time - just having a quiet time at the end of the day. And in some ways, it seems like a simple thing to add in but I'm sure at times it can be - it doesn't - it's not always guaranteed. So if you don't have that opportunity for that quiet time, what are some things you think about for - I

mean, are you okay with the fact that it didn't happen and kind of try to build something in for the next day?

MARIA: Yeah, I think, and getting to the weekend is definitely, I think, when it doesn't happen that that day or that evening it's about making it to the next, what's the next hurdle, and usually it's you know getting to that weekend.

One thing that is hard and I think again a lot of parents might identify is - sometimes self-care is about being with friends or meeting girlfriends. And I have a lot of that, you know, let's go out to dinner and again, frankly, I'm so exhausted at the end of the day or at the end of the week that that's a hard - even though that is self-care, it's still an extra activity. And for me, I sort of regroup in that sort of introverted way of just being to, you know, trying to get to be just in - like you said that solitude in that quiet time. So that will often wont happen on the weekend.

I really preserve our weekends to kind of just come back from the busy week and then to prepare for the next week. If I don't have that it's very difficult. If our family doesn't have that it's very difficult. Because again, they are so used to being on the go.

And as I have explained to families in my advocacy work in the school district it's about understanding what it takes for our kids to get through the day. And so getting to the weekend, it's really important to, you know, kind of figure in those quiet times even just for them and just to kind of regroup and you know have down time. I think that that's to me just simple downtime is very, very important.

JEN: So what does a typical weekend - a typical weekend, I guess, look like as far as downtime for you, down time for your boys.

MARIA: Sometimes it's, you know, we live here in Clintonville. And so it's nice well take walks down to the ravine when it's nice out. You know, watch movies. That's a really fun thing to do. It's so close and we walk and we order pizza. Maybe a little game night between all of us and then just kind of hang, you know, watching movies, hanging out.

I think again, it's just that that quiet - that time together is just really valuable. And it's a hard thing for those who are outside of I think understanding the realm of autism because a lot of families are on the go and their families can bounce back from that. Where our, I feel like, our family, our kids, myself can't do that as easily.

If we have a busy weekend, then we go into a week that's very busy for them. And so that makes it harder, I think, to then come back from that. It just makes it a little more challenging- the sleep gets disrupted. So you have to build in that time for downtime for our kids and our family because there's so many other challenges physically and then medically that if you don't get that, then it sets off a spiral.

I wish I could have everybody understand that life of the medical challenges and the sleep challenges because you know, it makes you seem like, oh they're just, they just wanted to do their own thing and they don't go out and do very much. It's not that I don't want to. It's just that I can't, you know, I have to preserve sort of our sanity if you will.

JEN: Right! Well, but it sounds like what you guys have also created is almost like a thing to look forward to with the weekend. You have this busy week ahead of you. But everyone in the family looks forward to that weekend downtime and if you do get out to a movie, that's just a plus. If you take a walk. So I think it sounds like you kind of have created this ritual or routine that your family looks forward to.

MARIA: It's funny because we're sort of a night owl family by nature, which is you know, so we then tend to love to sleep and doesn't bode well for our middle and high school kids and myself as a high-school person. So that's also a sense of the recovery that we need. And so I think just kind of that being able to sleep in, that hanging out on that Friday night and ordering pizza - "pizza Friday night". The biggest thing is to figure out which one gets the pizza because there's as you may know there each one likes a particular pizza place. So we have to figure out who ordered it last week, what do we get this week? So if we can all agree on that it's,

yeah, but it's not beyond ordering two different pizzas from two different restaurants. I think many families may recognize that as a common thing.

JEN: Oh, yeah, different meals for everybody so that you can enjoy the moment together.

So you've mentioned different things that you - you're currently doing - acupuncture, the quiet time, the family rituals. Is there any other self-care habits - or things - or things that you've tried that worked in the past or maybe didn't work?

