CW Towers: October 29, 2023 – Story 1

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00:02
INTERVIEWER: My name is Mike. My name is Michael Ruderman.

AKI: And then the other folks are?

INTERVIEWER: David and Araslan. So, yeah, that's right. Arsalan is one of our volunteers today. So, yeah, I'm Mike Ruderman. It's October 29. This is our first contribution of the day: October 29-01. So, I was wondering if you could tell us about yourself and what kind of story you'd like to share today.

AKI: Okay, so, my name is A.L., and my mother has been here since February 2020. Just a month before pandemic started. She was diagnosed as a dementia patient in 2017. And after that, she started moving to retirement home and she was admitted here one month before pandemic started. So, it was very difficult transitioning because after thirty days, lockdown started, and I could see her online quite soon. And after that, we were able to see a bit over the windows. There was a window between, and she was inside and I was outside and we were talking.

01:20
INTERVIEWER: And was that outside the building or her room?

AKI: Yeah, I was outside of the building. She stayed inside at the auditorium there and I was outside. So, I mean, it was okay to see her. But with dementia, you don't have the ability to manage your life properly. And so, she had to learn a lot of things, like where she has to put laundry and things like that. She couldn't learn that—it was a disaster. And I didn't know what was going on in the room. So, my caregiver role is more organizing her room, making sure everything is neat and nice. And back then, you know, it was a life-threatening situation. PSWs are so busy doing other things, right? Like, they probably had to wear masks, gowns to go to each room and they just don't have time to make room neat and tidy. And I couldn't get to her room until October. So about six months. Nothing.

INTERVIEWER: Six whole months it was like that?

02:23

AKI: I was able to see her outside in the summer months or, like, over the window when it was cold. Or even inside after September. I think it was like physical distancing. But that's not really caregiving—meeting is not. It's not, you know, enough caregiving, right? So, it was very difficult. So, when I first entered the room, I was like, I don't know how to describe my feeling. It was, I can only say, disaster. Like, when were these clothes washed? Like, my mother changes her clothes, but she doesn't know which ones are clean or whatever.

INTERVIEWER: So, did you feel like, during that time, maybe she wasn't receiving the kind of support to do that in the rooms or?

AKI: I can't blame them. It's so hard. Like, if there's an outbreak, what you have to do is wear a gown. I mean, probably now it's a little different. But then it was gown, mask, face shield, and then gloves. And then PSWs and nurses have to do that for each different rooms, right? Like, it's a lot like serving—then, why can you ask for more normal care, per se? This place didn't have anybody die from COVID? Really.

03:48
INTERVIEWER: Yeah, that's what I heard.

AKI: Yeah. So, they did the right thing. But they just didn't have enough resources to do normal care. Now, it's not bad. But again, like, I just have to say thank you, thank you for saving everybody's life, right? But it was very difficult. You know, so transitioning completely failed—she couldn't learn how to put out laundry. Like, it was really a disaster. But, again, you really have to appreciate that nobody died. That's a really huge thing, and this is a big accomplishment for them.

But, you know, I did work with the staff management team and tried to do good things for my mother and other people. And things are getting better, of course. And, you know, for some people just to sit down and have tea or coffee and chat is caregiving. But for some people, that's not necessarily the way that caregiving is. Like, today I had to go to her room, and I was not able to see her for a month because I was traveling and then after that I got COVID. So, this is my first visit. And I had to kind of make her room a little bit neat and tidy. So, this is not the perfect way I want. I had to spend a little bit more room. But, again, it's my preference. Now I'm not blaming PSWs, or anybody, but my caregiving is just to make her room more comfortable and nicer. It's quality of life, right? As opposed to just surviving.

05:42
INTERVIEWER: There are a few things I wanted to ask you about based on what you were saying. One is, you mentioned you were helping out during COVID in whatever way you could. Could you tell me a bit about what that looked like?

AKI: Yeah, one good example is, unfortunately, the social worker left and went somewhere else for a better job. But then he was really helpful. Like, he was always giving me suggestions on what I could do better, to make my mother's life better. And then one suggestion was a meeting. He said, you know, why don't you bring a portable DVD with Japanese CDs? Or whatever. I don't watch Japanese movies, so I didn't have anything. And that was a time, remember, when you couldn't buy non-essential items in the store.

06:33
INTERVIEWER: Oh, my goodness. Yeah.

06:38
AKI: It was difficult. So, I ordered portable DVD online, of course. And then I talked to Japanese organizations. And, you know, there was a social worker. So, I said, here's the situation: can you have somebody sell me DVDs? 'Cause I could have gone to, like, Pacific Mall or something and then gotten the knockoff DVDs, but I couldn't do that because of that restriction. So, everybody was actually willing to donate DVDs. Yeah, that was nice. There were four or five people willing to give me DVDs. And the one person was actually living in Newmarket. And I live in Mississauga. She actually drove me to Mississauga. I said, I can meet you in the middle. "No, no, no, I'll go down to see you." That's amazing. So, yeah, that was kind. It makes me cry when you think about it. People are connected through COVID.

