

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 109: The Randy Rainbow Debacle](#)

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He writes back, "Yes." And that's when I started to cry. And just, there's nothing. Absolutely nothing. And it's--he showed me a picture, a bus with our friends and.... I'm going to cry again. It's just.... When I say there's nothing, I just don't, I don't even know how to describe the nothingness.

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.

The good news today for our Phil Phans is Phil Gutis, our Assistant Sherpa, is with us today. The bad news, as you've probably already figured out by starting this episode, is this is a tough one to listen to.

It is a very emotional episode. It was tough for me in the midst of the conversation that we were having. It was really hard to be on the other side of the country because I just wanted to put my arm around Phil. Not that he would've let me, but that was what I wanted to do.

I think the other thing that it's important to know about this episode is we talk through how the situation could have been handled differently and how we could have arrived at maybe some different outcomes in a similar type of situation.

And finally, before we launch into the full episode, I do want to make very clear, again--I don't want there to be any misunderstanding whatsoever--Phil was really generous in sharing this story; in no way is any discussion of what happened meant to shame the other person involved in the story.

This, as you'll hear me say in the episode, it was truly a situation where the other person didn't know what they didn't know, which can happen for any care partner. Which does happen for care partners every day, multiple times a day. And because of Phil's generosity in sharing this story, I hope that our listeners will have an opportunity to think about it and how similar situations with your person in your life can be handled in a way that leads not only to a better outcome, but to both of you feeling good in the moment and afterward.

Phil: So, I had another little incident with memory, the vast memory hole, which left me crying in a restaurant.

Christy: *Oh, gosh. What happened?*

Phil: So you know I'm a Randy Rainbow fan, right?

Christy: *Yes.*

Phil: And last week--last week? Yeah, I guess it was last week, I got a very last-minute invitation to go see him on a panel at *The New York Times*, but I couldn't figure out a way to do it. I just couldn't make it happen. I had pet-sitting responsibilities, blah, blah, blah, blah. So I was telling my friend about this unfortunate circumstance. And we were at breakfast on Sunday and she looked at me and said, "Well, at least you've gotten to see him live."

And I looked at her and I said, "No, I haven't."

And she said, "Yes, you have." And we went back and forth a couple of times like that, like the adults that we are and--

Christy: *Well, for point of clarification, Phil, did her insisting that you had, did that convince you that you had?*

Phil: No.

Christy: *Okay. Was it anywhere near convincing you that you had?*

Phil: Uh, no, it couldn't because I have absolutely no recollection of doing it.

Christy: *Okay.*

Phil: She launched into this whole story about how she had gotten the tickets and had two things go to that day, and sold us the tickets. And there were four of them and Tim and I and two friends went, and dah, dah, dah, dah, dah. And I'm like, "No, it didn't happen. I wouldn't forget that." And then I finally texted Tim and said, "Did we see Randy Rainbow in concert?"

He writes back, "Yes." And that's when I started to cry. And just, there's nothing. Absolutely nothing. And it's--he showed me a picture, a bus with our friends and.... I'm going to cry again. It's just.... When I say there's nothing, I just don't, I don't even know how to describe the nothingness.

I have been, since Sunday, I've been thinking about it almost nonstop, trying to pull something out of my mind that says I was there and there's, it wasn't that long ago. Of course, the Universe, I think, has fun at our expense because I was playing with the, my wallet on the iPhone, which I never look at. And you know, they have a new credit card, so you can get it if you work through your wallet or something. I don't even know how to describe it. But I open my wallet, and what's sitting there but the e-ticket for Randy Rainbow? And I was just like, *Okay, I guess I was there!* It was March 8th.

Christy: *Of this year?*

Phil: It doesn't say. I don't know. It might have been last year. But, and then of course, I run into, completely randomly, the friends we were with [at the Randy Rainbow

show] last night, who I don't run into all the time, sitting at a restaurant and trying to, getting some takeout. And I told this friend, Michael, I said, "You know, I just saw a picture of you," and he looks at me. I said, "Yeah, it's--Tim showed me the picture of us at the Randy Rainbow concert."