MARIA: I think that I also have another added little challenge of being a breast cancer survivor. I'm not sure. I mean, I think that adds a whole different challenge in medical care. So before I used to really try and get to yoga whether that was outside of the house or a lot of times it was too difficult and I wanted to do that, you know, in the house. But since the multiple surgeries, it's been a real challenge for me. So again, that could be just that solitude and that quiet time - just coming from that sense of how challenging it was to kind of recover and also take care of the kids during all that.

JEN: So you talked about how self-care works for your boys. Have you had an opportunity to work with your - the students that you support or the families that are involved with the program that you're in on self-care. Have you been able to...

MARIA: We talked about that? But I think it is a common theme that with the many barriers our families face with their children with autism sometimes that self-care gets, I think it's the one thing that gets lost in the journey. And so it really, as I kind of stress, is about - because there can be a lot of

heightened anxiety with our students, with the students and our children, it is about just kind of helping to remain calm and how do we sort of that self-regulating thing that we become good at - of what is it that they need? Do they need time to pace, do they need time - how do we get them to kind of self soothe a little bit?

So it really becomes, one about educating that it's okay because a lot of times you don't realize, I mean, I don't think I realized until I may have even met you at some of the autism support groups that you realize not getting sleep is a common aspect to our, you know, children. So how do we, you know, just understanding and recognizing that it's difficult, is sort of the first step in saying okay, now, what can I do to look at that journey of self-care.

JEN: So that- you make a really good point about the autism support groups. I think that - that's helpful to know that there is another parent, another family, another individual that is facing some of the same things.

MARIA: Again, I just stress that I think that when we don't do well -very- do very well at taking care of ourselves that we do risk that sort of, you know, the dysfunction in the family. It becomes a more difficult thing for our kids to function at school and for the parents themselves to kind of deal with certain aspects.

I worked with an older young woman with autism and during her anxiety, I said sometimes the only thing we have is to breathe and just kind of taking in the moment when you're stressed. And so I kind of have to sometimes remind what I give my students and families is something that I'm also telling myself at the same time, which is important because, again, I go back to how much we - how often we lose touch with what it is that we need ourselves.

So when you're reminding someone else in that it's also becoming about - here it is - you're telling yourself that too. But I think again, it's just very small and simple things you can start to do even if it is 15-20 minutes of quiet time or reading, you know a chapter in a book, create some sort of ritual in that way. I think that, that will just help ease some of the difficulty and hecticness to the day. I think it's just really important to think about what works for you and then kind of stick to that ritual so you can kind of make sure you take care of yourself.

I'm not the best at that. Here I am telling people to do that. It's been a while since I've done acupuncture and I say to myself I need to get back. And when you can't do it don't feel so guilty. I think that's also the piece of it. It's don't feel guilty. And that's a hard thing.

JEN: I think you've made a couple of really good points. One, don't feel guilty, I mean, but also start simple. Start with something that could only take 5-10 minutes, even if it is just the breathing, taking a walk outside, getting some fresh air, and then just kind of realizing that you can build that in. Yeah, if it's once a week, maybe then it becomes twice a week, but it's finding what works for you.

MARIA: Absolutely - and you - and yeah, it doesn't have to be a lot. It doesn't have to be very long, and again, people may want to see you doing something different. You know, its like I go back to, it's hard. I want to spend time, more time with family or friends and sometimes I just can't and that has to be okay, as well. So, you know that guilt piece is something that we have to, I think again, as moms and especially as moms with children with autism we have to kind of just

put to the side because we're taking care of something larger than ourselves and that often folks don't understand. And so it's not about trying to explain to them what it is that our family needs.

JEN: Maria, I really appreciate your time today and everything that you have shared. I think it'll really help others to hear this.

MARIA: No problem. Thank you for having me. Thank you.

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JEN: Thank you for listening to this episode of From My Perspective. If you would like to learn more about OCALI and its resources, please visit ocali.org.