07:44
INTERVIEWER: Yeah, it brought so many people together.

AKI: That was a really good example I wanted to share with everybody. They also arranged a video call every week. And it was really great. And a person was organizing this call. Before we started a call, she always, you know, buzzed me. And then she actually gave me an update on how my mother is living, what she does. That's amazing. You know, we are really connected virtually. I didn't feel like I was isolated.

INTERVIEWER: That's good. I'm glad because I know the virtual connections didn't work for everybody. But I'm glad to hear that it helped.

AKI: I heard from a social worker from the Alzheimer's Society. Fortunately, for people with dementia, they can't figure out whether it's virtual or real. And I also heard from other caregivers, when they—I mean, after two years or so from the first lockdown—they had a family gathering online, but then her mother was trying to give her candies or whatever — "here, you should have some." So, they can't figure out whether it's real or not. Which works. I mean, it doesn't matter, right, as long as they're happy? You know, we may feel like virtual's horrible, but at the end of the day, it's about them. As long as they're happy, that's okay. I think it worked. At least for me and then for some others, which is a great thing. Staff here are unbelievable. They came up with a lot of creative ideas. And then we tried to, you know, understand my mother's situation.

Everybody's different, but they try to do as much as they can. And they gave me a lot of suggestions on what I could do. No, it was amazing.

09:50
INTERVIEWER: That’s wonderful. Yeah, I've heard that a lot from people, about the staff here being so amazing and helpful.

AKI: Definitely, yeah.

INTERVIEWER: I wanted to ask about your mother's experience during COVID. Did you have a sense of how she was experiencing the isolation and the lockdown?

10:11
AKI: No, actually. Because she has dementia, she doesn't understand what lockdown means—why people have to wear masks and things like that. But, fortunately, my mother's situation, as far as I know—her level of decline is not significant. I mean, she's slowly declining, of course, in the last three and a half years, but I don't think COVID significantly affected her. I mean, you know, she moved here a month before lockdown. And, you know, it was her new life. Of course, it was different from moving from a retirement home versus here. But then, I guess I lucked out. I didn't think she was noticing, “oh, my God, this is not nice.” Actually, it was funny. At the very beginning, the assigned meeting day was Monday for me. And I was working from home, and I live in Mississauga, so the only time I could get here was Monday night after dinner. She got mad at me. I had pyjamas on, and I had to change. Like, “Why are you showing up this late?” And I'm like, okay, so that kind of tells me she's happy. She's complaining. Like, “Why are you visiting me after dinner? You're disturbing my life.” So, I was kind of convinced she was having a good life, but that's thanks to staff here, right?

INTERVIEWER: For sure.

AKI: Yeah, it was amazing. It made me feel better.

11:56
INTERVIEWER: I wanted to know a little bit more—we haven't talked to too many caregivers. And it sounds like that's an important part of what you do. And I would love to hear a little bit more about how the pandemic and being isolated from your mother affected, you know, your role as caregiver and what that meant to you.

12:18
AKI: It’s certainly a challenge because for me, like, it was a big change. The first thirty days, I was working hard to transition suddenly—no physical contact whatsoever. It's shocking, but at the same time, this place did a lot. And also, I think, the Alzheimer’s Society of Toronto started calling caregivers: “We're going to organize a support group (virtual). Why don't you join?” That kind of

thing. So once a month, I had this virtual group to share. And then, you know, they had social workers available to speak to caregivers, by appointment, and that was great.

And the support group was, to me, about exchanging what's going on in different long-term care homes—as well as, you know, there's some people carrying their family at home or away, but then they had to commute to see their loved ones to do something. I mean, like, it was really good. And, you know, did I feel I was isolated? It could have been better if COVID didn't happen, of course—the pandemic wouldn't have happened, of course—but I think a lot of organizations and things like that try to connect caregivers together. So, I mean, you do have to go out and reach out, but then there are resources available, so that was great. So, as a caregiver, I think it's kind of funny. Without pandemic, I wouldn't have been committed as much as I do now.

14:08
INTERVIEWER: Was it because of all these support groups?

AKI: Yeah. And also, you know, at a university level, there's a lot of research started, right? So, I started joining all the questions, questionnaires, and even focus groups and things like that. I've been attending stuff like that just to, you know, share my experience. This is something I always want to do, so I'm more than happy to share any experience whatsoever. Yeah, so I'm probably over the top but, you know, I'm trying to do something in the caregiver community.

INTERVIEWER: So cool. Could you tell me a little bit about—you were telling me before we turned on the mic about what kind of commitments you have now that you say were influenced by your time here during COVID.

