

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
Episode 102: Everybody Does the Best They Can

Christy: I think that everybody does the best they can with the information they have, the knowledge they have, the skills they have, in that moment. And sometimes, just like any other area of life, we're going to say something or do something that we're like, "Ugh, boy, if I could hit the rewind button on that, I totally would." And you get better over time, as you have more practice. And I promise, neurodegenerative disorders will give you so much opportunity, so much, so much practice.

Christy: 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 thanks for joining us. Phil Gutis, our Assistant Sherpa, is with us again today. This episode is part of a much longer conversation we had; in fact, I think this is the third episode out of just one conversation. The reason I mention this is Phil references "that lady I mentioned earlier," and unless you hung on Phil's every word in Episode 99, you probably have no idea what he's talking about.

To refresh, here's what Phil said in Episode 99: "I talked to a woman today, as part of--I'm doing a little bit of writing for...a website called the MemoryWell, where people are hired to write stories for folks who are older or maybe have dementia, stuff like that. And her mother is 94 and in a memory care facility and...she was describing her mother's life and how...she doesn't remember that her husband has passed away and she's always asking about him." Well, we are going to talk more about that situation and ways to handle it in this episode.

But everything starts with us answering a listener's question. Which leads to Phil to talking about a symptom that you may not know is related to Alzheimer's and a

few other types of neurodegenerative disorders. I've put links for more information about that in the show notes at DementiaSherpa.com/episode102.

I think the recurring theme in this episode is, for the most part, we're all doing the best we can. When we know better, we do better. Until then, we handle things the best way we know how. And I believe that this is a message care partners can never hear enough. Your sister or stepdaughter or just the nasty little voice in your head likes to second-guess you and help you feel miserable. So I would just like to remind you that you're doing the best you can. And also? You don't have time for nonsense!

Christy: We have a question from someone that didn't stay in their email if I could use their name. So, I'm going to read the email, and it says:

“Dear Christy,

Recently, my partner and I were sitting having our usual 6:00 PM glass of wine together when he looked at me, looked at the closed patio door at the other end of the living room and said, in a slightly demanding tone of voice, “It's too hot in here.”

Clearly, in my mind, he expected me to get up and open the door. Then I said to him, in a matter of fact way, “You know how to open the door.” With a somewhat hurt expression on his face, he got up, walked across the room and opened the sliding glass door, and sat down again. His mood had changed and he was more or less quiet the rest of the evening.

The next day I thought about how I could have communicated to him in a way that didn't sound in the least bit critical or so abrupt or judgmental. For example, I could have said instead, “Would you like me to open the door, or do you think you could do that yourself?”

But of course, that's in hindsight when I've had more time to think. My point is that I'm trying to balance my need to offer help whenever I feel that he cannot cope with the problem on its own, but not help him when he can easily do something by himself and for himself. He's getting used to calling on me more and more to do things for him or help him out when he's having difficulty managing something like a cell phone call, a computer, etc. I'm happy to help him when he needs it, but I want to encourage him to do as much as he can by himself. Any thoughts or comments here? Do you think this is an issue that you could raise in one of your podcasts?

Best regards

This person.”

So, there's a lot to unpack in that. One of the first things that popped into my mind--this goes back to, I think it might've been our first episode together, Phil--when we were talking about that learned dependence or learned helplessness and somebody being encouraged to be as independent as possible versus kind of leaning into other people doing things for them. So, I have some thoughts about all of this, but what are your thoughts, Phil?

Phil: My short answer to the question was, “Yes.” Which wasn’t very helpful.

Christy: *What were you saying yes to?*

Phil: The whole thing. It’s kind of a no-win situation.

Christy: *Mm hmm.*

Phil: Yes, he should encourage, or she should encourage--I don't know if it's a he or a she, what kind of partner we're talking about--but, the partner should be encouraged to do as much as possible. Even the suggested alternative language left me a little cold.

Christy: *I agree.*

Phil: And I'm not sure I know what I would recommend as the alternative. I kind of know that I'd want Tim to say to me, “You still have legs. Get up and open the door if you want.” Because sometimes I think you can get too dependent, and we need to fight against that.

