OCO S02E08 - Caregiver mental health & cultural differences in caregiving with Nicole Waldron

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[00:00:00] Michelle Jobin: Hi everyone. I'm Michelle Jobin and you are listening to Time To Talk, a podcast for caregivers. This podcast is dedicated to helping family caregivers in Ontario. Through expert tips and resources, you will gain knowledge and validation for the ups and downs that come with caregiving. More importantly, you'll learn that you're not alone.

It's so important to take this time for yourself. We're glad you're here.

Today, we're joined by Nicole Waldron. Nicole is an inspiration and mental fitness coach and a caregiver for her son. She is an advocate for caregivers within the BIPOC community and is the host of the podcast Victory Speaks, a podcast to assist people with their mental fitness.

Nicole, thank you so much for being here with us today.

[00:00:54] Nicole Waldron: Oh, well it is a joy and a pleasure, Michelle. Thank you for having me.

[00:00:57] Michelle Jobin: And it's going to be a joy and a pleasure to speak to you as well. So wanted to dive right in. You have been a caregiver for six years. Can you tell us a little bit, or maybe even a little bit more about your caregiving experience?

[00:01:10] Nicole Waldron: Well, my son had a bike accident at the end of 2015 and in the beginning of 2016, he ended up in a mental health crisis. I was working at the Senate at that time. I was in Ottawa. He was living in Toronto and we started seeing some interesting behavior manifesting on social media and we started to recognize something was wrong.

The beautiful thing is I live in a co-op and the thing about co-ops is it's very family centered and you know, your neighbors know you and my family is here. And they knew that something was wrong. And so while I was in Ottawa, he had to be admitted to hospital. And that started our journey in, in the mental health realm and me becoming an AKA caregiver.

He probably won't like that term, but it's typically what you, you end up becoming in the system. And so over the last six years, he has had to deal with his mental health and it's been impacted by this traumatic brain injury. And so, it's been a, a different ride navigating the mental health system.

And because of that journey, you know, I don't believe that we go through something just for ourselves. We have to, you know, take what we've learned and help others. And so it has propelled me into helping other caregivers. And if I can give you know, advice or share my story, And I say my story because his story is harder to share because you know, it's hard in the mental health space, but realizing that a lot of caregivers are going through a lot of the same journey.

And so, yeah, this is how I'm here and the whole caregiving space. And I mean, I've had to deal with my dad it previously before coming over cancer, but this is really where this is the meat of it all.

[00:02:46] Michelle Jobin: So you're speaking about your experience as a caregiver and as a mother. Sort of those are intertwined and you're dealing with a mental health issue with your son.

But when we look at caregivers, there's so often an impact on their own mental health. So how did caregiving have an impact on your mental fitness or mental health and what are some of the techniques or resources that you turn to.

[00:03:14] Nicole Waldron: Well it was a rollercoaster ride because unfortunately when anyone's loved one gets diagnosed with a mental health illness, you there's really very little support and trying to navigate the system and then to find the support.

And so it takes a toll because, you know, depending on your loved one's diagnosis, it's a personality change. And when they go through things like psychosis, you're looking like this is not, this is not my, my loved one. And so it's navigating the system and it takes a toll. People don't know what to tell you.

It's, it's unlike, you know, unlike cancer, somebody's got a heart attack, you know, people are showing up, you know, it's a really bad with in our realm that people say, did anybody bring you a casserole? And so, you know, if you, if somebody else was, you know what, they will call a tangible sickness, they will show up at a casserole,They will show up at food. Do you need this? Do you need that? With mental health, people tend to disappear. They don't know what to say. And they don't realize that it's a brain disease that affects our mind. And so it's navigating through the stigma with others, but even, you know, with a young person it's navigating through his stigma.

So I had to manage my emotions, managing his emotions, managing families' emotions. And so, you know, it took a toll on my physical health. I know my, my pressure went up. I wasn't eating properly. I'm still not eating properly. Some days I try to do better. And. And it just really just really trying to understand this whole system because they say the system is broken, but I don't think the system is broken.

