

The Alzheimer's Podcast

Episode 141: “What did you do? What did you say?”

Christy Turner, CDP: The lack of empathy and compassion that I've seen consistently across what is happening in long-term care, not by the people who work there, but by the people in positions of power who easily could have changed the outcome that we're seeing now, I...it is--I *cannot* wrap my brain around that.

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! This episode is part two of my conversation with Mikaela Wilson and Spencer Coombe, co-founders of Senior Support Services of Southern Ontario and co-authors of Any Game for Any Brain. Last episode, we talked about the Canadian military's report on five nursing homes in Ontario and the awful conditions they found there. As Spencer said, it was shocking, but “we weren't shocked.”

John Lewis had it exactly right when he said, “When you see something that is not right, not just, not fair, you have a moral obligation to say something, to do something. Our children and their children will ask, ‘What did you do? What did you say?’”

And that's exactly why we continue to speak up on *The Alzheimer's Podcast*. We discuss more problems in long-term care in both Canada and the US in this episode. Bringing problems to the light is the important precursor to solving them, and we talk about some solutions in this episode, too.

I think one of the things that would be really helpful--and this is one of those things where I think we, speaking broadly as a professional in long-term care, can really grab a shovel and just keep digging and digging and digging that hole because it's a vicious circle--staffing shortage is often a root cause of a lot of other problems.

Like, is everyone getting a meal timely? If it's supposed to be served hot, is it still hot when it gets to a resident? If a resident needs assistance in consuming that meal, is it still hot? Are they getting the

assistance they need timely? Personal care needs: is that happening timely? All the root cause there, typically, is a staffing shortage.

Spencer Coombe: Yeah.

Christy: So, so often what happens is a company--and I'm speaking for the United States when I say company, because most long-term care communities are privately owned, [though] some are nonprofit-- but they hire somebody who has a pulse rather than somebody who has a heart. And I've contended for pretty much 20 years now that if you hire somebody who has a pulse, that checks the boxes on the technical skills, you're wasting your time and you're wasting your money because it's going to create more problems.

Versus if you hire somebody who has a heart, but doesn't have the skills, who cares? You can teach skills. That's the easy part. You can teach those specific skills, but if somebody has the heart to serve that population, to be in a community, they are going to be fierce advocates for the residents. They're going to soak up knowledge like sponges. They're going to create an amazing environment for everyone who works there, and more importantly, for everybody who lives there.

And I think so often companies think they can't do that, like hiring for heart is a luxury because they need immediate help now. But that mindset, if that doesn't shift, it just continues to dig the hole deeper.

That's what I think, anyway. What do you guys think?

Spencer: Yeah, it definitely is what needs to be fixed in Ontario's long-term care homes, the staffing issue. There needs to be--right now there's a shortage of staff in most homes, I'd say. Especially now during COVID, a lot of staff because staff, because they are part time, they're only hired part time, in some cases, in homes.

So that they don't have benefits and whatnot. So they work at multiple homes. Sometimes two, sometimes three. And what's happened during COVID is that now they're restricted to only staying at one home. So they had to choose that. So now I think we're seeing, you know, a staff shortage like we've never seen before, especially during COVID.

Definitely even before COVID hit, there needed to be more staff. Needed to pay them better. They're not being paid enough for what they do, Mikaela and I think. And, you know, making sure that they're getting the same respect as anyone else does. And I think, what we see is that the PSWs--

Christy: Can you explain what that means?

Spencer: Yeah. So PSW is our personal support workers. So they're, I think you guys call them the health care aides.

Christy: Right. We like to have 50 names for everything. So, home care aides, personal care aides, certified nursing assistants, nursing assistants, et cetera.

Spencer: Okay. So yeah, the PSW are our health care aides and we think they're, most of them in the homes that we see, are great.

Mikaela Wilson: They're the heart and soul in most of the homes and, you know, they're burnt out. They're tired. The homes that had COVID, they're scared to go in because they're going to bring it back to their family members.

Or, you know, before COVID, it's just they're so burnt out. They're working so hard from what we see, and we don't know what it's like in the States, but in Canada the personal support workers, we think, take care of our loved ones and our seniors really well. And they do try their best. It's just, you know, it starts from the top and trickles down, right?

Christy: Absolutely, it does. then I'm going to keep moving. When people who work as direct care aides, when they are not valued--as a society, when we are not valuing them, this is a rather predictable result.

And yes, I absolutely agree, in the United States, same-same. These are people who are working their petunias off in exactly the same conditions as you described, where they need to work more than one job because companies think it's really cute to screw them out of benefits by not hiring them full time.