He's like, "Why?"

And I'm like, "Cause I don't remember it at all." And he started to tear up. It's, I mean, this man, Randy Rainbow, you know ever since the Trump election, has been kind of a hero. Okay. And to just not have....

To have nothing, not a shred, not an ounce. Not a gram, not a microgram of memory about it. Like, the day--I don't know. I just, I don't even--I'm trying to write about it and I have, I don't have the words to describe the emptiness. And then what that makes you feel like.

'Cause this is, I guess, going to be everything. Right? I mean, this is going to be all my memories. Eventually are just going to be nothing, not there. And that's a very scary proposition.

Christy: I'm so sorry, Phil.

Phil: Yeah, it's, it's...You know, I go through life knowing that I have Alzheimer's, but being, as I say, feeling fine. Maybe a little bit more forgetful, maybe a little less able to do math, but then it just comes and, *WHAM!* Whacks you in the head.

And then, what do you do with that knowledge, right? You know, what do you--in some ways, it's almost, it's almost harder than if it were to creep up on you. Like, you know, I guess traditional Alzheimer's is much more steady, slow and steady kind of forgetting things. But this is just like fine, fine, fine, fine, fine, fine, fine, fine, fine, 500 pound anvil dropped on your head.

Christy: Well, I would point out that I think you were trucking along just fine until someone--quite innocuously, I'm certain--pointed out, like, "Hey, at least you've had the experience!" and then when you said no, that was kind of the decision point there.

And the reason I'm saying this is not in any way to attack your friend that you were having lunch with. But to point out to our listeners that decision point right

there is, is where you as a care partner have the choice of backing off or pressing forward and getting the result that Phil is describing to you right now. Which is he feels really, really bad about this. And wouldn't feel really, really bad about this had the point not been pressed and it been a back and forth.

I think that's just really important for care partners to hear. You may be looking at it as, "Well, I'm factually correct, and it's so important," that this other person--and let's call this other person Phil, what the heck--"that Phil remember or understand or acknowledge that I am right. I am factually correct on this."

And what happens is people cannot come up with information their brain will not let them access. So, you still don't get that acknowledgement of being right, but you do end up with a person feeling awful. And I'm guessing, Phil, that in that moment, your friend felt pretty bad, too, when after you had texted Tim and he said, "Yes, this did actually happen," and saw your reaction to that information.

Phil: Yeah. I'm sure she did. But--

Christy: *'Cause I don't think people do it on purpose. I just don't think they don't know, they don't understand or have the experience in situations like that to know that that's kind of a predictable outcome.*

Phil: Such a kind of... I mean, I don't blame her in any way, shape, or form. Because had she said yes the first time, which, you know, why wouldn't she say, "Oh yeah, you saw him," you know? Then I wouldn't have let it go either. I mean, I would've insisted, "No, I didn't, because how could I have?" So, we stumbled into this by accident.

Christy: *Oh, I definitely see that. But for our care partners who are listening, a better way to handle a situation like this is if your friend said, "Oh, but at least you've had the experience of seeing him live before," and you said, "No, I haven't," the next response back, a better way to handle it, would be like, "Oh, I must be thinking of someone else." Or, "Oh, I thought you had." Like, backing off of the situation.*

Phil: Right, right, right, right, right.

Christy: *Rather than trying to press the point, which doesn't really matter one way or the other. Right? I mean, what if you had said, "Oh yeah, I have"? Even if it had come back to you, I mean, what--honestly, what would that have done? In the grand scheme of things, in that interaction?*

Phil: If I had remembered, ultimately?

Christy: *Well, if she had said, "Well, at least you've seen him live," and then you had said, "Oh yeah, I guess I have"? I mean, you probably, I'm guessing, would still not feel great about the fact you hadn't immediately remembered that. And it probably wouldn't have done a lot for her, either.*

Phil: Yeah. I hear what you're saying, but putting the care partner in the impossible situation, once again.

