

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 107: Are We Making a Difference?](#)

Phil: Care partners are in a no-win situation.

Christy: *Okay, folks, you heard it straight from Phil Gutis's mouth.*

Phil: No win. There's no win in this battle.

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.

Phil: Do you--you don't tend to work with folks early on in the disease process. But this, this feeling of the diagnosis is wrong.

Christy: *Well, I've certainly heard that.*

Phil: That one is odd. I mean, I continue translating at one point from feeling so good that I feel like the diagnosis is wrong, to feeling so not with it that I'm not aware that the diagnosis is right. If that makes--you know, that there's a, there's a point

on the, on the scale where it's not 'cause I feel good. It's actually 'cause I feel bad that I'm not aware of the diagnosis.

Christy: When people are at a point and they're saying they don't have that diagnosis, or they hear about somebody else who has a diagnosis or maybe they live in an assisted living or a memory care and, you know, they ask another resident or staff, like, "What's going on with that person?" [and hear] "Oh, they have Alzheimer's," [people say] "Oh, that's terrible."

So, it's not that people are feeling bad necessarily, it's more that there has been disease progression and they have either forgotten that they have that diagnosis or they now have anosognosia--hey, I finally pronounced that right! They have anosognosia and their brain is telling them that they're okay. And so it's not any type of distress. It's not feeling bad, but it is progression.

The distress, or the feeling bad part, comes when others--for reasons that always surpass my understanding--feel that it is extraordinarily important for the person with the diagnosis to know they have the diagnosis.

And I always wonder, What is the benefit of making sure that a person who has either forgotten or has anosognosia and does not understand at all that they have a diagnosis-- their brain is telling them they're fine--what is important? What changes, what is different? What is the benefit of that person knowing they have the diagnosis? And I've never heard an answer that I find plausible or understandable.

Phil: Right. Because they're at the stage where they're gonna deny it anyway. What is the value that you're getting by insisting on telling them that over and over and over again?

Christy: Yeah!

Phil: They don't remember.

Christy: *And I think we've talked about this before. I think it's a leap in our logic. And when I say "our," I mean family or professional care partners who, we're making that Grand Canyon-size leap in our logic, thinking that if we use the word Alzheimer's or dementia or Lewy bodies or frontotemporal degeneration, whatever it is, that if we use that specific word, then that will connote something to the person with the diagnosis and then it's going to be like a flood of memory, or a flood understanding, and it is going to change something.*

And I think when people say it, when they're very insistent that the person needs to know the diagnosis, it's not that they expect that is going to restore memory, in the sense of the diagnosis would be inaccurate. But more like it is going to cause comprehension of what that particular diagnosis means and that comprehension is going to solve some other problem. Like, "You can't drive." Or, "You need to live in this specialized place." I think that's what's behind it.

Phil: Right. I mean, "If only they understood. If only my person could understand that there's something wrong, and I'm trying to help them."

Christy: *Yeah!*

Phil: Not just penalizing them.

Christy: *I think that's it, Phil. I think you just hit it right there. "If they would understand that I'm trying to help. I'm not trying to be mean." I think that's it. I think you nailed that. So, it really does come down to a very human thing, which is we all want to be liked.*

Phil: Right.

Christy: *And it is excruciatingly painful when you love, that you've had a relationship with for decades, believes you are trying to harm them, that you don't love them. Or when they just are very angry with you. It's painful.*

Phil: When they're just very angry. Right. Right.

Christy: Yeah.

Phil: It's understandable that they're angry, you know? You could absolve them for being angry. But yeah, I mean, nobody likes, I mean, most people don't like hearing no and most people don't like saying no.

Christy: Yes.

Phil: You know, I think most of us want to say 'yes.'

Christy: Yes.

Phil: It's a real challenge for somebody when you have to start saying no. And you know, we've talked about--I think our first episode, we talked about, well, one of the first--we talked about when is it too much? When is trying to be helpful too much? And I said it was an impossible line to figure out. Some days, anything is too much, 'cause I feel good. Other days, I don't feel good and I need Tim to be very aware that I'm not feeling good and to offer a lot more support than I would typically want or need.

Christy: Mm hmm.

Phil: Key is want. Keyword is want.

Christy: Right.

Phil: Ah, give in.

Christy: Give in?