Christy: *Mm hmm.*

Phil: But at the same time, I also want Tim to recognize that even though I still have legs, sometimes they don't work so well and I don't feel very balanced. And you know, yesterday I was walking down the street with my nephew and I was, I was egging him on about something and he gave me a little shove, you know, nothing--not a shove, you know; he sort of like, you know, pushed me as though to say, *Shut up, I'm done listening to you.*

And I almost fell into a tree. And that wasn't his intent, obviously. And I said to him, "You know, you would have been very sad about--if I had fallen on my head." And I said, "I'm just not as good on my legs as I used to be. And we just have to be careful about that." So, you know, it's this--that's why I say, "Yes," because it's this really kind of weird thing, as there is no right answer.

Christy: *Mm hmm.*

Phil: And that's what makes the challenge of being a caregiver, I think, so challenging: is there is no right answer. And you know, yes, I want Tim to say, "You still have legs. Get up and open the door your damn self." But I also want him to know when I can't open the door my damn self.

Christy: *Well, you brought up so many good points there, Phil. Number one, and you have said this pretty consistently, in that you feel like for Tim, he is often in a no-win situation because it is such a fine line and such a balance. Right? So, that's one thing. And I think our writer, writer/listener here, is maybe finding themselves in that type of situation also, right? Where it feels like it's no-win. I guess the first thing that jumped out at me was that he says, "He said in a slightly demanding tone of voice, 'It's too hot in here.'" And so what jumped out at me at that was that is the writer's perception of what that tone of voice was. Right? So, and sometimes that happens for care partners, where, for whatever reason--it's, maybe it's been a tough day and somebody says something that's even just, it might just be very innocuous, like, "Oh, it's too hot in here."*

And it can kind of tip us over, like, “Are you kidding me? I’ve done all this stuff today!” and all these things. And it might not have anything to do with your person at all, but it's just like, whoops, that was the last thing to jump on the nerve and Boom! Then we're off to the races. So there's that. Then, being able to say in a very matter of fact way is usually not a bad thing, but maybe instead of, “You know how to open the door,” maybe something like, “Do you need help with fixing that?” or, “Is there something you need me to do?” Asking questions a lot of times just helps you get more clarity and obviously more information about what's going on. I think your point, Phil, is huge. And I'm so glad you brought that up, because so often when we hear the word Alzheimer's or dementia or any type of neurodegenerative condition, we automatically go to memory or confusion or something like that.

And so many people are unaware that there's so much more that happens with those conditions. So, speaking specifically to Alzheimer's disease, dementia with Lewy bodies, or Lewy Body Syndrome, or Parkinson's disease with dementia, frontotemporal degeneration, those conditions specifically often have pretty significant balance problems. And so I'm so happy that you shared that story about just walking down the street with your nephew. There are times when people just don't have the balance that they used to have and this is something that can progress over time. And then for somebody like with Lewy bodies, sometimes they just freeze; they couldn't move if their life depended on it. They just physically cannot pull that off in that moment. And sometimes they can't control the movements that they're having. So there's so much complexity that happens with our brain sending signals to other body parts that most of us take for granted until the wheels start coming off the bus, until it is a challenge to coordinate everything. So we can all think about what else could be going on beyond what we think is right there at the surface level. And--

Phil: You know the other--

Christy: Go ahead.

Phil: --thing that I think of, you know that note you got from me, asking you to contribute [to Phil & Tim’s Longest Day team, Row2Remember] talks about Tim as “the bright spot of my life.”

Christy: *Mm hmm.*

Phil: And I showed him my note when he came home, and he said, well, he wanted to edit that part and make him the shining supernova of my life. He was joking, but at the same time I said to him, “Well, you are the bright, shining light of my life, except I want to kill you virtually every day.” And that gets to the other--I mean, I think it gets to the core of what the writer was trying to deal with is, you know, yeah, I'm going to increasingly rely on Tim for everything. And I see it happening day by day. But that doesn't mean I'm not gonna resent the hell out of him. Or, you know, I'm going to, you know, as long as I can, continue to challenge decisions that he makes or things that he does, because that's just who I am. So go back to the no-win situation.

