

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
Episode 099: Anosognosia & The Bliss of Ignorance

Phil: And you know, you hear these, you know, hard to hear stories about what it's like for somebody living in the later stages of Alzheimer's. And you know, *that's* what I wish I just didn't have to know.

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 welcome. Phil Gutis, our Assistant Sherpa, is with us again today. We're talking about The Longest Day, which is just around the corner (on June 21st!), as well as answering a listener question about anosognosia. So stay tuned!

So, I have a whole list of stuff [to talk about]. Oh my gosh! How you doin', Phil? Let's start there.

Phil: How'm I doin'?

Christy: *Yeah.*

Phil: Well, unlike usually, we're talking at the end of the day, and I've been on the phone all day, so...

Christy: *Oh, wow!*

Phil: So, at some point, I might start babbling.
Christy: Okay. Then we'll know it's time to end. You're done.

Phil: Right, exactly. Phil has reached the end!

Christy: Okay. So, I have a whole list of stuff. So, we have a viewer email. A viewer? Nope. Phil and I don't do video. We do audio, thank you. 'Cause Phil likes to keep his shirt off when you're recording. Is that true?

Phil: I'm wearing a shirt today.

Christy: You're wearing a shirt today! Okay.

Phil: A Longest Day shirt, believe it or not.

Christy: Oh, I do believe it. And *The Longest Day*, we're going to be talking about that, too, because Phil and his husband, Tim, have an event that they're doing for *The Longest Day*. It's called a Row or Owe [Note: Actually, it's called [Row2Remember](#), although I call it by the wrong name throughout the episode.-CT], which I think is the most clever name ever. So, Phil, why don't you go ahead and tell us about that while I'm thinking of it and it's top of mind.

Phil: Sure. We are holding a little rowing marathon at Oar Studio in Lambertville, New Jersey, which is right across the river from where we live. And we've agreed that, if we can raise \$25,000 for this little adventure that we will, as a collective, row one million meters that day. And that's a lot of meters. So, we're saying to people, you can come and row with us, or you can choose not to row and you could owe and help us get to the level we needed to commit to those million meters. We also have interim levels. If we raise \$5,000, we'll do 100,000 meters, and then it goes \$10,000, \$15,000 then to \$25,000, I think is the way we set it up. I don't recall.

But last year, we did a big party at the mill where I used to work. We called it the Purple Party, and it was very successful. We raised over \$10,000. Sadly, I don't remember it at all. And it was a lot of work. Tim put a lot of work into it. And this year, we decided to do something a little more modest. But even modest things take up, take a lot of effort. I've made a list of 70 some people I need to email. I post every day. So...

Christy: *Yeah, fundraising is a lot of work.*

Phil: *And thank you, Christy, for your donation.*

Christy: *Certainly!*

Phil: *Very, very much appreciated.*

Christy: *Absolutely. So, we appreciate having you on the show and you being so super generous with your time. So, we are going to put a link in the show notes, to Phil and Tim's team, to the Row or Owe event. I have to say, this is one of those things where I was quite happy to owe and to be nowhere near New Jersey, so I can't show up to row. But I thought that was super clever. Name plus folks will get to see Tim's mad graphic design skills because people may not know this, but Tim is a Renaissance man, so he has a dog walking and sitting business, and he also previously had a graphic design business. So he's a talented graphic designer and it's [a really cute flyer](#), so we'll include that in the show notes so everybody can just hit the link and donate there.*

Then, I'm broadcasting from the Portland, Oregon area and in my area--in my, um, what do you call it? Social milieu? Anyway, [we support Krista's Crew](#). And that's in honor of our friend Krista Davis Tonn, who was a big Alzheimer's advocate. She passed away way too young from pancreatic cancer, and so we do Krista's Crew to honor her and to raise money for The Longest Day for the Alzheimer's Association.

Krista was legendary for throwing amazing parties that could wrap a dollar around some worthy cause, especially Alzheimer's. So she was a volunteer for the Alzheimer's Association for years, and co-facilitated a support group. [I'll] also put a link to that in the show notes. For any listeners who are like, Gosh, should I support Phil and Tim? Should I support Krista's Crew? What should I do? Don't worry about it. You can do both! We're happy to take donations on both ends! Or if you're doing something cool for The Longest Day and raising money for your

own team, fantastic! We totally support that, too. But we're giving you lots of opportunities to jump behind the cause.