Phil: There's the give in statement, or the fact statement: care partners are in a no-win situation.

Christy: Okay, folks, you heard it straight from Phil Gutis's mouth.

Phil: No win. There's no win in this battle. I mean, just like it is a no-win for the person. You know, it sucks every which way around.

Promo: Hey, care partners, this is Christy Turner, your Dementia Sherpa. If you've been feeling the same as Phil--like "it sucks every which way around," it's important you know there are resources available to help you.

Both the Alzheimer's Association and The Association for Frontotemporal Degeneration have 24/7 helplines staffed by real, live humans! And I'm pleased to offer you a complimentary Dementia Caregiver Strategy call with me.

Dementia can last for up to 20 years or more. That's a long time to fly by the seat of your pants, struggling through trial and error! If you're ready to step into the life you and your loved one deserve, go to DementiaSherpa.com/podcast and click on GET SHOW NOTES under the player. You'll find links to the Alzheimer's Association, The Association for Frontotemporal Degeneration, the Lewy Body Dementia Association, and to schedule your complimentary Dementia Caregiver Strategy call with me.

Again, that's DementiaSherpa.com/podcast, then click on GET SHOW NOTES under the player.

Christy: I've been thinking about this more and more and more, recently. Especially as you've been wondering about that question--and we've talked about it, not on the show, but we've talked about it in other times, via email and text and conversations that we don't publish--but, your question has been, "What is the point of telling our stories? Why are we doing this? Why are we sharing all of this?"

And I know you're talking very specifically about sharing your story and your experiences and your diagnosis. And what your life has been like just prior to that and through that process.

And my question, for me, about why do we do, you know, why do we do this? Why do we share this? Why do we share these experiences? That comes up for me when people just say, "You know, this is a really awful, horrific disease."

And I mean, they talk about all of the really bad things and it's a no-win situation and that's when I really start questioning, Why am I doing what I do? Because I'm trying to put out a positive message, and, Here are things you can do to make a situation better. And I think the general public and the general perception of the whole thing--and when I say the whole thing, I mean any type of neurodegenerative disorder--is that really, you know, I'm, I guess a Pollyanna. And there's no silver lining, there's no upside. So that's where I feel like, Well, I'm really shouting in the wind here. Because it is a message that people essentially do not want to hear. Or are not open to. Or believe is just flat out untrue.

Phil: Meaning what? That we shouldn't be telling these stories? Or...? I lost your train of thought there.

Christy: Yeah, I think that the general perception about neurodegenerative disorders is that it's awful. And that it's awful to love someone who has one. It's awful to be someone who has one, obviously. And that's that.

And so my message of, Here are things you can do to make it better, or, Here are ways that you can turn a negative into a positive is generally not received. Because people take it as Pollyanna-ish or untrue or pie in the sky or whatever, however you want to put it. It's just generally not received. And that's where, on my part of it--when you say, Why are we sharing these stories? you're coming at it

from a different angle. And when I hear that question, that's what I come to is, Yeah, that's a great question. Why am I doing this?

Phil: I can answer your part of it: it does make a difference.

Christy: *That's funny, 'cause I feel like the same. I can say I can answer your question easily. But go ahead and tell me more.*

Phil: I stumbled upon some videos from, I guess it was UCLA, I think, about how to handle some various situations correctly. And they did a--obviously they were actors, so they did a "Here's how NOT to handle the situation" and "Here's how to handle the situation."

And the "how not to handle situations" was so over the top! It was kinda like, *Duh!* But at the same point, I'm thinking, *Yeah, that's probably the way some people handle these situations.* And the way that they suggest to do handle those situations were very much Christy-like and they were correct. And then, it was, it made me think, once again, how important it is for you to be able to get out there and help people deal with these unwinnable situations and make them better. Even though it's never going to be great, you can make them better. And I think that's [an] incredibly important message. Now, why do you think it's important I tell my story?

Christy: *I think it's so important that you tell your story and that, you know, Jeff [Borghoff] and Pam [Montana], and anybody who has the insight and the knowledge that they have with a condition or a diagnosis. It is so important because people like me are constantly learning from the people that we get to work with, that we have the privilege of serving.*

And in my particular case, I feel like when I spend time with people living with a neurodegenerative disorder, I feel like they understand on a visceral level that I get them. In a way that is just like, "I like you for who you are right now. I accept you for who you are right now." I don't bring grief to the situation. I'm not bringing this undertone of "Why can't you be how you used to be?" I'm just with you, right now.

