

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 110: It Just Doesn't Ever Stop](#)

Phil: Umm...it just doesn't ever stop.

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! This episode is part two of the conversation Phil and I start in [episode 109: The Randy Rainbow Debacle](#). That episode gives you the backstory and context to fully appreciate this episode, so if you haven't already, go check out episode 109 first.

As our Phil Phans know, he's a columnist for MemoryWell. In his [most recent column](#), Phil shares more of his thoughts and feelings about the Randy Rainbow-related incident that sparked these two podcast episodes, plus he adds a sort of post script to the story that gave me a great big smile. So, definitely go check out Phil's column on MemoryWell. And as usual, everything is linked up in the show notes for your convenience. Just go over to DementiaSherpa.com/episode110.

Meanwhile, in this episode, Phil says we go "off the rails." I prefer to think of it as a little color commentary. Where else can you tune in to get an insider's thoughts on living with a neurodegenerative disorder, plus catch the host do a weird yet oddly appropriate mash up of Hank Kingsley and Joey Tribbiani--and then have it all tied together with a big purple bow at the end?

Enjoy!

Phil: This is maybe stating the obvious, but on a day like an anniversary of shared experiences, the landmines--or, just reminds you of the landmines, I guess. Because it's so hard to know where to step. I mean, how do you talk about a 15 year relationship when you--or did you just assume that the person doesn't remember anything?

Christy: *The guidance I would give is not necessarily different for an anniversary day than it is for any other day of the year. So, if you're feeling particularly close to your spouse or feeling a burst of love, appreciation, gratitude, then it's always okay to share that. To say, "My heart feels bursting today because I love you so much and I feel so lucky that I'm married to you. I love the way you look at me. I don't think anybody else in the world has a better smile than you do." Whatever it is. So you can talk--*

Phil: You're making me nauseous. Be careful.

Christy: *Well, my point being is, you can focus on how you feel--*

Phil: Right.

Christy: *--rather than going through chronological details.*

Phil: Right. So, so your answer, boiled down, is, "Yes. Assume that there are no memories unless proven otherwise." So if your person says, "Gosh, didn't we have a great time doing xyz?" then you can assume they remember doing xyz. Otherwise, don't go there. Don't, don't bring it up. I mean, I'm being overly simplistic, but I think that's what it boils down to, what you're suggesting.

Christy: *I think it depends on your person because when we talk about the utterly thankless role of care partnering, I think, you know, Tim is the poster boy, right, because you say all the time it is a no win situation for Tim.*

And so you are, I think, very up front about the fact that it tips you over when there is some assumption that you remember something. And now I'm extrapolating here, but I believe the reason it tips you over is because this is kind of a well-documented thing at this point, that you were complaining about what you call holes in your memory well before you were diagnosed.

So, anyone in your orbit having an assumption that you would remember a specific event or detail is, I guess, being super-duper optimistic. So, for you, specifically--which is always the main point, right? We want to look at who our person is, specifically, and not fly with broad generalizations to the extent that we don't have to depend on that--for you, specifically, I would not do anything that has dates related to it, or chronology, or dependence on memory.

I would focus more on feelings.

Phil: Mm hmm.

Christy: *And really living in the now. For other people, I'm thinking right now, I'm looking, I have a picture of them on my desk. So, these were my very first clients when I opened this business a little over eight years ago now. And I love these people dearly. They've both since passed. And in fact, they had a dog when the husband passed and so the dog lives with me now.*

But anyway, for their anniversary--the last one that they celebrated together, or next to last one they celebrated together--I took out their wedding album and you know, did a little cake and all of that and had a celebration with the staff where they lived. And opened their wedding album and looked through pictures with her. I just pointed to a picture, for example, of her in her wedding dress and said, "Wow, that's such a beautiful dress!"

So I made observations about things and then by the time we were through the wedding album, which was probably about 20 minutes later, she told me, "I made that dress."

I wasn't trying to lead her there. She was just enjoying looking at wedding pictures. And I could see some stuff was coming back, but I wasn't trying to push her into that. Does that make sense?

Phil: It does.

Christy: *Yeah. So, it really depends on each person and her husband, you know, he was sitting there too on the other side of her and holding her hand, and he was enjoying looking at the pictures again too. He just really wasn't saying much. Always just look at who the person is and kind of take it from there.*

Phil: It's really the mirror view, if I'm saying it right. Of sort of the person living with the disease and everybody else who's interacting with that person is a, the reflection that you're seeing, or not seeing, and how to deal with that.