We're going to now jump over to a listener email. Listener, not viewer. And this is from--I don't know if I can say her name. She didn't tell me. She'll, when she hears the question, she'll know, Oh, they're reading my email. So I'm not reading the whole thing cause some of it is personal, but she says--and I can't make this up, obviously-- "Phil is great. And you guys make a very good podcasting team because you are empathetic and energetic, and Phil is thoughtful and more careful in his word choice." Okay, here's my aside: Thank God Phil is so careful in his word choice because after you hear me go ranr ranr, ranr, ranr, you're like, Phew! Phil is the measured grownup in the room. "Plus, you guys have fun together." We totally do!

Phil: That we do.

Christy: *"I am so grateful to Phil for using his narrative talent to give a view into what it is like to live with Alzheimer's. I was wondering if it is more common for people with early onset to be aware of their condition while those who get Alzheimer's or similar conditions later in life tend to be more likely to have anosognosia. My mom, age 80, seems to have always had anosognosia while Phil is quite aware of his situation. It is a little easier to help someone who is aware of the situation, or so it seems to me. Maybe Phil wishes he had the bliss of ignorance. Maybe you could cover this question in a show. Thank you." What do you say, Phil?*

Phil: I don't know the answer to it's more, whether it's more common or not.

Christy: *Oh, I can answer that one.*

Phil: You can answer that one. But the bliss of ignorance? That is a very, very interesting question. And I think many people would wish for the ignorance, truthfully. This is life-altering, devastating knowledge when you get it, and.... But at the same time, I'm going to now argue against myself because that's what I like to do. And, I've written several times saying that, you know, while receiving the

diagnosis was obviously a blow, it was also in some way a relief because I knew something was wrong. And being able to put a name on that something was somewhat of a relief. Obviously, I wish it wasn't *this* something. I wish it wasn't [an] illness without a treatment or a cure. But it's still, it's good to--ugh, it's not good! I mean, these words are so hard to find because it's not *good* in any way, shape or form. The only thing I can think of is that story that I'm sure I've told, Christy, but you know, that day when we were walking by the local theater, and I turned to Tim and said, "We saw something here recently, didn't we?" and he said yes.

I said, "With my sister and her family?" and he said yes.

I said, "What did we see?"

He looked at me and said, "Guys and Dolls." And I still have no recollection of actually seeing it. I know we went to the theater. I can sort of remember us finding our seats. But once the curtain went up, nothing. Absolutely nothing. And had I not--and then the next morning, I was sitting on the bed and I said to Tim, "It's coming, isn't it?" And he, you know, he said yes. And I cried and I still almost cry every time I talk, think about it and talk about it. But, it was, still, it's a relief to know, to have a term for what is wrong with you. Right? 'Cause there's clearly something wrong with me, and if I were sitting there and saying, "There's something wrong with me, I really don't know what's going on. I think I'm going crazy!" Right? I think I'm going crazy and to know that no, I'm not going crazy, that there is something wrong--like I said, I wish it were something else, but at least I know what it is. And I think that is of some comfort.

Christy: *Right.*

Phil: I think.

Christy: *Yeah, thank you. Well, I'm remembering from some past conversations we've had, Phil, where you've said that you feel like there's been like a memory hole, is the term you used, going back into your 20s.*

Phil: Right.

Christy: *And it was something that you complained about so much that when your sister saw the ad for the Biogen trial, she knew this was something you'd want to be connected with. So in that sense I can understand where having a diagnosis, would be almost a relief. Like, now you have a name for this thing that's happening. And at the same time, I think, obviously, when anybody gets a diagnosis that does not have a cure, the word relief doesn't apply anymore.*

Phil: Although it somewhat does. You know, that's the hard, the strangest thing about Alzheimer's is, or I guess any disease that doesn't have a cure or treatment: it is a relief to know what is wrong, but it is devastating to know what wrong, what's coming. I mean, I think that's the place where you probably want the ignorance, to sort of circle back again. You know, it's great to know that I'm not going crazy. There is something wrong with me. It's really bad to know what that something is and what is coming up. I talked to a woman today, as part of--I'm doing a little bit of writing for this thing called the MemoryWell, 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 you know, she was describing her mother's life and how, you know, she doesn't remember that her husband has passed away and she's always asking about him and, and you know, and you hear these, you know, hard to hear stories about what it's like for somebody living in the later stages of Alzheimer's. And you know, *that's* what I wish I just didn't have to know.