And then my job after that is to go explain to the family or professional care partners, "This is going to be a really better way of interacting," or, "This is going to be a thing you can do to make it better for your person," or, "This is a thing you can do that is going to help you feel like you've got, you know, the energy and the strength to do what you need to do to make life better for your person."

So almost like a, I don't know, like a translator, maybe? I think that's not exactly the right word, but I think because you have the ability to share with us what you're feeling, what you're experiencing, where you find challenges, or saying things like, you know, "I feel great. I kind of have to think about this diagnosis. Intellectually, I understand the evidence behind the diagnosis, but that's not how I feel. And how I feel a lot is like, is this diagnosis actually true? Because it's not consistent with how I feel."

You know, things like that are so important, and so the more that people do share their stories, people with the diagnosis, do share their stories and how they feel, and what their experience is, the more it allows both families and professionals to respond in a better way. In a more effective way, in a more loving and kind way.

Take a look at public policy and to question things that fall into the category of "We do it this way because we've always done it this way," to instead say things like, or to look at things, like, "Why isn't there a transition program for people who get a young onset diagnosis and are still working, still have a job? Why isn't there a transition program for that, from working to suddenly not working with, you know, an unplanned retirement?"

Things like that. Things that people just typically, for whatever reason, don't give a lot of thought to. And just in a broad generalization about anything, coming completely out of this neurodegenerative disorder world, nobody thinks about a lot of things until they are pointed out.

Like, "Oh, I didn't know that that was a problem. I didn't know that that was an issue, until I started seeing more stories about it. Or I started hearing more about it. I just didn't know." Because people can't know what they don't know. And so when things are brought up to the surface, when they're brought to the light, then that gives everybody the opportunity to do something about it. That's why you talking is so important.

Phil: Right. And then the question that comes to my mind, and I'm sure in your mind too: Who's listening?

Christy: *Right. Right.*

Phil: And you know, are we making a difference? You know, these things don't always make huge intellectual sense. Especially in my mind. When we were talking about this the other day and I was saying I was struggling with it. And I said, "Oh yeah, I got it now."

The light bulb, the moment that went off, was that I've always felt that I wasn't making as much of a difference as I needed to or should be, or--you know, when I was a reporter at *The [New York] Times*, I got angry at some politicians and said, you know, "I can't be a reporter if I'm going to be unbiased. Instead, I need to go off and be an advocate."

Looking back on it now, yeah, I'm sure reporters get angry all the time. And I guess the question is, how do you deal with that anger? And I didn't need to say I can't be a reporter anymore. I just needed to channel it and find a way to work within ethical boundaries but to highlight things, highlight why change was needed, blah, blah, blah, blah.

When I was at the ACLU, I always felt like, *What difference is this making? What difference is a well-written press release making versus a poorly drafted press release?* Or, you know, when you're out there doing legislative action with a field budget of, I don't know, \$100,000? For the *country*. What kind of difference can that make?

And you know, so there's always been the struggle that I have needed to push past, of, *How is what I am doing making a difference? How can I make a bigger, how can I make a bigger difference?* And you know, I said I got it. But I have yet to put words to screen, and I still need to do that. But I think that's the unifying piece.

Christy: *I think that's right. For people like you, who, whatever the job title may be, the bottom line is you're an advocate.*

Phil: Right.

Christy: *Right. And I think maybe the same is true of me. And I certainly have been in many, many situations where I know I've gotten raised eyebrows--at the least--because when it shakes out, I always land on the side of the person with the neurodegenerative disorder. Always. 100% of the time.*

Christy: *I mean, I definitely want to help care partners, family or professionals; of course I do. And I have a heart for them. And I identify with both of those groups of people because I'm part of both of those groups of people. But I always land firmly on the side of the person with the diagnosis. And am advocating for them and their point of view to the best of my ability.*

And so I think, you know--my theory, I guess, on the fly as we're talking about it--is for people who have that, that advocacy heart, I wonder if it ever really feels like enough. I mean, I remember, oh gosh, I had been doing this for about five years-- and so this was quite some time ago--and I had looked at files that had old census reports and whatnot. And so I was looking at all the people that I had worked with over you know, like five years.