Christy: *Right! And I think, you know, relationships are a tricky business. And any configuration that I can think of, be it a romantic relationship, or parent-child, or adult grandchild-grandparent, siblings, what have you--we all have history with this person. And so whatever the dynamics are of the relationship, that's happening. And then on top of it, there's this diagnosis, there's this condition. And it will bring out both the best in people, and the worst. The relationship doesn't stop happening. It's not like, Okay, well we noticed there was something that seemed unusual, went to the doctor, got an accurate diagnosis. And then that magically changes the dynamics in a relationship? It doesn't. But it does add, like you're saying, more stress. And you're saying you want to kill Tim every day, and also at the same time you always recognize how much, how often, he's in a no-win situation because he is trying his booty off to make sure everything's cool and groovy for you.*

Phil: Right.

Christy: *Yeah.*

Phil: And I'm going to resent that sometimes, and I'm going to appreciate it other times, and it's not necessarily going to make any sense when I appreciate it and when I resent it. And he just tries, needs to try, to do the best that he can and we can't, he has to call you.

Christy: *Anytime! And I just say again, for our listeners: Tim is an incredible guy. I love him. I mean, he has the best energy. And Phil is a great guy. I love him. He has great energy. So we're talking about two people who are just good guys in a tough situation. And the other thing is that--I don't know, I'm not going to speak for Tim--I don't know that he wants to kill you every day, but there's no doubt--*

Phil: Sure, he does!

Christy: *--that he has, times where you can be really challenging or frustrating for him, too. So there's this reciprocity that happens in these situations. Like the person who wrote this email to us asking about this, I think that everybody does the best they can with the information they have, the knowledge they have, the skills they have, in that moment. And sometimes, just like any other area of life, we're going to say something or do something that we're like, "Ugh, boy, if I could hit the rewind button on that, I totally would." And you get better over time, as you have more practice. And I promise, neurodegenerative disorders will give you so much opportunity, so much, so much practice.*

Phil: That lady I mentioned earlier, that I was speaking with today, you know, she told me her mechanisms for diverting her mom's attention, since her mom doesn't remember that her husband passed away and she's always asking for him.

Christy: *Mm hmm.*

Phil: The nurses basically get to the point of saying, "Yeah, he'll be here later after work, honey," you know, kind of thing to divert her attention.

Christy: *Mm hmm.*

Phil: And her daughter doesn't, doesn't want to lie to her, so she basically just skips the question, "When will Dad be here?" and just moves onto a different topic. And it's just interesting how, you know, various people choose to handle these very challenging topics.

Christy: *Right. I know that there are people who feel very strongly that if they lie to their person then that's getting them an express ticket to hell. And some people, just because they're moral, ethical people, feel like lying is wrong under any circumstance. And you said something interesting. You said the nurses, as a last resort, say this is what's happening. I didn't really have to give this one a whole lot of thought because--I mean, going back to even when I was green, green, green--the evidence shows us that what's called reality orientation, which is, was still actually a thing back when I started. It was being phased out, but it's who you can still go places now and see it happening.*

So reality orientation is where you say to someone, "Oh, well, I'm sorry, your husband can't come because he passed away 15 years ago." That's reality orientation. That's orienting somebody back to reality. The problem with that approach is twofold. Number one, you're saying something to a person whose brain is under attack. If somebody was married for a few decades to somebody and they don't recall that they're deceased, that should tell you everything you need to know about what's happening in their brain. Right? That's not something you randomly forget when nothing's happening in your brain. Number two, I think it's just damn mean.

Phil: Right.

Christy: *I can hardly think of a meaner thing to do to someone. And so the question I like to ask, and I encourage other people to ask, is, What is the kindest, most loving thing you can do in this moment? And I think this works, whether your objection to lying is moral or religion-based or what have you, because I don't think that--I would certainly hope that--no religion would tell you it's a good idea to do something unkind to a person with a neurodegenerative disorder. That's not*

moral. So, if someone has a condition that is attacking their brain, they can't recall information, there are some other approaches you can use. So Mom's asking, you know, "Where's Dad? When's he coming?" You can say something like, "Well, let's see... what time is it? It is about 10 til 2. So he, that's usually, those are working hours, right?" "Oh yeah, that's right." "Yeah. Okay. So, Mom, I brought you some fresh tomatoes from the garden. I think they're, they're really good. Should we slice some up and see how they taste?"