15:00
AKI: I do actually work with some researchers. And right now one is sort of developing, you know, what some call "namaste care." I think it's dementia care—that's a nicer way of saying it. And then she's trying to develop, like, a real program. So, I'm actually doing trials and she gives me instructions. So, what it is, is like, we try to use scent product. I didn't bring it today, but, like, hand creams and face lotions and little exercise balls, lip creams, and things like that. My mother is quite independent—she wouldn't let me touch her body. So, I just give them to her and then say, "Why don't you try?" "Oh, nice smell, blah, blah." And then some other people are actually coming and then, "Oh, can I try?" And then they try. It's like exercise, right? A little bit. And then, you know, they put the lotion on and, you know, they're like, "Wow, this is nice, smells great." They're smiling, and it is working.

INTERVIEWER: Yeah, that's huge.

AKI: And the exercise ball is my mother's. After that for a while, she says, "I'm getting sweaty, I don't want to do this anymore." But, again, it's stimulating. So, I have to actually, you know, make a record of what I did and then submit it, and I don't know what happens afterwards. But she's going to probably formalize the program and then deliver it to all the caregivers probably. And, also, I think she's trying to develop more caregiver community. So, I'm part of a sort of work group and I give research and, you know, assist her research. Give my feedback.

16:50
INTERVIEWER: I'm really sort of impressed by everything that you're doing. And by your passion for this. Is there somewhere that you think this passion has come from? Is it from caregiving with your mother, or is it something that's been with you for a long time? Maybe you could tell us a little bit about that.

17:06
AKI: Well, I studied business, I was in business, and I work for the government. But social work or, like, social welfare—I never thought about it. I'm still learning, but I can't quit being a caregiver, even if I want to. So, I might as well learn, be good at it, and then try to help others. And I'm also trained to be a peer mentor. So, there's an organization called Ontario Caregiver Organization. So, last year, I was able to get training through a Japanese non-profit organization in British Columbia. They offered a program called Peer Counselling. And so, I went through the training for one and a half months, twice a week. And so, I got certification. And after that, I applied for this volunteer position as a peer mentor. So, at the Ontario Caregiver Organization, then, I've been mentoring caregivers. So, on a volunteer basis, it's just one-on-one calls, whenever the person wants to talk. It's just to try to help people.

And I do have great relationships with staff members on my mother's floor, so they teach me a lot of things. "If it doesn't work, you should do this." That kind of thing. Because my mother could be stubborn. So, we learn. Like, what's happening while I was away, they told me. And then we come up with some sort of solution or whatever—we always have very good communication. So, I learn something and then, you know, when I go to support group and somebody is struggling—some similar situation—I can give them, you know, tips. So, we try to help each other. So I think I'm expanding my social network. And then, of course, the first, second year of the pandemic, we didn't have a lot of physical contact. But I think I had my social life, somehow, as a caregiver. I was quite active, which did probably help my mental health, I think. And then, of course, I'm not super active about my social life right at this moment either. But it's okay. I started, like, having a different social life with the caregivers, which is pretty interesting. So, my future goal after retirement is to go back to school and do something. That's my little goal for retirement.

INTERVIEWER: To do something in this field?

20:02
AKI: I don't know. You know, I don't have any details yet, but I just want to get involved in research projects in a small way and see where it can land.

INTERVIEWER: That's amazing. Yeah. I can't think of any other large question to ask, except, do you have any final thoughts? If you want to impart anything—any final thoughts about your story during COVID in relation to long-term care.

AKI: Well, I think COVID highlighted a lot of issues in long-term care homes. And, of course, Canada. But, you know, it was actually on top of a lot of people's lives, right? Lost lives. So, it was terrible. But at the same time, I think the general public has more awareness of long-term care sectors as well as other senior care sectors, including retirement homes. So, people work in at-home care types of businesses. So, I mean, eventually people may forget, but I think—I don't really think we should waste this experience. Because a lot of people died from COVID. So, I think we need to make things better in the future. It shouldn't happen again. Like, let's say, if something happens five years from now—something similar—we should be well equipped. We should be able to do better, right? We shouldn't lose a lot of lives anymore. So, I think everybody has to be aware that we know, we experienced that. And we can't make the same mistake in the future. Hopefully, it doesn't happen, but even if it does happen.

22:08
INTERVIEWER: That's beautiful. Hopefully, all this loss can amount to something. Let's not waste it.

AKI: Yeah, that's how I feel.

INTERVIEWER: Thank you so much. I think that's everything unless you have any final thoughts. It was good to talk to you. Thank you so much.

AKI: Thank you. I hope I was able to help you research.

INTERVIEWER: Oh, yeah, absolutely. Yeah. Okay, this was October 29. Contribution number one. Akki Langdon. Thank you.

AKI: Oh, I'm the contribution one!