Christy: *I don't think it is an impossible situation, and to be 100% clear, I am in no way, shape, or form trying to shame your friend at all. She literally had, like, no idea it was going to go this direction and probably no experience in being in a situation like this before. And the reason I'm pointing this out is so that the care partners who are listening to us can learn from this experience without accidentally wandering into it themselves. My larger point is, it doesn't matter, care partners, if you're factually correct or not. That's not the point of an interaction. The point of interactions is we want to spend time with somebody we love and have a good time. That's the point of interactions.*

Phil: So let's play act this out a little bit.

Christy: Okay.

Phil: Here's Phil, sitting at breakfast, going, "Oh, I had this opportunity--it came up really, really late--to go see Randy Rainbow at *The New York Times*, and I just couldn't make it happen." And you know, it was like, "Oh, dammit."

Now should she have, what would her response have been to that? See, I'm in the point where I wouldn't have let it go then, because--

Christy: *That would be your choice, then, which is fine.*

Phil: Be me.

Christy: *Exactly. You, you can do whatever you want. But from a care partner standpoint, there is zero advantage to pressing the point.*

Phil: Yep, I agree.

Christy: *And also, you know, we are talking about humans, right? So number one, mistakes happen. Number two, people are different. So, if I had heard that story, you know how you had described it with the disappointment of not being able to pull that off, I, personally, I am more likely to say something like, "What a bummer! That's too bad it couldn't work out," because that's what I would be thinking about.*

Phil: Even if you had known that I had seen him before?

Christy: *Yeah, because you're not--because you were talking about an awesome opportunity where circumstances prevented you from being able to pull that off. You were talking about the disappointment of it. So, that's what I would have responded to. And it could have been that or anything else. I personally, I'm not someone who says--and I mean, for as much as I can be a positive Pollyanna, I*

don't always look for the silver lining immediately. I'm more apt to validate what I'm hearing first.

Phil: Right.

Christy: *And take it from there, which was, to me, the way I'm hearing you tell this story, is there was a great deal of disappointment. And so that's what I would have responded to. And I think that's probably a good tip for care partners also, is to kind of start training yourself to listen for the emotion behind the words and not focus strictly factually on the information that is being conveyed.*

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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 rock star in dementia world.

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Phil: I mean, I guess had I said something like, “Gosh, it would’ve been so good to see him again,” then you could have, then the care partner or other person, could then obviously assume that I remembered the first time.

Christy: *Right, right.*

Phil: If I had said, you know, “I’m so, so upset that I didn’t get to see him,” maybe having the knowledge that I already once seen him, you don’t need to press that. You don’t need to say, “But don’t you remember?” I guess it comes back to, it ultimately is a, “Don’t you remember?” moment.

Christy: *Yeah. Yeah, I think that’s right, but I’m thinking just kind of next to that, parallel to that, is whether we’re talking about somebody who has a neurodegenerative disorder or not, the fact that you had seen this person before is not the point of your story!*

It’s, “I’m really disappointed I couldn’t make this thing happen.” That was the point of the story. That’s what I heard.

Phil: Yeah.

Christy: *And I don’t--I mean, I guess again, trying to put myself in your shoes, I wouldn’t give a rip if a thing I had done before and enjoyed--like, that wouldn’t make me feel better in that moment, when I’m expressing disappointment. It wouldn’t make me feel better that I had already had the experience--whether I remembered it or not--because that’s not the point of my story. The point of my story is this time, this thing, that it didn’t work out. And that’s disappointing. And that’s the moment I’m in.*

Phil: Yeah.

Christy: *Not like--like, I'm expressing disappointment, and whether you think I'm acting entitled or greedy or whatever, I don't care. I'm disappointed right now. I don't care about previous experiences. I'm talking about something that I was looking forward to that really excited me that I couldn't pull off.*

Phil: Right.