We think the system is doing exactly what it was designed to do. And the mental health system is a very complicated system, deals with things like capacity and consent and privacy issues. And so imagine you as a mom, or you as a father, a brother, a sister, and your loved one goes into phsycosis is where they may be experiencing paranoia or, you know, changes in behavior.

Or could have a drug addiction, whatever. And then the system is telling you when you take them emerg that they need to give you permission to speak, but they're not acting themselves. So it takes this kind of toll on you when, like, what are you saying? I'm bringing my loved one to emergency because they need to care.

And you're telling me I can't speak to you or you can't speak to me. I can only speak to you up until emergency entrance. And after that I need their permission. So it's, it's a very big roller coaster ride, anxiety sets in. You don't even realize the sleep deprivation that sets in. And I tell you, you have to find a village, find some peer support, find a group you know, hopefully you can encounter somebody really good at the hospital or the clinic that can help you navigate the system.

And I also had, for me, what also helped me was my faith. And I had some really great people praying with me and for me and for my son. And that has really grounded me. And that's part of hope. It is says hope deferred makes the heart sick and it literally makes your heart sick because it affects your whole body.

And so just trying to say, okay, nope, I got to believe this is going to be better and it's going to be in waves, but it's a different journey.

[00:06:12] Michelle Jobin: Well, it's, it's very likely a journey that many of our listeners are on as caregivers, caregiving with loved ones with mental health issues along with other issues. So it's, it's really important that you're here today, sharing your story.

And we thank you for that. I wanted to turn to sort of a more current situation and an ongoing situation, which is, you know the pandemic. And at this point in the pandemic, 58% of Ontario's 3.3 million caregivers say they feel burnt out. It's a whole extra layer, right. And 42% of caregivers say their mental health is worse now compared to a year ago.

So what are some ways, in your opinion that caregivers can alleviate their feelings of burnout and support their mental health. And I mean, I don't know if this is specific to the pandemic, but it has certainly just sort of amplified any sort of feelings of stress that caregivers have. So do you have anything to say that might be advice for that?

[00:07:10] Nicole Waldron: Caregivers have to, it's a hard piece, that you have to take time for self care. And I know that word is thrown out on a lot. You know, you got to do self care, you got to do self care, but you literally have to do self care. You have to recognize your limitations and you have to take care of your body.

If you know that, you know, as a caregiver, you may not be eating well. I would say to any caregiver, you know, speak to your doctor or get a nutritionist. Get your vitamins in there, because when you're not eating you going to need that. Find things like smoothies and tell your friends or relatives “I need help” because sometimes they don't know what to do.

I literally one day made up a list, Michelle, of how to help a caregiver, just texting them and checking in on them. And, and someone's just still in saying, you know, what do you need? You have them some for, even for family and friends, give them some flowers, give yourself some flowers for crying out loud. Right. Treat yourself to that, that extra treat. And you've got to come out of the guilt because no matter what your loved one is going through, it's not your fault. And you have to take time, get some fresh air when you can. And if you have the ability, get a therapist or find a place that you can call into just to release because sometimes you need more than just family to release too.

And especially if you're taking care of family. Right. And so taking care of yourself and finding those ways, being honest with yourself, and it may even mean journalling. And having a really good cry. Your shower is your friend. So the tears, you know, the mountain of tears you tear in the shower, and it's okay to be angry. And anger is a healthy emotion. It's how you handle your anger. And so there's a lot of emotional ways that one can go through, but, and be gentle with youself.

[00:08:52] Michelle Jobin: That's all very good advice. You have found in your way through your journey, a place in being an advocate for caregivers within the BIPOC community. Can you give some insight into how the caregiving experience is culturally different for those in marginalized communities?

[00:09:13] Nicole Waldron: It's such a big conversation because culturally, depending on where you're from, certain illnesses are not spoken enough. So like in the Caribbean, we wouldn't say cancer. We would say the C Word.