Spencer: Yeah. And, you know, just the fact that the chronic staffing shortage before COVID, and then when COVID hit, there were a lot of homes that were being hit. And often the homes that were being hit, they didn't have those protocols in place. And that's why COVID was really spreading, as they were-- COVID-infected residents--were being put in the same room as others.

And a lot of the PSWs didn't have that proper PPE. In the private homes, you know, there was a fear of being fired for using too many supplies. Like in the report, it talks about reuse of syringes and PPE. You know, they were re-using these syringes, that they didn't want to use too many masks and shields.

How do you expect people to work in these homes and under these conditions? And you know, that fear was why their staff weren't coming into work. They were dropping like flies because they were either getting COVID or they were scared they were going to get COVID, because the home didn't have the proper management and the proper regulations and protocol for what should have been done.

Christy: Right, for that infection control. And I know here, I don't think it's a spoiler alert for anybody anywhere in the globe, or listening here in the United States, it's been a shit show as far as how this has been managed. There were places that were begging for PPE. We had nurses in hospitals wearing garbage bags.

Mikaela: Wow. Yeah.

Christy: Yeah. For real. So, if that happens in acute care hospitals--I promise long-term care is always the redheaded stepchild of the healthcare system, at least here in these United States. So, if you've got nurses in garbage bags in hospitals, it was much, much worse in long-term care.

I don't understand why it appears to be so difficult for people in a position to do things differently, to wrap their brain around the fact that if you are reusing PPE, essentially you might as well be using none.

I'd like to see the next person in power who needs a surgery done, be A-OK on having the surgeon and the surgical support staff walk into the room saying, "You know, we just did five other surgeries, but we're conserving PPE. You're cool with that, right?" Nobody's going to say that's okay.

The lack of empathy and compassion that I've seen consistently across what is happening in long-term care, not by the people who work there, but by the people in positions of power who easily could have changed the outcome that we're seeing now, I...it...is--I cannot wrap my brain around that.

And of course, you know, here in the United States, we have that whole, *Let's open up the economy and you know, Grandma's not an income earner, so pffft who cares [what happens to her]?* That is far too prevalent a thought here and leading to horrific results.

Spencer: Yeah.

Mikaela: Christy, Spencer and I had a question for people in the States. So, when they get older, is it just kind of a, *you get older and you have to figure it out for yourself?* Or is there a government intervention to help them kind of either live at home or go into a long-term care home through the government? Or is that kind of just a Canadian thing?

Christy: Most long-term care is privately owned and there are some nonprofits. But in the United States, you are very much expected to pull yourself up by your bootstraps and fend for yourself. If you have means, then you get to choose what your situation will be in your later years.

So, if you want to stay at home and you want the support of in-home care, then you use your funds to pay for that. Or if you'd like to live in a retirement community or assisted living, or what have you, you use your funds and pay for that.

There are some companies that accept Medicaid. And again, we like to call it 50 different things here, but Medicaid is a government program based on financial needs and medical need. So it is essentially for low income seniors, so they can get assistance that way.

And it also covers more than low income seniors, but again, it varies widely state by state. But people with disabilities, and then you've probably heard of the Affordable Care Act, more popularly known as Obamacare. And some states have that.

So, it depends on geography and it depends on what's available. So for example, in a rural area, there would be very few long-term care choices about where somebody might live or what services might be available. And within that, it would depend on, do they accept Medicaid as a payment source?

Some in-home care companies do accept Medicaid as a payment source. Some long-term care also accepts Medicaid as a payment source. But then there's also, they can say, "Well, even though we're a hundred-bed community, we only have four Medicaid beds and we don't have any available right now."

So it's very profit driven.

Mikaela: Okay. Yeah.

Christy: Yeah. And, and there's also a gap where people who are not wealthy and who are not completely impoverished. There's that gap where they could not possibly, they do not have the funds to pay for care monthly, but they have too much to qualify for Medicaid. That's a massive problem also.

Mikaela: Yeah, they kind of are the, they slipped through the cracks because they're not in either.

Christy: Yeah. Shorter answer is, it's a hot mess.

Mikaela: Yeah, 'cause we were kind of talking about that Canada, even though in the system right now, we've seen a lot of flaws and a lot of negative things, you know, when you do get older in Canada, you have a lot of options through the government.

And, you know, you call the government and a social worker will come and they'll help you figure out if, to age at home or in long-term care or where you want to go. So Canada is very kind of good in that

sense, where, you know, we really try to make sure our seniors are comfortable. Which I don't think is kind of at the same level of the States.

Christy: You are correct.

Mikaela: Yeah. It's a little, it's a little different with that.

