

The Alzheimer's Podcast

Episode 140: "We weren't shocked"

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So yeah, Mikaela and I, you know, we were shocked, horrified, disturbed by everything in the report, but we weren't. We weren't shocked.

Christy Turner, CDP: You're listening to *The Alzheimer's Podcast* with Christy Turner of Dementia Sherpa, where we're all about bringing the Good Stuff --that's respect, kindness, love, empathy, and compassion--for people living with dementia, their families, and the professionals who support them.

I'm Christy Turner, AKA The Dementia Sherpa. I've enjoyed the privilege of working with over 1,500 people living with dementia and their families so far, including multiple experiences in my own family. In the course of my career, I've transformed from total train wreck on my first day as a professional to local go-to expert, speaker, trainer, and consultant. And if *I* can go from scared spitless to confident care partner, I promise *you* can, too!

Hello and welcome! Recently, I grabbed [a favorite book](#) from my shelf and 'randomly' flipped to a page entitled "Acts of Friendship." If you heard the air quotes in my voice around the word randomly, you aren't wrong. I don't believe in coincidences, and this short essay spoke to something I've been thinking about for months now.

People are dying in long-term care. I'm not talking about situations in which that's the expected outcome for people who are at the end of their lives; I'm talking about this happening because we as a society are allowing an accelerated path to the end of life in long-term care via the coronavirus pandemic.

I've gone back and forth between shock that there hasn't been an angry outcry demanding a competent, comprehensive response, and wondering if I'm not shouting loud enough about it or not using the right words when I shout. That's why this particular page in my book really spoke to me, especially this passage:

“If you are aware of a truth that you believe friends would benefit by knowing, it is your responsibility to tell them. You do not have to argue, justify yourself, or force your opinion. Simply state the situation as you see it, and then allow individuals to do with it as they wish.”

The page ends with the following prayer:

Give me the confidence to speak the truth I see. May the words serve.

The following is the first of a two-part episode. In our last episode, Phil mentioned [a Washington Post story about 81% of COVID-19 deaths in Canada have happened in long-term care](#). And on the show today, we have Spencer Coombe and Mikaela Wilson, who are the cofounders of [Senior Support Services of Southern Ontario](#).

They're going to talk about the report that the Canadian armed services—the Canadian government sent in military personnel into long-term care to try and get a handle on what was happening regarding COVID-19. [They issued a report and had some findings that were pretty disturbing](#) for all of us who are professionals in long-term care or who love people who are living in long-term care.

In the United States, often we think Canada pretty much has it figured out. My heart sank as soon as this hit the news. I was like, Oh, my God, if it's like that in Canada, there is assuredly a problem everywhere. And [we saw this in Italy](#) and [in Spain also, in long-term care](#).

In the United States, the most recent number that we have, which I believe is vastly under reported, is [42% of our COVID-19 deaths have happened in long-term care](#).

So with that preamble out of the way, Spencer and Mikaela, thank you so much for being on the show today.

Mikaela Wilson: Thank you for having us, Christy. Last time we kind of talked, we talked about how shocked you were, that Canada was in this position and you did feel Canada was better than this.

It kind of left Spencer and I really torn because we truly feel as though Canadians regard seniors as important. And we do think, in general, people care about the wellbeing of our seniors. Obviously with this report and things coming to the light, we have a very far ways to go. So, that's been hard to kind of, you know, hear families talk about it and see how they're feeling about all this.

Christy: I totally understand, because I think as a professional—this is what I find; I'm interested what you two think—I see a story hits the media, whether it's COVID-19 related or not, but something goes awry in long-term care.

And on the one hand, you know, there are the colleagues, the professionals that I know; the heart that is poured into caring for our population. And I just think, *Oh, my God, no, it's not like that. And people are going to get the idea that it's like that everywhere.*

And on the other hand, I shake with fury because why can't we weed out these people who don't care, these places that ought to be shut down that are screwing up on such a massive scale?

In a widget factory, if you screw up, okay. The production line has to run again. You have to maybe change the design of the widget. But typically, people don't die. And in our line of work, screw ups can cause death.