Things are hidden, you know, certain families don't like to talk about illnesses. Getting your family history, which is important, is not always easily shared and certain things carry a stigma and are taboo. And then there's the distrust that can happen, in in the, in the medical system where, you know, if you look in it right now, COVID is a great example where, you know, you will find people of color may not want to take the vaccine.

One of the reasons being is that how vaccines were tried and use as trialed on black people, right? So you have that taboo and you know, the data wasn't collected and we've been used as Guinea pigs. So people are very adverse to really sharing and in, in this space of their health and their healthcare.

So that's some of the challenges in the BIPOC community. We've been really I don't like to call the BIPOC community marginalized, but we have been marginalized. We have been treated less than, and not treated as human beings. we're having a human experience, just like everybody else and each community, the Indigenous community has, has a similar, yet different experience of the brown community to the black community.

We're all intertwined in different parts and our history is important. And when you understand the history of our people, you will understand why their behaviors are changed, the way that they do and change the way they respond to the medical system. And Lord, like in Trinidad, my mom, my mom's doctor could still come to her house.

She still us house called, who does a house call up here. Right, right. And here you're limited to going to your doctor where you spend 10 minutes. So when you come from a culture or cultures that are very family oriented and you, you go into this very clinical setting, you feel like you're not cared for.

So people resist going into those setting and they have a lot of fears. So fear is that false evidence that appears real comes in and you, and you have to ask yourself from then till now, what is the evidence that appears real to me that is no longer there. And you have to get over those fears and we have to address those fears as real for our individuals in the BIPOC community.

[00:11:30] Michelle Jobin: What do you think the biggest challenge is for caregivers within these communities? And do you have any particular tips? I mean, you you've already given us some, but someone within the BIPOC community that finds themselves in role. And obviously it's usually not a role that anyone plans to be in. As a caregiver, it's not something you necessarily plan to wind up doing in your life, but many of us are here.

So for those that are in the BIPOC community, do you have any ideas of, in terms of what the biggest challenges are and what tips you might have?

[00:12:02] Nicole Waldron: I would say that you need to get educated. You need to learn the system. Whatever illness that your loved one has find a group, find people that can help you navigate the system to recognize you and advocate and speak up.

And don't be afraid. And if you don't like what one doctor says, move on. You know, if it's your family doctor, if it's a specialist, if you're not sure, get a second opinion, don't move in fear. Move in power, be empowered. Don't be a bully and treat your caregivers with care as well. You know, the clinicians, the nurses, the specialists, because they are people too. Right. And they may be going through their own experiences. And sometimes we don't know. You know, we, we walk into the room and there are two things that happens. We think the doctor knows it all because when you come from communities like us, we we've been trained that we respect our doctors, lawyers, judges, it's this particular respect, you know, you know it all, but you have to understand that there's so many things that have changed in the medical field and things are changing daily.

And so you need to do your research. You need to talk to other people, but also treat them with respect and honor, and hopefully you will get the same. And if they're not. I fired my, my father's first cancer doctor, because he looked away from him and he says, you know, if you don't have this operation, you're going to die.

And I'm like, and he, wasn't not even speaking to us. And I'm like, what are you talking about? And I said to his family doc, I said, you need to find us somewhere else. And we moved from there to the Princess Margaret Hospital. Can I tell you it was night and day. So you have to talk, you have to speak up and you've got to find people that, that will tell you the truth and get over.

Sorry, sorry to, I don't mean to be rude, but get over yourself. Don't be slow to offense and really reckon it's not about you. And yet it's about you. You have to take the time to really do the work and really search it out and just be compassionate to everybody around, including yourself.

[00:13:58] Michelle Jobin: That's great advice. I even remember with myself when my father had cancer, there was you know, just feeling a barrier of fear to ask the questions, to receive the answers, to be in that space.

And you just have to find a way to educate yourself, remove those feelings, because your role there really is to advocate for the person that you're caregiving for. And you are also yourself, an advocate for encouraging conversations within the caregiving community, which is one of the reasons, many reasons we're here talking to you today.