Spencer: Yeah. And what we've seen in Ontario, as I believe it was 2010, is the Ontario government started to begin putting a larger focus on aging at home and setting stricter criteria for admission to long-term care homes.

So that's why as a result, we see people are now coming to long-term care at a later stage of their cognitive and their physical impairment. So, when their health is more likely to be unstable, you know, they're more likely to be physically frail and their care needs are definitely higher.

So, I think going back to talking about the long-term care homes and the report specifically is the percentage of residents who have that severe cognitive impairment and physical impairment has risen drastically over the last many years.

And, I think that's why we're seeing a need for more staff, staff better trained. They're burnt out because the residents are just higher needs, right? So that means more work for them. So the numbers [of staff] need to increase with that.

Christy: Absolutely. And it's the same, like in the state of Oregon, for example. Same philosophy of aging in place. And it's been, gosh, I'm going to say at least 15 years of a concerted effort to assist people in aging in place and divert resources that way so that they can stay at home, wherever their home may be. And also making admissions more difficult, raising that criteria.

That's great. Let's do that. That's fantastic. I've never met anyone who ever said, "You know, my dream when I am in my eighties is to live in a long-term care community." Never met that person, because I think that person does not exist.

However, when we are seeing people come into the long-term care system, whatever piece or part that may be, they do have the higher care needs, as you're saying, and there is like--it's like a deafening silence about, okay, if we have less people in the system, but they have higher care needs, that seems pretty obvious that they need more intervention.

They need more assistance. They need more attendance. They need people paying attention to them. They're often more medically fragile, medically complex. And there seems to be a big disconnect on that, as you were saying.

I think one of the most important things--and I think it would be one of the cheapest things to do, no matter where we're talking about--and this is something that I've noticed over 20 years: Why on earth don't we talk to people like you two, and say, "You go into care homes all the time. What do you see? What do you think the biggest problems are? What ideas do you have to fix them?"

To say that to--what do you call them, PSWs? Or to CNAs here, or care aides, personal care assistants, whatever you want to call direct care staff. "You know, you work in these communities every day. What do you see? What do you think the biggest problems are? What are your ideas to solve them?"

There's really an easy solution. Just talk to people who actually spend time in communities, and let's come up with some solutions.

Spencer: Yeah. And I think, I think, yeah, family members are--

Christy: Yes. Yes. Thank you.

Spencer: And you know, one, one of the most difficult feelings is powerless[ness]. And I think a lot of family members who have their loved ones in these homes that have been hit so hard--and in any long-term care homes, for that matter right now--is, you know, all that these family members are feeling powerless because, you know, they may have filed complaints many times before, and they were the ones that were visiting their loved ones constantly.

And in Ontario, if you file a complaint, it can take time for that problem to be fixed. And I'm sure in the States as well; like, specifically if your loved one isn't being fed enough, or you may put a, a family member may put in a complaint about that, but it doesn't necessarily mean that inspection is going to be done and that problem is going to be fixed.

We saw a lot of families feeling really guilty about sending, putting their loved ones in these homes. They feel, you know, just very guilty that they put their loved ones in a home that when they didn't know the extent of the care that was being given in these, in these specific homes.

And I don't know, Mikaela and I have seen a lot of stories on the news of family members talking about the issues that they're seeing, or they're doing window visits with their loved ones, and they're seeing that they're not dressed or they don't look like they've been showered in many days. And those issues were being brought to attention, but--

Mikaela: I'm sure we'd hear people want to live in long-term care homes if a long-term care home was created by loved ones, PSWs--personal support workers, the people themselves. Then maybe we would hear people excited to go live in long-term care homes, right? But that's not what's being done right now.

Christy: That's absolutely true and a really good point. And I don't think that families ever, obviously, intentionally say, "Okay, we're choosing this place," knowing that it has problems. Families really agonize and struggle over making these choices.

And then of course, sometimes, at least in the United States, they're sort of backed up into a corner and really told, "This is where your person is going," because it's a hospital discharge and this is the only place that can accept [the person]. And I mean, that's a whole other show.

But one of the things that I have always kind of scratched my head about--and I understand one reason for it--but especially, in this day and age, where there is social media and the so-called cancel culture, I have always scratched my head that family members don't use social media to their benefit.

Like, I'm not waiting for surveyors to show up and deal with the fact that my person isn't getting fed three meals a day, or isn't getting the assistance he needs for three meals a day, or whatever it is.

Families are so intimidated and they do not treat this as a financial transaction, and I think that is one of the problems, honestly, because families have such a fear of retaliation. That's the thing I think that keeps them from saying anything, but in so many situations, especially in large urban areas, there are so many choices.