Spencer: Yup. A hundred percent. Mikaela and I, we were not surprised to read what was outlined in the report, but of course, you know, we were shocked, horrified, like anyone else who has read it. But we have been seeing these issues first-hand for quite some time. And Mikaela and I have known for a long time that the system has been ignored and neglected for decades.

You know, this is why families, specifically—families hire us to come in as extra help for their loved ones living in long-term care homes. You know, some of our clients, families want us to be there just to ensure their loved one is actually getting their brief changed regularly or getting fed all of their three meals a day.

So yeah, Mikaela and I, you know, we were shocked, horrified, disturbed by everything in the report, but we weren't. We weren't shocked, if that makes sense.

Christy: It does. And this goes to something I saw in the Washington Post yesterday: a couple of doctors had written an editorial saying [it's unethical to keep families from visiting their loved ones during this pandemic](#). We need to, obviously, have very stringent guidelines around visitation. We don't want to encourage the spread.

But the point he was making is people get better care when their families are participants in that, when they visit routinely and regularly, because often they are providing care, doing things like changing briefs or ensuring that someone is not in need of a brief change or making sure that they are eating all their meals.

And on the one hand, I mean, I completely agree. It's unethical to keep families away from people living in long-term care. There are ways that we—I mean, obviously PPE et cetera, and [that's a whole other failure conversation](#), at least in the United States.

But it also struck me, Wait, where are we as human beings that we have accepted a system, no matter what country we live in, where we will pay money for a service that is promised and not delivered upon? And we still have to show up to supervise to make sure that it's done.

If I order a new Chromebook online, I don't need to show up to the factory to make sure it's actually being made, or that it's actually getting all the parts in it that it's supposed to have.

Mikaela: Christy, in the States—'cause in Canada, it's a little bit different in each home. So, we have obviously private, so people that pay out of pocket for homes, and then some through the government, where they're not paying; it's through their tax money. And each home right now in COVID kind of has different regulations.

So, some of the private homes, private caregivers and families are allowed to visit. And then some homes aren't. Is that kind of happening in the States too?

Christy: Nah, [there is one state \[Rhode Island\] right now that is relaxing the guidance](#). I'm sure there are places like, we call them adult care homes here where there's a maximum of five residents, where they are probably flying under the radar, letting families be closer. I don't know that they're letting people come in.

Mikaela: You talked about that it's inhumane for families not to get to go visit. And for us, you know, we see the staffing issues and that there is a huge lack of staffing--shortages all across these homes. Adding those family and adding the private caregivers is just a way to add that extra support. But right now everyone's just so fearful that as soon as COVID enters into a home, it's a horrible, a horrible thing that's not going to be regulated or controlled. It's just the fear is really stopping the homes from allowing families to be part of the care, which Spencer and I think is really important.

Christy: Absolutely. So let's set that aside for a moment. Can you name a few things that were in the report that both shocked you and didn't shock you?

Spencer: Yep. So, the report specifically touched upon the five Ontario long-term care homes. I'll just name a few things that the report touches upon. Some of the most disturbing: cockroach and bug infestations; rotting food in some homes; this is common: seniors calling out for help repeatedly for hours on end.

COVID-19 infected residents being put in the same room with those who are healthy and who didn't have COVID; individuals, residents being forced fed, missing their meals. Seniors left in their soiled diapers and linens for days. Those are just some of the, some of the disturbing conditions that we read about.

Mikaela: And I think one thing important to note too, is that this is in Ontario, and I think some people-- and we've heard people talk about the other provinces: "Why is Ontario, you know, being the one in the news?" So, Ontario actually has, is the highest [population] for individuals with cognitive impairment, neurological diseases, in long-term care homes.

So, Ontario is the province that's dealing with it. It's more end of life individuals in these homes. So, you might not see that in other provinces as much. So that's also why. Things might not have been going as smoothly because the care was a lot higher in Ontario.

Christy: So, the care wasn't higher, but the care *needs* were higher. Right?