There are some people that I, you know, the family had said something kind to me or appreciative to me or there was a moment I could recall, you know, with that person where I felt like I did make a difference, at least in that moment. And then there were just so many other people where I felt like I, I didn't help at all. I didn't do anything positive.

And I had said something to my sister about this, like, you know, "There are just so many people that I've interacted with in these last five years and I just didn't do enough." And, you know, this is what sisters are for, right. She said, "Calm down, Schindler. You're doing as much as you can."

The larger point being, it requires maybe a shift in perception. So, is it enough if I make a difference in one person's life? Or is it, does that not count? Does it have to be a hundred people or a thousand people or 10,000 or a million? Or--do you know what I mean?

Phil: *Yep, yep. If you've touched one person, you've touched one person and made a difference in their life. That's probably more than most people could say. And yet, we both want to do more. We want to do more, we want to do more. And, you know, I think that's the frustration, that no matter how much you shout into the wind, you know--well, it's two things. No matter how much you shout into the*

wind, no one's going to hear you unless they are [inaudible] to hear you and prepared to hear you.

Christy: Right.

Phil: And suddenly interested in hearing what you have to say, which probably means they got a diagnosis or somebody they love got a diagnosis. And it's repetition, repetition, repetition, too, right.

I mean, you know, that's why you see an ad so many times on television. It's not because the company likes throwing its money into advertising. They know through scientific testing and study that we don't even hear an ad or know we've seen that ad til we've seen it 20 times.

Christy: Right.

Phil: It doesn't even break through our minds. And you know, that's mind-boggling. How are we ever going to make a difference? I mean, yeah I know I'm making a difference, but oh, my God, how many times do I have to say this stuff, you know, before it reaches somebody?

Christy: Right!

Phil: You know, there is no answer. I mean, there's never--I guess you just have, for my case, I just have to keep talking. Until I can't. And I've said several times that I speak out for those who can no longer speak. And I think that's something that I have to remember, a lot too. That I'm doing this for the people who can't tell their stories anymore. And it's important.

Christy: It is. And I'm thinking of, again, this would have been, well about the time I was looking at, How many people have I actually helped? What good have I actually done? I had to make a decision at some point--and it was around that same time: what's the important thing here? And so, is it enough that I made one moment

better? I guess it's kind of like doing the dishes or cleaning your house. You know, Well, what's the point? Because I just end up with dirty dishes again, or, What's the point? I just end up with dust bunnies again. Well, some things just require repetition, I guess. It is what it is.

I don't know. I feel like I'm way out here on an existential branch and then I start thinking of course, the people who hear the message have to be ready to hear the message and are we on the same vibration? And you know, some things are going to resonate with people and other things aren't.

I think one of my big fears, always, is I think, Oh my gosh, I'm saying the same thing over and over and over again. And I'm afraid there's going to be like an angry mob going, "SHUT UP! You've said it a billion times. Shut up. What makes you think that people still want to hear this?"

The reality side of that is, unfortunately, every 30 seconds or so, more people are getting a diagnosis. It's every 32 seconds developing Alzheimer's; that's not counting any other neurodegenerative disorders. So, there unfortunately are always new people coming into our universe who need to hear what you have to say.

Phil: Absolutely. And you know, people aren't going to hear us until they need to hear us.

Christy: *Right.*

Phil: And in most cases, we're all very self-focused, because we're struggling to survive. We're self-focused. Is that the right word?

Christy: *I think that's a very nice way of saying it, yes.*

Phil: I can't think of the mean way, so that's good. So it is important we just keep saying this stuff over, because somebody's going to hear it when it's time for them to need to hear it.

Christy: *Okay. Well, I'm going to let that be the definitive word on this discussion.*

Phil: We went all over the place again, didn't we?

Christy: *We did. We did.*

Phil: I think it was good.

Christy: *Yeah, I think so. I mean, at the very least, I feel like it was therapeutic for me. Thank you.*

Phil: Yeah, me too.

Christy: *And that's our show. Thank you so very much for listening. Hook up with the resources in the show notes by going to DementiaSherpa.com/episode107.*

You've been listening to The Alzheimer's Podcast with Christy Turner, wishing you a blessed and easy week ahead. Be sure to check out the show notes and subscribe by going to DementiaSherpa.com/podcast.