And I'm speaking particularly to the United States. There are so many choices. There are so many places that are under capacity. You know, why don't they call a local news reporter? Why don't they post on social media? Why don't they write a letter to the editor?

And I'm not saying start there. Obviously, you want to bring it to the attention of the person who can help you within the community and say, "Hey, this is a problem. When can I expect this to be addressed?"

And if we're talking about somebody in a soiled disposable undergarment or somebody who's not getting a meal, the correct answer is, "Immediately." There is no other good answer for that.

but continued problems, or problems that don't require immediate, immediate attention, but you could reasonably expect a little bit more time and it doesn't happen? If you're getting the run around as a family member, I don't understand why they're not using the leverage they have.

Mikaela: I wonder, Christy, as you're saying that--you know, we're on social media a lot, and we see, and it's a lot of the shock culture, right? You see a video that's, *Oh my gosh, this is horrible. This is shocking.* And then, you know, you get into the cancel culture, but when it comes with seniors and you're posting a picture of a senior going, *Oh my gosh, you know, they haven't been fed. They're so*

skinny. It might not look any different than someone who's just a senior and that's what they might have looked like. You know what I mean?

Like, I think it's really hard to get that shock kind of video to make that change in the social media, to get that attention from people. Unless, you know, you're putting a video camera in a room, which you've seen, and I've probably seen on YouTube, right, of a staff member, things like that. Those are the videos that get attention. But to just post a video of a senior being like, you know, my loved one's not getting fed and things like that, it's not that instant shock that I think people really need to make a change. Which is sad, because I don't think people really care unless they're completely shocked and horrified by a video. If that makes sense.

Christy: Yeah, and I'm really glad you brought that up, Mikaela, because I am in *no* way saying, "I don't understand why families don't post a video of their person in a horrible condition." 'Cause that's *not* I'm saying. Personally, I would never, ever. Because that's a human being at their most undignified, through no fault of their own. So, no, I am not in support of that in any way, shape, or form.

What I am saying though is, let's say Shady Acres has super crappy care? Drag Shady Acres! That's what I'm saying. I don't understand why families don't do *that*. Like, *Hey, did you know this is what happens at Shady Acres?*

I'm not saying you walk in, your mom is wearing somebody else's sweater and you're then you immediately start doing a Facebook Live about how Shady Acres doesn't care about anyone or anything.

But for these situations, these real situations like we're talking about, families have so much more power than they realize. And they're thinking that they're lucky to be in XYZ place. And the reality more often, at least in the United States, is the community is lucky to have you.

So, let's really look at this. And that the, at least the corporate parent there, is looking at your person living there as a financial transaction. They're thinking heads in beds. And that's what they call it: heads in beds. They're not thinking, *your beloved father, your precious mother, the love of your life*. That's not how they're thinking about it.

I mean, obviously I think there are a lot of things that could change in long-term care for the better. I think one of the quickest ways to help affect that change is for families to start speaking up and advocating on behalf of their person.

Spencer: Yeah, no, we completely agree. We saw a lot of videos and we were seeing a lot of news articles on the family members of these loved ones in these specific homes that were brought to attention and that they're saying they feel terrible.

They feel as though they should have been more of an issue advocate. But you know, they were going through other things or maybe the fact that, you know, that I think one, one video we saw was that someone's saying, "I'm angry. I'm angry at myself." And they're angry at all of us.

The fact that they didn't speak up until this report was brought to attention--one newspaper article saying, you know, "I think we have ourselves to blame as well." And that, just the fact that these family members are realizing, "Wow, we should have spoken up. We should have done more, because we were seeing these issues before COVID struck," is, you know, quite awful and it's something that I'm sure these family members are gonna have, you know, feeling guilty for for a long time.

And, Mikaela and I, you know, we feel awful about that.

Mikaela: And we talked to our families about what they can do. And I think what you were talking about, Christy, is advocating for your loved ones. And we have family members that bring a book with them when they go in to visit their loved one and write down everything they see and who's on staff and what's going on that day, how clean it is, to really have a leg to stand on if they do need to file a report, so it just doesn't come out of left field. You know, figuring out really how to advocate for your loved one and how to do it properly, I think is really important, what families need to look up to.

Christy: I agree. In fact, I have a course called Effective Advocacy, where it helps families figure out What are you looking for? It helps with documentation, with how to, who do you complain to, what's a reasonable timeframe, all of that kind of thing.

And I think you're right. And my heart goes out to families. I think one of the key differences between the three of us and family members is we have the benefit of the experience, right, of going into communities, of seeing patterns across various communities, across time.