Christy: *Mm hmm.*

Sponsor: Hey, care partners, just a reminder: you don't have to go through this by yourself. If you don't have a strategy, if you're looking for answers to questions like this, please visit DementiaSherpa.com. Right there on the home page, you can get your complimentary communication guide. If you've already done that, you're a part of the tribe, but you're not sure what the next step is, please book your complimentary [Dementia Caregiver Strategy Call](https://DementiaSherpa.com/Episode110). Just go to the show notes at DementiaSherpa.com/Episode110. Scroll toward the bottom of the page and you'll see the button where you can book your complimentary [Dementia Caregiver Strategy Call](https://DementiaSherpa.com/Episode110).

Phil: Just part of the complexities of this disease, I guess, right? You know, in some ways, so much more difficult than well, most, any other challenge out there. I mean, cancer is terrible and, but there's no loss of shared experience. There's no loss of xyz, but to lose your mind slowly....

The friend I ran into last night [Note: In episode 109, Phil recalls he ran into his friend Michael and told him he'd recently seen a picture of them together at a Randy Rainbow concert. Phil told Michael he couldn't recall the experience, even after seeing the picture. Michael teared up. -CT] called Tim this morning and said, "Did Phil tell you what happened last night?"

Tim's like, "Yeah," and the guy said to Tim, "You know, it's just such--you know Phil has been diagnosed with Alzheimer's, but day-to-day, you don't see it. And when you know, you hear a story like that or you see something like that, it just becomes so real."

Christy: *Mm hmm.*

Phil: That's why he was explaining why he teared up and then, I guess that's why I teared up too, again. I mean it's, you know, very much like [the story that I wrote about in The \[New York\] Times](#), you know, not remembering the play that we had gone to see at the Bucks County Playhouse. Sitting there the next morning and saying to Tim, "It's coming, isn't it?"

And him saying, "Yes, it is." It just doesn't ever stop. I mean, I guess, I don't know, like at some point I guess it will stop being surprising, but right now, it doesn't stop being surprising. What did you call it? A, ag? I was trying to about this. Since I'm trying to write about this, I was looking up at the show we talked to, starts with an a?

Christy: *Are you talking about anosognosia?*

Phil: Yeah, that one.

Christy: *Yeah.*

Phil: Which I still don't quite get, but I look it up and I go, *Oh, un huh, un huh, un huh*, and then....Knowing what you don't know? Or *not* knowing what you don't know?

Christy: *Not knowing. It's the brain really actively partitioning. To me, there seems to be a parallel to trauma. And I mean, in my understanding of it; I don't mean that there's anything medically that backs up my theory of the case, so no one misunderstand.*

For any new listeners, anosognosia is a condition in which a person has some type of medical condition that creates limitations for them. And the person's brain is telling them they're fine. What it's communicating is that it is completely unaware of any type of limitation. And this [anosognosia] is not specific to people with Alzheimer's or other types of neurodegenerative disorders, but it is pretty common.

In the case of, let's say, somebody with a diagnosis of Alzheimer's who is, let's say, maybe six years into the disease process, they would be completely unaware that they have Alzheimer's disease. So, saying to them, "You have a diagnosis of Alzheimer's disease," changes nothing.

But more important, from a practical standpoint, it screws you as the care partner, when you try to press a point with someone whose own brain is telling them, That is not true! And so it makes the person with the diagnosis look at you, as the care partner, as somebody who is untrustworthy, who is lying to them, who cannot be relied on, who cannot be depended on.

And so, as a care partner, you can see where you do not want any of those labels attached to you because that dramatically decreases your ability to be of assistance, to be of service, to be helpful to your person.

With people with neurodegenerative disorders, about 80% have anosognosia at some point in the process. And we don't know exactly when that might happen. For the other 20% who don't have anosognosia, who are--like you, Phil--able to say, "I have this diagnosis," that other 20% ultimately forgets that they have the diagnosis.

So, either way, it is not helpful to tell somebody they have the diagnosis if they are unaware that they have the diagnosis.

About 30% of people with young onset have anosognosia. So most people with the diagnosis of young onset Alzheimer's disease are like you, in that they are aware of their diagnosis and able to talk about it.

Phil: And aware of what they are forgetting.

Christy: *Not of what they're forgetting, but aware that they do have holes in their memory. So because if we could recall what we forget...that's kind of circular.*

Phil: Right, right, right, right.

Christy: *But yes, having an awareness, like you do, that there is a gap there.*

Phil: Mm hmm, that there's a problem.

Christy: *Yeah.*

Phil: I can't remember if we talked about this or not, but, my most recent MRI for [the Biogen \[study\]](#), the last MRI came back with a mild cardiac--mild cardiac? Mixing up my diseases. Mild cognitive impairment. Well, it said mild cognitive impairment, with amnesic mild cognitive impairment. Or something like that. So, mild cognitive impairment with memory loss. And it was the first time I'd seen that word described, or that word attached to it. And it made ultimate sense because--

Christy: *Do you mean the MCI?*

Phil: No, the amnesic part.