So you can do that. You can acknowledge. There was no direct lie there. That's one way. The other thing is when you kind of skip past a question and move to--you know, when Mom says, "Where's your dad? When's he coming?" And you say, "Look, I brought you tomatoes"? That's kind of putting Dad and the emotion around that on par with a tomato, which, clearly, they're not equal, right? The more that we skip over somebody who's emotional needs, the likelier they are to keep coming back to them, because the need isn't being met.

And then another way to handle it is to say--again, right out of the gate, not waiting for a longer period of time--but to say, "Oh, I know he loves you very much, and he'll be here as soon as he can." Or, "Let's see, five o'clock is when he's off work. So I bet it's going to be after dinner," or something like that. People--and we've talked about this before, Phil--people need to be seen and heard and acknowledged as humans. And reassured sometimes. So I personally don't have any worries whatsoever about my eternal soul, based on reassuring somebody living with Alzheimer's or a similar condition that they're loved and that somebody they love is going to be with them soon.

Phil: I really liked your first answer, which was, "Oh, what time is it?" and then, "It's the middle of the workday," and then just kind of leave that be.

Christy: *Mm hmm.*

Phil: It's not a lie and it does recognize need to get an answer.

Christy: *Right. Another thing too, a lot of times when people will ask about somebody who's deceased, it's because they're thinking about them, they're missing them. Another way to handle that, "When's your dad going to be here?" "Oh, you*

know, I've been thinking about Dad too. I miss him so much. I'm thinking about that time that we all went to Arroyo Grande and we had such a good time. I thought the beach part was great. What was your favorite part?"

Phil: Mm hmm.

Christy: *Or you know, just telling some type of memory, or looking at some pictures or something like that. And often that satisfies a need also. Or, "What's your favorite funny thing that Dad says?" Just acknowledging the topic but going in a different direction with it.*

Phil: Right. And you know, your bottom line is don't make the person feel badly.

Christy: *Right!*

Phil: Make them feel good. And that's, it seems to be such a good idea.

Christy: *Yeah.*

Phil: There's no reason, as you said, to say, "Oh, don't you remember?" Uh, no, I don't remember that. Thanks for reminding me. I mean, you know, if the person could say that, that's probably what they would say.

Christy: *Right, right.*

Phil: They don't need to know that. They really don't need to know that.

Christy: *Exactly. And when it's somebody, let's say it is a loved one who's passed and they're asking about that person. To then come back and say, "Well, they died," is to retraumatize the person. Because for them, they're hearing this information for the first time. I actually saw this happen, unfortunately, where a woman had been super, super excited that her son and daughter-in-law were coming to visit her from a couple of states away. And she sat out front all day waiting for them and didn't want to go any place because she wanted to make sure she saw them. And so she was so excited, she actually started bouncing in her chair when she saw them. And they came in and she threw her arms wide and, "Hey Mom, how's it going?"*

"Oh, it's so good to see you!" And they said, "Well, what are you up to?" And she said, "Oh, I've been waiting for my parents to come pick me up!" It was clear, if you witnessed the interaction, in the context of it, she recognized them. She was excited to see them. She had been waiting for them. And the daughter-in-law said, "Your parents? Your parents have been dead for over 20 years!" So first of all, that was a snarky thing to say.

Phil: Right.

Christy: *Then the daughter-in-law, I feel like, kind of pushed her into that reality then. At first she had misspoken or maybe [was] mixed up, but she was clearly excited and happy that they were there. The daughter-in-law switches the focus to, Your parents are dead. So the lady immediately bursts into tears, "Oh, what's going to happen to me?"*

Phil: Right.

Christy: *That didn't need to happen. You know, that initial reaction, those first 10 seconds, those were so positive. For me, and I'll grant you, I have some, some practice--but I just always think whatever the thing is that I can do that is going to make this moment better for this person I'm interacting with, that's the thing I want to do.*

And that's our show. Thank you so very much for listening. You can find links and other goodies in the show notes at DementiaSherpa.com/episode102.