Christy: *I don't know. What, for you, Phil, what would--how would it ideally have gone?*

Phil: I think it was a no-win situation. I mean, because I don't, I don't--blame is the wrong word; fault is even too strong. I mean, I think I would, given the same situation and I'm talking to somebody, I'm talking to a friend without thinking, I would say, "Oh, but you saw him already." Except, you've trained yourself to realize that this is a "Don't you remember?" moment. And "Don't you remember?" moments are never good because chances are you're not, your friend, your partner, your whatever, *doesn't* remember. Or else he would bring, he or she, would bring it up. Like I said, "Oh, I had a chance to see Randy Rainbow again and I couldn't pull it off." That, that's the hint that, *Oh, he remembers seeing Randy Rainbow, so we can talk about it.*

Christy: *Right.*

Phil: But if I just out of the blue say, "Oh, I had a chance to see Randy Rainbow and I couldn't pull it off and I was so disappointed," that's probably a big glaring sign, blinking, saying *Danger! Danger!* And you maybe don't want to go to the "Don't you remember?" because we all know that "Don't you remember?" is not helpful. See, I didn't look at it as a "Don't you remember?" moment until we're talking about it here. And yeah, now that we're talking about it, it was a big "Don't you remember?" moment.

Christy: *Yeah.*

Phil: Yeah.

Christy: *Just another thing that I'd like to point out is yes, I have had more experiences in those types of conversations than probably a lot of people listening to the show right now have. And so I have consciously trained myself to respond in a different way. Although, of course I like to think that I'm empathetic and would have listened for the emotion behind as the point of this story rather than trying to get it factually right. So that might just be myself liking to think good things about myself.*

But the larger thing is, again, this isn't a blaming or shaming situation. This is, you know, the cliched teachable moment.

Phil: Right.

Christy: *And it's just important for care partners to know that, as I frequently say, dementia will give you a billion and a half opportunities to up your game, to be fully present in the moment, to consciously think about how you want to interact in this moment and what the best way to move forward is. And so just taking a beat is always okay. And if you blow it, you blow it. You do what you can then after to fix it, to repair. But getting into that habit of taking a beat before responding is always okay. That's a good thing.*

Phil: Yeah. You know, it's interesting. Tim still the “Don't you remember?” instincts and you know, he'll say it and we look at each other and he goes--

Christy: *Tim is still saying that? I am shocked!*

Phil: It's such a normal--

Christy: Timothy Weaver, come on!

Phil: I don't blame him because it's, I mean, that is--I mean, it's our anniversary today, right?

Christy: Oh, it is? Happy anniversary!

Phil: 15 years, right?

Christy: Wow!

Phil: What are those 15 years but shared memories? It's 15 years of shared memories, and to not be able to say, or to know, that your husband/wife/significant other/love bunny/whatever, doesn't remember those 15 years of shared memories or maybe remembers--maybe remembers the bad moments and not the good ones.

That's, that's--it's a landmine. It's gotta be incredibly difficult for the other person. And you know, here I am going along, doo doo doo doo doo, nothing's wrong; all's right in my world. And you know, because I don't know what I don't know, or I don't know what I have forgotten, and there is poor Tim walking along, doo doo doo doo doo, "Didn't we have a great time at...?"

Christy: Well, that's different than saying, "Don't you remember?"

Phil: You think so?

Christy: I do, I do. Because he can't know what you don't know.

Phil: Right, right.

Christy: *Yeah, that's totally different. That's different than you saying that. So, the "Don't you remember?" would be kind of the next round of that. So if he's like, "Wow, I really enjoyed that we did XYZ, that was so awesome. We had so much fun," and you said, "What? Huh? What are you talking about?"*

If he then came back with, "Don't you remember? Blah blah blah," that's a different thing. That's a totally different thing than accidentally bumping into a pothole.

Phil: But it doesn't matter. I mean, once he says, "Didn't we have a great time?" and I sit there and look at him like he's got three heads, the "damage" has been done.

Christy: *Well, that's one way to look at it. Another way to look at it is, at that point, a care partner can double down, which is saying something like, "Don't you remember?" Or back up a step, take a breath and then talk it through. Always respond, of course, in a very loving way. Bring The Good Stuff. "I'm sorry that that isn't coming to mind."*

A lot of times you don't even need the words, but the expression, holding a hand, offering some type of comfort, arm around somebody. When someone is letting you know, "I don't have a recollection of that," acknowledging that that's a loss, right? In real time, somebody is feeling a loss; that's a time to comfort somebody. So, I do think there's a big difference between doubling down and offering comfort.