When you first started your caregiving journey, how did you start dialogue within the caregiving community itself?

[00:14:40] Nicole Waldron: Well, it was interesting. I was fortunate enough that I'm well-connected in my community. So I started having conversations with different people. So they linked me to different individuals in CAMH.

They had linked me to the SASI program, which is a program there for black and Caribbean youth started having those conversations. And I was also, really blessed with having a good social worker attached to our case. And when I would talk to her and tell her the challenges that I was having, and I would give suggestions, she, one day said to me I think it'd really be good for this family advisory committee at CAMH.

And that started the ball rolling. And I started getting more involved in the community of CAMH so now I sit on a family advisory committee for CAMH and subcommittees, but CAMH. And so what we do is that as family caregivers, we give input into the whole hospital the whole team of us, and we sit on various committees, and we have our input.

And this has opened up a whole new world. And just, just having those conversations and along the way, just meeting people and having the conversations, because we realized when you speak to individuals on the same journey, whether it's cancer, heart attack, whatever mental health, you speak the same language.

So you don't even have to finish certain sentences because you can say girl, and he can say, you know, when they said, and, and you're like, and you just know what they're talking about. If I said the casserole joke to anybody in the mental health community, I knew exactly what I was talking about. So. Yeah.

[00:16:06] Michelle Jobin: And definitely helps people feel less alone in the experience. I've had other guests say, you know, your, your community, when you're going through this experience of being a caregiver shifts and change.

And, and you may still have your family and friends, they may be more or less available to you, but they don't necessarily speak the same language as you anymore, in terms of what your experiences.

[00:16:28] Nicole Waldron: I don't want to feel like a burden because that's the other piece, right? Cause sometimes you can feel like you're being a burden to others even though they may not see, you know, they ask you how your day is going, but you really don't want to tell them the truth because it's just been a crappy day every day. And you don't want to be a, as we say, a Debbie downer, sorry for the Debbie's out there, but we don't want to be a Debbie downer. And, and then I also have a group of people, I really feel if, when I say to any young caregiver, speak up. Find a community of young caregivers because young caregivers are overlooked. We kind of think of, you know, the, the, the mature ones. I'm not going to say old, us mature folks, you know, but the young caregivers or caregivers who are in the twenties taking and going through a lot, and we need to create space for them.

[00:17:11] Michelle Jobin: Well, you are a part of the Ontario Caregiving Organization Advisory Group. Can you tell us a little bit more about that advisory group and it's purpose?

[00:17:21] Nicole Waldron: Yeah so fun fact. I'm there. I'm now going onto the board as of next month.

Michelle Jobin: Yeah, that's wonderful to hear.

So the, you know, we just had our meeting today and it was, it was so good. Cause we, we talk about the experiences and we give a lot of information and feedback into the research of what caregivers are going through in every facet, you know, and we have young caregivers, we have middle-aged caregivers, we have senior caregivers. Every type of illness we're talking about and the experiences that we all go through.

And what OCO has been able to do is really take the information that we sit as caregivers and be able to, to take that information back after our conversations and help educate, form conversations with policy makers and inform government. And, but also one of the things that happens in that group, we become like this little family of peer supporters, even though each person has a different caregiving experience, I will say it's very humbling.

It's very nurturing and it's very empowering. So when you listen to what Michelle has gone through and what Maria has gone through and what John has gone through, whoever it is, and you go, okay okay, you know, and so it's a multifaceted in what it does and it's an ex it's an exciting committee. And I would say if anybody's a family caregiver and they want to get involved, I would say, please, please, please reach out to OCO because I know we need more

voices on that team from all communities, especially the BIPOC community, because we need to know what each person is going through because everybody's experience is different. And it's just fascinating, the learning that goes on. And I just hope that we are able to, you know, one day make that difference in how caregivers are looked at.