Whereas for many families, this may be the first time that they're in this situation and they don't know what to expect and they're frightened and they're overwhelmed and they're emotionally exhausted. And even for so-called experienced family members, they may be in the situation for what, the fourth time? If it's been both their parents and both their in-laws. And that is a--you know, if we all think back to the beginning of our careers, you know, what did we know after four people?

Mikaela: Right.

Spencer: Yeah.

Christy: Not nearly as much as we know now. I think that a lot of times--I mean, obviously a hundred percent of the time, hindsight is 2020. And my heart goes out to families who are thinking, *Oh, I should*

have known better, who are beating themselves up. Because the fact is they couldn't know what they didn't know.

And I think that's why it's really important for professionals to speak up and to help point people in the right direction and to let them know that things can be different and how they can use their voice effectively. And what support services, like, let's say, Senior Support Services of Southern Ontario can do to assist and complement the efforts that families are already putting forth.

Spencer: Obviously, family members can't be visiting their loved ones in long-term care homes. And I think family members right now are feeling powerless and, you know, they can't do a lot. But there's still some that they can do.

There's window visits. You can give them a call. If they're in a home, the nursing staff, if they don't have a telephone in their room, they can set up a call. You can say hello from a distance. So, window visits. We're seeing a lot, specifically in the homes that we go to, loved ones are coming and bringing signs at the window and saying hello, and maybe writing a little message.

We've also been seeing loved ones dropping off care packages to them, to their loved ones in long-term care homes. So they're bringing flowers or body wash and little letters to them. So, there's still so much you can be doing though, you're not able to visit your loved one. And checking in with the nursing staff. Maybe every day, maybe every other day, saying, "How much did my loved one eat? Are they eating? Are they sleeping okay?" Just still having that relationship with the staff members at the homes is a big one, though you're not able to go in.

And maybe you were doing that every day when you were coming in, but the fact that you aren't [now], you can still call them. You can still email, you can get up to date information about how your loved one is doing.

Christy: Absolutely. One of the last clients I got to see in person had just recently moved into a new community, thank God. I believe that's why he's still alive. His family actually lives in Canada. Obviously, all of my clients have dementia, but what I did was--and I didn't want to, it's, it can be tricky with dementia, of course. So you don't want to creep somebody out by coming into their window: "Oh, my God, it's some weird lady outside!"

But I had a sign made that said the family's names, a yard sign, so he could see outside his window. And it's just this constant reminder, with family names. It says "[family names] love you." And so it's that constant reminder.

And then the family had already installed bird feeders, so I put it right there 'cause he knew where to look for the bird feeders, and just made sure that the bird feeders were overflowing with bird food, so there would be lots of activity out there.

And that's something that I think a lot of times families don't necessarily think of. But I think that, particularly when we're talking about people living with dementia, is yard signs. Something that people can see from their window. You want big print, to make sure that it's prominent and eye-catching; that is great for people living with dementia.

You know, even back when families were able to freely visit, people may forget that their family had come to visit that morning, or even an hour ago. And to have that constant reminder that somebody loves them and is thinking about them is really important.

Mikaela: And one thing that we've seen, that's been really working for a few of our clients is a photo album. The front of the photo album will say "Read me" and then every photo will have sticky notes of the people's names, so they're able to see. And it's been working really well for our clients who might not understand or remember their family, but are able to read and look at pictures too.

Christy: Love that! Love that it says "Read me" on the front. That is, I have not heard that before. That's so obvious now that you say it. Genius.

Mikaela: Yeah, and it's working. Our clients are actually opening them and starting to read them.

Spencer: And without us being there, just having it on their side table and opening it up every morning.

Christy: That's fantastic. Well, ladies, I know I have kept you longer than you intended to be here. For our listeners, it's important to note that this is actually not my first conversation with Spencer and Mikaela; you're going to be hearing more from them. But I am going to link in the show notes for this episode something that we're going to talk about the next time they come on the show--which has already been recorded--and that is, they have written a book.

So speaking of, *Oh my gosh, it's in the time of COVID-19 and I can't visit!* they have written a terrific book that will be really helpful for things that you can do with your person. If you're at home together, or if your person is in a care community, there's staff that can help them with some of those things.

I'm going to link up to their book in the show notes. You want to check that out sooner rather than later. This is an important resource any time, but especially now as we're all thinking, *How can I help my person have meaningful days or improved quality of life?* Their book is a solid, concrete way you can do that.

Mikaela: Awesome. Thank you, Christy.

Spencer: This has been so wonderful. Thank you so much for having us on the show.

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