Phil: Yes, and I don't disagree at all. I think we may be dancing on the head of a pin here, but...So much to say, and all the words are fighting themselves. I'm trying to get it out. You know, I suppose--well I... Sorry, like, my mind is going in 6,000 different directions at the same time, and I can't get one thought out without jumping to the next one. But...

So, Care Partner A, innocently walking along, you know, "Didn't we have a--?" Sees something, or of something that they--a shared experience, and says, "Didn't we have a great time?" and gets the two-headed snake look, or the vacant stare, or

the whatever. The damage is done, because then if you're me, or if you're, you know, you're trying to be with me, you know, then I'm going to press for details because I don't remember.

Phil: But how does the care [partner]--I mean, do you just walk along in silence and don't bring up anything until your person brings it up?

Christy: *I think that is a great question.*

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/Episode109). Just go to the show notes at DementiaSherpa.com/Episode109. 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/Episode109).

Christy: *So, I have a couple of answers to that. One is, like, I do have a relationship with you. You're my friend, so I know that this is a sore spot for you, big time. So I probably would not be likely to say, "Hey, didn't we have a great time? Blah, blah, blah."*

Let's change to generic person living with neurodegenerative disorder that I'm walking down the street with. We go past a place where we've been and we've had a good time. I could say something like, "Oh, I love that we're right here in front of this place. Because the last time we were here, I felt so happy because we were spending time together. And it just makes me happy all over again."

I could say something like that, which is I, I get to come back to how I was feeling, and what I'm doing in that moment is sharing how I was feeling, and am feeling. And then if the person says back to me, "I've never been here before," then I can say, "Oh, I thought it was this place. But you know, the main thing is I get to be with you and I love being with you. That always makes me feel happy."

So I could go into a different direction there, and usually it is not remotely offensive to people when you share how you're feeling. Like, "I saw something that reminds me of a good time we had together and I'm having all those same

happy feelings all over again,” and kind of reaffirming the relationship again in that moment. Does that make sense?

Phil: It does. I think--I suppose that if you've been living with somebody who would, it--if you'd been sharing the journey for quite some time, you can train yourself to get to that point, but that probably doesn't come right away.

Christy: *I think it's kinda like in any other piece of human development, right? Like, everybody who walks now doesn't really think about it. Whereas when we are all learning to walk, you know, there's so much that goes into that. Which is just from the being able to pull your head up, to being able to roll over, to being able to stand up, to all of those things.*

It's a more complicated process and it takes time. So, learning anything new feels very daunting. It can feel very overwhelming. And the more we keep at it and the more we practice, the more ingrained it becomes until it can become something that we're not even consciously thinking about.

Phil: Right. Right. And that, I guess, is what everybody who is dealing with this disease has to be thinking about: is, you know, retraining yourself to walk.

Christy: *I certainly believe that's true, because I come at it from the angle of, “This person is somebody I care about.” So, by virtue of that alone, I am always going to want to interact with that person in a positive way, in a way that we are both going to come away feeling good about.*

If I care about somebody, why would I want to do anything that is going to upset that other person? Where does me being factually correct on something come into play at all? What do I have to do with it?

So if I'm in this relationship with somebody that I care about, I always want to see what is going to be in that person's best interests, what is going to create joy and peace and harmony in our relationship. And fun!

Phil: Yeah. Yep, yep, yep.

Christy: *I think most humans are like that. Just the main point being, I think a lot of times when we use words like Alzheimer's or dementia or a neurocognitive disorder, that's when when unintentionally, or unconsciously, we kind of throw an extra degree of difficulty on top of the thing.*

And that's why I encourage people to step back from that, and instead of, you know, trying to figure out, "Is Phil a diamond or sapphire or a pearl? Level 6? Stage 5?" Whatever it is, instead of that, just going like, "Oh, this is Phil, and I love Phil. So, how can Phil and I have a good experience together?"

Phil: Right, right.

Christy: *And that's our show. Thank you so very much for listening. Head on over to the show notes at DementiaSherpa.com/Episode109. 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.*