Christy: *Okay. So going back to the first part of this question, and I'll say it again to remind folks, the first part of the question is, "I was wondering if it is more common for people with early onset Alzheimer's to be aware of their condition, while those who get Alzheimer's or similar conditions later in life tend to be more likely to have anosognosia?" So, first part, for those that don't know, anosognosia--which I always pronounce wrong, and I apologize; I'm putting an emphasis on the wrong syllable, but I can't quite wrap my brain around the right way to say it. So you know, you can look it up on the internet if you want to know [the right pronunciation](#). Anyway, what it means is, a person who has this condition is in a situation where their brain is not perceiving that they have any type of impairment or a lack of insight or what the reality of the situation is.*

So it is not unique to Alzheimer's or other neurodegenerative conditions, but it is something that we certainly see a lot. So for folks with younger onset, the statistic that I've seen most recently is about 30% of folks with younger onset, which is what Phil has. About 30% of those folks have anosognosia. And then 80% of folks

that we typically think of as the, the population that we typically think of, meaning people who are in their late 70s, 80s, 90s who have Alzheimer's or similar have anosognosia. So about 80% of people don't know that they have that condition. And we say, Well, what happens to the other 20%? And what happens there is that people forget that they do have the condition. This is one, to me, one of the big reasons why we want to be really careful. I know some family members can get kind of frustrated when their person isn't aware that they have the condition and will say things to me like, "You know, Christy, if my dad would just admit that he has dementia, everything would be okay.

And actually when we say things like that, we're actually using a shortcut in our own reasoning, our own logic. Because what we're really getting at is, I don't think we would get into any more arguments about him driving if he knew he had dementia. And it's usually in a context like that. My person won't do this thing that they need to do, or, They won't stop doing this thing that isn't safe for them to do. And so if they would just admit--that's the word that's used--that they have this problem, then that would change their response or their behavior about whatever the issue is. And so one problem is that you can't admit something that your brain is telling you everything's okay. That's one problem. Then the other problem is when we say admit, it's really a shortcut to if somebody knew they had that diagnosis, that then their brain would be able to comprehend what all that diagnosis means. And so typically by the time somebody is at a place where their brain is shielding them from this information, they wouldn't be able to fully process or comprehend the magnitude of the information. Does that make sense?

Phil: It does, it does. I love the way you, yeah--I mean, I can certainly see how not admitting that you have the condition and saying, *But I'm fine to drive!* or fine to go walking myself long distances, or whatever it is, could be deeply frustrating for a family member. But it is interesting how it is from their perspective, what they're struggling with, as opposed to what their person is struggling with and simpler for the person too. But yeah, I understand their perspective. How do you get somebody who thinks they're driving just fine to stop driving? It's very challenging, very challenging.

Christy: *Yeah. And that's the funny thing, is that typically it is about driving. And so where this bone of contention comes in is somebody will, say, grab the keys and say, "Okay, I'm outta here!" You know, 'cause there's already been some tension there. Or they're going to say, "I'm going to go to the store."*

We certainly don't want anybody to do anything that would be unsafe for them or the larger community around them. But often when someone is at this place in the condition, grabbing the keys is about as far as they get. Or they grab the keys and open the door and realize, you know, there's a foot of snow out there or they open the door, walk outside with the keys, and, Oh look, a cat just went across the yard and the leaves need to be raked, or whatever it is. So people can become more easily distracted. And then certainly there have been situations where people have had keys in their hand, gotten into the car, and weren't exactly sure what the next thing to do was. So--and I'm not saying that it always plays out like that, but I guess one thing that I always want to make sure that families know is that when someone is so-called not admitting, it's never anything--like, they're not trying to be difficult. They're not in denial, they're doing what all of us do, which is believing what their own brain tells them is true.

Phil: That raises an interesting question in terms of being a caregiver. I mean, instead of fighting over the keys, does it make sense to let the keys sit there, and move the car? So that it's not easily accessible, or that it's more of a challenge? Instead of having initial fight, let it play out a little bit and see; maybe you don't need to have the fight because Mom or Dad will get outside of the house and they won't be able to do anything anyway.

Christy: *Oh, yeah. This is something that I've talked about, what feels like I'm kind of a broken record on this topic and I have a particular client story that I tell a lot around this particular topic, so we can definitely take a deeper dive into that. I know we have on our list to do an upcoming episode all about driving, and so we can dive into that, but you're headed in exactly the right direction, Phil. There's a lot we can do to mitigate a situation before it ends up there [in an argument].*

Phil: Yeah.

Christy: *And that's our show. Thank you so very much for listening. Be sure to check out the show notes by going to DementiaSherpa.com/episode99.*

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.