Christy: *Oh, okay.*

Phil: But I had never seen the--my doctor has told me that I am mild co--you know, I'm at the stage of mild cognitive impairment and I understand. I get that; I get that completely. But I've never seen the memory loss attached to the mild cognitive impairment.

Christy: *Memory loss, or amnesia?*

Phil: Amnesia. Well, isn't amnesia memory loss?

Christy: *Um, well I guess the distinction in my mind is when I think of amnesia, I think of somebody's memory kind of completely wiped out. Whereas, if I have memory loss around a certain thing, somebody might be able to cue me to remember.*

Phil: Mmm, not with me. Well, yeah, sometimes it does happen that way, yes.

Christy: *No, I'm talking about me. Yeah. So I don't know. I mean, those are the distinctions I make in my mind. But I think, yeah, you're right. Talking about it out loud now, and when we're talking about memory loss in the world of neurocognitive, or neurodegeneration, typically we are expecting that memory loss is permanent.*

Phil: Right. Yeah. You just stumbled on something which is interesting. There are times when if prodded, I do remember.

Christy: *Please say cued rather than prodded. Please, please listeners, please don't prod someone.*

Phil: Okay.

Christy: *Cueing is different.*

Phil: Oh, yeah. I always say that. You know, whenever I go to for these studies and things like that, you get poked and prodded.

Christy: *Well, that's true for you. 'Cause they do, they take your blood and the whole enchilada. Yeah.*

Phil: They prod your memory too, right? I mean, you know, part of the memory test was Tim had to be there to tell these folks things that we had done.

Christy: *Right.*

Phil: To see if I remembered them. And you know, at first when she said, you know, very generic, pro--prods? Yeah. They're memory prods.

Christy: *Cues.*

Phil: Cues. Okay. Teaching Phil a new word.

Christy: *See, I'm from a ranching family, though, Phil. So when you say prod, I automatically hear the silent 'cattle' in front of that. So I'm picturing poor Phil in an MRI tube with a cattle prod coming at him, like, "You will remember!" Like, No, no, no!*

Phil: Okay. When they're *cueing* me, try to remind, or offering me some cues, and I don't remember at first and then they get a little more descriptive, and then I *do* remember, versus this kind of absolute emptiness. Like nothing happened. I mean, they're very different, in my mind. I mean, maybe if--and you know, it may just be a stage, right? I mean, had I not been reminded....

So we went to see *Mamma Mia!*, the show *Mamma Mia!*, and that's what she was trying to get me to remember. She started off by saying, you know, "You and Tim did something special a couple weeks ago. Do you remember what it was?"

And at first I didn't hone in on that. I said, "Well, I guess we went to the movies, dah, dah, dah, dah, dah." And I don't remember how she got me to remember that we had seen the show, but once she did, it all came rushing back.

I wonder, had that not happened and that memory hadn't been sort of brought to the forefront, if it would have ended up being absolutely erased. You know, like *Guys and Dolls*, like Randy Rainbow. Who knows, right? You know, I mean, I guess if we were neuroscientists, we might know, but we're not.

Christy: *That's true.*

Phil: And if we were neuroscientists, we may not know.

Christy: *That's also true.*

Phil: But they admit they don't know. And how new a field it is. I was just reading something this morning. Temple University, where my sister went to school, sent them a magazine, you know, one of those alumni magazines and there's a big piece about Alzheimer's and the research that's going on down there, and they noted how new a field neuroscience is, and just how little they know about the brain, still.

Christy: *Yeah. It is still, I think, largely a mystery. For as much as we do know about it, there's just infinitely more that we don't.*

Phil: Yup. Yup. To infinity and beyond.

Sponsor: If you're like most family care partners, you know you could some help with your person...but you're kind of nervous about the quality of help out there. Like, what if you hired someone and they didn't know there's a subtle yet significant difference between prodding and cueing?

Good news: the professional CAREgivers at Home Instead Senior Care-[East Portland](#) and [Clackamas County](#) absolutely know the difference, and a whole lot

more. I've known the folks over there for 8 years now, and I can't say enough good things about them.

I love them because the people who work there genuinely care about the clients they serve and they have a terrific dementia training program that was developed by David Troxel, a total rock star in dementia world.

What I love even more is that the Home Instead-[East Portland](#) and [Clackamas County](#) offices don't just say they specialize in dementia, they actually *do*. They take training their CAREgivers very seriously.

I don't recommend any product or service I wouldn't trust with my own family and Home Instead Senior Care-[East Portland](#) and [Clackamas County](#) definitely get my seal of approval.

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Christy: I want to circle back to the fact that it is your anniversary today.

Phil: Yes.

Christy: *And ask, what are you planning on doing to make it special for Tim?*

Phil: I bought him electric or battery operated salt and pepper grinders. What are we going to do? I don't know what we're going to do.