Mikaela: Yes, exactly. Right.

Christy: Okay. That's important for people to understand. The other thing that I'm hearing from what you're saying is none of these things were caused by COVID-19, right? Like, the first thing you said was cockroaches. That's an environmental services problem that was not created by COVID-19.

Mikaela: For sure. Yeah, we knew about these issues before, and COVID really pushed the system into the brink, but we, you know, we've heard about malnutrition and dehydration issues way before COVID.

Spencer: And pest control issues too. Mikaela and I think that there are many signs that the provincial government knew or should have known what's happening inside these homes, but it's just crazy to us that it took military intervention to really bring these details to light.

81% of COVID deaths have been in individuals in long-term care, which is such a high number. It's pretty crazy. Mikaela and I believe that there are many signs that the provincial government knew, so Ontario should have known what's happening inside these homes, and it's just crazy to Mikaela and I that it took military intervention to bring these details to light.

And it's just something that everyone in the healthcare field in Ontario has known about for years or should have known. And that our population is aging, long-term care is continually being ignored and neglected. It's the fact that it took a constant watchful eye from the military to truly uncover the scope of this problem. It's crazy they had to be there. The military was there 24/7 to really see these issues.

Mikaela: One thing: so, the military goes into war zones and, you know, sees some horrifying things. We watched this video of a man, a military personnel who was helping in the home, talking about how this has been the worst thing he has ever seen.

And just the fact that, you know, he's in the military, he goes into war zones. And the fact that he's saying that this has been one of the worst things he's ever seen is quite, quite startling. I just kind of wanted to add this too, because Spencer and I truly do think, you know, people care about our seniors and care what was going on.

And there was a lot of reports of daughters that had their mothers in the home or fathers that had no idea. And, you know, they expressed that they felt terrible and really didn't realize the extent of what's going on. And I think, you know, the army individuals being in there 24/7 really brought it to light.

But I think from an outside person, you wouldn't really know what was going on, if that makes sense. So I don't think people were seeing the cockroaches, seeing the malnutrition, and going, "Oh, whatever. They're just a senior." I don't think that's what's going on. I think it was just genuinely people not realizing the extent of the lack of care that was going on.

Christy: Well, I'm wondering because in the *Washington Post* story, a person in there is quoted as saying, I think it was perhaps a Canadian journalist, but I'm not sure, but a person was quoted as saying, "I've been talking about this. I've been ringing the bell about this for 20 years." And certainly I saw that on social media when I was following the story and the links to the story there.

And there was a thread from a Canadian journalist who was saying essentially the same thing--might even be the same person that was quoted in the story--this has been going on for a very long time. And for me, that is one of the most frustrating parts. And I'm not singling out Canada; I can say this definitively about the US. I've been ringing the bell about the same things for 20 years.

Specific to dementia for sure, but I think this may be true more broadly in long-term care: whether conscious or unconscious, there's sort of a thing where, "If it doesn't affect me, I'm not going to pay any attention to it." And I guess the closest thing I can say is like in the United States is the Black Lives Matter protests, where now there are just a whole lot of white people saying, "Oh gosh, I guess this really *is* a problem." Yeah. Whereas it's not that suddenly there's a problem; there's been a problem. People have been clamoring for attention about the problem and to bring attention to the problem for a long, long time. But it takes something, and it seems to be like some, I don't know, almost mystical connection of timing and amplification where everybody else actually starts paying attention.

Mikaela: For sure, yeah. I agree with that.

Spencer: And that's, yeah--what happened is the military started helping out in these homes that were having these issues with COVID and then, you know, it just, it took many of the military personnel, I'm sure, to just start talking to one other and saying like, "This is something that we can't *not* bring to light and we can't *not* write a report on this."

And it's crazy that it took the military personnel to be the ones to really shine this light on it.

Christy: This report came out four weeks ago, five weeks ago?

Spencer: May 27th, I think it was.

Christy: Okay. So it's been even longer than that.

Spencer: Yeah.

Christy: And have you seen anything change as a result of that?