And I think that's one of the great things that OCO is able to do is shine a light and make caregivers no longer invisible, to, to policymakers, to employers, to families, to everybody at large, you know? So that's, that's part of the beauty of being part of that advisory committee.

[00:19:22] Michelle Jobin: Well, we're glad that you are there. And we touched on this a little bit. Why do you think peer support is so essential for caregivers?

[00:19:31] Nicole Waldron: Because you need to know that you cared for, you need to feel that camaraderie. It helps you not to be alone. You feel that strengthening, it gives you strength. And at times it's also a place of empowerment where it's not just you are taking, but you're also giving. And you realize that there's other people you're not alone.

There are other people on that journey with you. At the end of it, you can say, you know what? I can go another minute. I can go another hour. No, I can do this another day. I can, I can go another month doing this. And then just somebody, maybe you can call on when you just don't know what to do, who can give you new ideas or you just learn from each other.

It's just how. And, you know, what, if you don't have a therapist or a counsellor it's at other indirect counselling that happens with each other and just sometimes just sitting there. I remember one person, just one day said, Nicole, let's just go have a coffee. And we just went and had a coffee and then we ended up having lunch and it was just a minute to have a breath of fresh air with somebody who just understood. And I didn't have to over-explain myself.

[00:20:29] Michelle Jobin: That's a good feeling.

Nicole Waldron: It is.

Michelle Jobin: Just to sum up, what is one piece of advice you would give to a caregiver that is struggling with their own mental health?

[00:20:40] Nicole Waldron: If you're struggling with your own mental health, it's okay. Your brain is your mind and your mind is your brain.

And when you are under stress, your brain, chemicals in your brain are changing and reacting in your body. And it's not an indictment on you. You haven't done anything wrong. You have to stop, you have to pay attention and you have to take care of yourself. Whether it is You have to check your vitamins, whatever you need to do, you need to be honest with your family doctor, find a way to get the counselling, whether it's free or paid, but if you don't, if you do not take care of your mind and your brain, it will take care of you and you don't want that to happen. It will show up in your body as high blood pressure. It can show up as an ulcer. It can show up as a heart condition. It could show up as obesity. It can show up as a deep sadness. It can show up in so many ways because sometimes people just think it's just like, you know, I'm going to be depressed, but depression shows up it depresses your body. Your immune system. So we have to be very mindful and I would say, be very mindful, pay attention to your body, pay attention to your sleep, pay attention to your habits.

What has changed, I think is happening out of order. What is different about you and then find that person or whether it's your faith or both that you can be honest with and transparent with and know that it's okay to not be okay.

[00:22:03] Michelle Jobin: Thank you so much for that, Nicole, you know, I think our listeners will very much like to look into your podcast, Victory Speaks, and of course your YouTube channel because you, you really have a lot of great advice. You're very motivational. You're very positive. And we appreciate you so much being here with us today, sharing your own personal story as a caregiver and being an advocate for your community as well.

Thank you so much for speaking with us.

[00:22:31] Nicole Waldron: Well, you know, I say, thank you. And I should have said this to you. Victory is not about crossing the finish line first. It's about crossing the finish line as your best self. And what that means is victory is not a sprint. It's a marathon. I'm going to give the baton you, Michelle, you're going to give it to Greg. He's going to give it to friend. And the last person who comes across is going to cross the finish line. But at the end of the day, we all win the race. You know, so understand victory comes in moments. Write those moments down every day, create a victory box, a victory bowl, a victory jar, victory book, and go back and look at it once in a run and realize that you've had victory moments in your day. And it is well.

[00:23:09] Michelle Jobin: I'm going to do that. Thank you so much, Nicole.

[00:23:11] Nicole Waldron: You're welcome.

[00:23:13] Michelle Jobin: Thank you for listening. We hope you enjoyed this episode. You can access more details about support services on our website, ontariocaregiver.ca. Until next time I'm Michelle Jobin and you have been listening to Time To Talk, a podcast for caregivers. We hope you have a wonderful day.