Christy: *My question was how are you going to make it special for Tim? I think this really goes back to the importance of knowing your person. So you are comfortable in the zone of funny, witty, and not wearing your heart on your sleeve. That's not your starting point. This is where knowing your person is so important and what resonates with your person because you can have good results, very good results, in interactions with people living with a neurodegenerative disorder. But knowing what they're into is a really good place to start.*

Phil: It's interesting. I had this conversation with myself this morning, because I'm being asked by editors and documentarians to write about my relationship. And the emotions, you know; not just the, *Here's what happened when...* but the emotions of it all. And that is incredibly challenging for me.

And I'm not--I'm not that person. You know, I've never been rainbows and sparkling sparklies and all that stuff. My love is a constant. It's not unicorns and rainbows and glitter.

And I feel like often people want it to be, and that's probably because how we're trained through media books and things like that, romance novels and romances and all that stuff, you know, there's always the happily ever after and the blah blah blah blah blah. And you know, life, I find, doesn't necessarily go that way. You know, there may be a happily ever after, but it's not....

Christy: *You are a deep thinker, my friend. 'Cause I'm just thinking some people are more romantic than others.*

Phil: Yeah. Some are more romantic than others, but you know, it's not fireworks in my mind. It's a constant flame, I guess. You know, that's the way I am.

Christy: *That burns steady?*

Phil: Yeah. Yeah, yeah. And I'm not a fireworks person.

Christy: But what about the beginning of a relationship? That's usually when you see fireworks.

Phil: No. I'm not a fireworks--

Christy: No?

Phil: No.

Christy: You're just never fireworks.

Phil: [Deep sigh, or perhaps long-suffering sigh at this line of questioning.]

Christy: Huh. I think even if people typically aren't fireworks people, you know, you, when you are likely to see fireworks is at the beginning of the relationship when those eyeballs lock and you're like, "Well, hey now! How you doing?"

Phil: I mean, there is always the excitement of a new relationship and the possibility of relationship, but there's also fears of new relationships too, right? I mean, every--what is the statistical probability that, you know, this attraction is going to be shared? And this is, you know, every, every step of the way is there's a 50, 50% chance, but--maybe it's not a 50/50 chance--but that it's going to go off the rails.

Christy: You're taking the logic and reason and all of that to the next level! You're looking at mathematical probabilities and possibilities.

Phil: Which is funny because I couldn't walk, I couldn't read through a statistics book, but--and it's never been something I actually understood. Maybe that's why I struggle with it all the time, 'cause I never understand it. But, I mean, maybe I'm a hardcore realist, but that is reality, right? I mean, it's kind of a miracle that people can and do find partners, that that relationship develops into a 15 year shared experience. Because every step of the way, something could go wrong.

Christy: *Yeah, I think it's always a miracle when two people are in the right place at the right time. And there's what I call a soul recognition, like, Ahh, hey, you're my person.*

Phil: Right.

Christy: *Also being ready in that moment to step into the possibilities.*

Phil: Right. Kind of mind-boggling.

Christy: *It is!*

Phil: I guess moments like 15 year anniversaries cause you to think about things like that. I don't know. I guess, you know, from my perspective, I'm going to do what I always do, which is keep the flame at the same...

Christy: *Steady level? Not turning it up; not turning it down.*

Phil: Yes. Not turning it down, I'm not turning it up. But okay, I'll send a firework off. I don't know. I bought salt and paper, pepper shakers. I mean, grinders. Isn't that-- that's a little baby firework. I mean, I was thinking about him. That to me, you

know...Never with the flowers, you know, never with a fancy dinner, and never--that's never been me. And you know, never really wanted it or expected it and never gave it or anything like that.

Christy: *I think what you're saying is you're not a romantic.*

Phil: Yeah, most likely. Although I read romance, I read gay romances, but that's my escapism. So it's like so weird, that dynamic. It's my silly stories, as I call them. So maybe I'm looking for it, even though I'm not it? And I'm, you know, I--who knows! Talking about going off the rails, we have gone so far off the rails!

Christy: *You do so much. You serve our audience so well, in helping people have more insight into what it's like to live with a neurodegenerative diagnosis and what that feels like. And I know people really appreciate it.*

And I also love when we go off the rails in a different direction and we're talking about relationships or romance or whatever because that too helps our audience understand that first and foremost, and always you are Phil Gutis, a person.

Phil: Mm hmm. We're all people. I mean, it's Phil Gutis, and the person that is Phil Gutis and all the complexity, and Tim Weaver, and the person that is Tim Weaver and all the complexities and...

Christy: Yes, exactly.

Phil: And they, you know--that can't never be forgotten.

Christy: *And that's our show. Thank you so very much for listening. Head on over to the show notes at DementiaSherpa.com/Episode110. Visit our sponsor, Home Instead Senior Care-[East Portland](#) and [Clackamas County](#), and be sure to let them know that The Dementia Sherpa sent you.*