Spencer: Yeah, so, Mikaela and I have been able to visit clients in some long-term care homes; specifically, one of the homes that I visit. It was inspectors that came in, probably a few weeks after the report was brought to the public, is when the inspectors started coming to this home and checking in on things and seeing how things were done.

And, you know, all the staff knew that they were coming, I guess it was the ministry, it was coming. So not the inspectors. The ministry is the one that runs and looks at the government homes. So all the long-term care homes that are government run. So, that's when they started coming in and having an eye and making sure things were going smoothly.

And that was just a couple of weeks after the report came out. So definitely, definitely there's action being taken. It was last year, so in 2019, we--out of all 626 homes in Ontario long-term care homes, there were only nine inspections.

Christy: What? I'm sorry, can you repeat that please?

Spencer: So out of all 626 long-term care homes, there were only nine comprehensive inspections.

Christy: Shut the front door! Are you serious?

Spencer: Yep.

Mikaela: Yeah, and they were told about the inspections, what they were going to be looking for, what, what needed to be, you know, check marks and things like that before the inspection was done.

Christy: Is that usually how it goes?

Spencer: No. So the reason for that was that, [Doug Ford who runs Ontario, he cut back on inspections and he got back on a lot of things in long-term care](#). Specifically, these comprehensive inspections that are supposed to be done, you know, on more than nine. It should be done on all of them personally, is what we think. But the fact that it was nine was because they were doing a lot of cuts to long-term care homes.

And, unfortunately that would have been when Doug Ford came into Ontario a few years ago. And he made a lot of cuts to long-term care. Before that, a girl named [Kathleen] Wynne. She was doing really well with long-term care and we were kind of seeing some improvements.

But unfortunately, when we got a new premier, he did a lot of cuts to long-term care and--

Mikaela: The inspections was one of them.

Spencer: Inspections was one of them.

Mikaela: And just, it was awful that only nine were conducted out of all of 2019.

Christy: So for US listeners, just in case you don't know: how it works here in the United States is skilled nursing facilities (also called nursing homes), are surveyed every year. Annually. And they're surprise inspections.

And then depending on the state, they might also have what are called complaint surveys. So a family can call the department of health services in their state and say, "Hey, I saw cockroaches," or, "I don't think my parent is being changed," or whatever the complaint is.

And whether it's a complaint survey or the standard regular, annual survey, if there are deficiencies, then the community has to submit a plan of correction, which is either accepted or not. And depending on the scale of the deficiencies, whether it's something considered a minor deficiency versus something all the way at the other end of the scale is called immediate jeopardy.

And with immediate jeopardy, if a surveyor sees that, then the building is immediately put into stop placement. So there is a sticker on the door. There will be no more admissions. Everything needs to be fixed ASAP. the surveyors come back and make sure that after a plan of correction has been submitted, that it has actually been followed through on.

Assisted living is every other year, but again, this depends on the state. I know California for example, is really lagging behind on that. So that's a little difference between the United States and Canada.

Mikaela: He's [Ford] come on the TV a lot and has talked about the changes that are going to happen. And, you know, as horrible as COVID is, you know, I do think good things are going to come from this situation. He is putting more effort into it and realizing, and also the military. It's kind of now known that it can help internally.

I was talking to a gentleman who runs a front desk at one of the homes that I go into. He was like, "This is the first time that people have really realized that the military can help inside Canada." And they, anyone can request the military to come in and help them. So if a home is feeling like they need extra support, they can request military personnel to come in and actually help the home.

So I think that's a good thing, that Canadians are realizing that they don't necessarily have to be deployed. They can help within Ontario. And it won't be the government telling the military to go help a home. It's the home that has to request the help themselves.

Christy: I love that. That's great.

Mikaela: Yeah. So that's, those are great things, I think, moving forward. And Ontario is now launching an investigation into the oversight of these long-term care homes, which hopefully will obviously have some positive outcome with that.

Christy: And that's our show. Thank you so very much for listening! Head on over to the show notes at DementiaSherpa.com.