

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
Episode 94: "I Am Very Uncomfortable Talking to People with Alzheimer's"

Phil Gutis: I am very uncomfortable talking with, to, people with Alzheimer's.

Christy Turner: 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, 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 thank you for joining us. I'm delighted to say Phil Gutis is with us again today. Phil is a former New York Times reporter and current contributor, an Alzheimer's advocate, and a man living with Alzheimer's disease. Phil was diagnosed three years ago at age 54. Not only has he generously agreed to keep appearing on the show, but he's also willing to answer your questions. So send your questions to me via email or DM me on Facebook or Twitter. Contact links are in the show notes at DementiaSherpa.com/Episode94.

Communicating with people living with Alzheimer's or other types of dementia is a struggle for many people. Folks aren't sure what to say or afraid it's going to be awkward. Phil is right there with you. As he says, "I am very uncomfortable talking to people with Alzheimer's."

So in this episode we tackle communicating with people living with dementia at any stage in the process. Plus, reveal a couple of our pet peeve words and phrases. Now here's Phil.

Phil, you mentioned that you really were hesitant to listen to the first episode we did. Have you listened to either of the episodes we've done? [This episode was recorded before Episode 93.]

Phil: I've listened to both of them now.

Christy: *And what do you think?*

Phil: I think I hate my voice.

Christy: *Welcome to the club, buddy!*

Phil: Yeah. But I thought that they both turned out very well. They're very, very interesting.

Christy: *I think so too. You're fascinating.*

Phil: Wouldn't go that far, but you know, hey... You're going to get me a swelled head.

Christy: *That's okay. Today I actually wrote down some followup questions from listening to the last couple of episodes again, because I agree: I just think they're awesome. Okay. Last night you texted me the link to an article, and one of the pieces of advice in that article is, "Don't say, 'Don't you remember?' to a person living with Alzheimer's." And I'm bringing that up for two reasons. One, that was something that you told me back when we were on the cruise, that that is like a massive pet peeve. And I share that with you because I always think, What are we doing when we say that to people? Are we trying to taunt them, or what's the purpose here? And then the other is, I'm wondering, do you have any other phrases or terminology that are your pet peeves?*

Phil: Um, not that I can think of at the moment. And I understand the use of, “Don't you remember?” I mean, it's a natural, it's natural to put that in conversation. But boy, oh boy! It really drives me, and I imagine a lot of people who have Alzheimer's, sort of around the bend. Because no, we *don't* remember and no, we *can't* remember. And it's so frustrating to us that we can't remember. That is, it's just the normal conversational tic just almost does become a taunt. And it's not intended to be one.

Christy: *Right.*

Phil: But it becomes one, you know? And I think Tim has pretty much beat it out of himself. Although he'll slip every once in awhile and he gets a nasty look for it. And again, it's not that he's trying to taunt me or that he's trying to be mean. It's, it's natural in conversation. And I also think sometimes people want to help us remember. And it is true that sometimes if you do hear some facts of the event or the night and you know, dah, dah, dah, dah, it will help the memory come back. But just using that terminology is--it should be avoided.

Christy: *Yeah. There's some weird verbal tics we have as humans, where we say things like, “Don't you remember?” to a person living with dementia, or --this happened, unfortunately. Recently, I was at a memorial service and I was next to somebody who asked the widow, “Hey, how's it going?” I was like, Really? Maybe this isn't the best day to ask that question. And it was, I'm sure it wasn't meant to be mean, but sometimes it's just like rolling into autopilot.*

Phil: And you know, I think we've talked about this a little bit before, but those tend to be highly uncomfortable situations for everybody, and--

Christy: *True.*

Phil: And you know, and folks don't know what to say at a memorial service or at a funeral. And so you know, your mind takes over and it's not often saying the best things in the world.

Christy: *Right. I'm glad that you brought that up because we--and we talked about this, I think, on the cruise also--about people just generally being uncomfortable talking to people living with Alzheimer's or some other type of dementia, because they're not sure what to say. And so it just comes out of the gate sounding very awkward.*

Phil: And I went a step further and said, "I am very uncomfortable talking with, to, people with Alzheimer's."

Christy: *You did say that. And I almost fell off my chair, but I was standing. So, what is it that makes you uncomfortable about talking to other people living with Alzheimer's?*

Phil: I think it's the same thing as makes other people uncomfortable: you don't know what to say. Um, no. You know, obviously if I'm friends with somebody, I know what to say and I have no trouble talking to them. But you know, as, as meeting a new person living with Alzheimer's, I... Yeah, I don't....

Christy: *So you asked me at the time that we had that conversation originally--we had just had a dinner, big group of us on the cruise, and we were sitting at various tables because they didn't have a table big enough for all of us. But I was sitting at a table that had three couples. So that was three care partners and then three people living with dementia. Oops, no! Four. It was four couples. So four people living with dementia and four care partners. And I was having the time of my life! I so enjoyed that dinner. It was awesome. And later you said to me--and you asked the question very literally, like, "What do you say to them? How do you talk to them?" And I thought, I was--I was just so stunned by that question, because I don't--I*

guess I never really thought about the level of discomfort for most people, being so close to universal. But it is.

So anyway, what I said was--and this is just my little tip, how I start a conversation with pretty much anybody living with dementia--is first thing is to make eye contact. And depending on the situation, and I think, you know, most folks can figure it out pretty quickly. So if you're just meeting someone for the first time, you would have physical contact, typically, because you'd be shaking hands. But I make that eye contact and then kind of wait a beat longer than I would usually, if I was, say, at a business meeting or a networking meeting. And if it's somebody that I know is struggling for words as they're kind of, that's the usual way that it goes for them, or maybe they're nonverbal at this point, I will start by making a statement. Something along the lines of, "It's really good to meet you," or, "I'm so happy to see you today," or, "I really like that shirt," or, "It looks like you just got your hair done." Something along those lines that is non-threatening and just a statement. And then, again, waiting a beat to see, Are we off to, on the right foot? Is this something that the person is able to pursue? Are they understanding where I'm coming from? And that could be, Are they comprehending the words I'm using? Or it could be, Are they feeling the energy I'm bringing? And then take it from there.

Phil: And if they're not feeling the energy and they're not comprehending, where do you take it after that? I mean, I think that's the fear, right? I mean, is that you can't have a "normal conversation" with somebody living with Alzheimer's. And I'm not saying, I'm not saying that's my fear. Although in the later stages of Alzheimer's, it would be my fear. But certainly, I imagine that's the fear that most people have.

Christy: *Hmm. You think it's that fear of, like, feeling awkward? Just like, Ugh, okay, well what do I do?*

Phil: Oh yeah, *What do I do?* I mean, what do--Okay, let's say we start off with that conversation. You know, "Hi," look in the eye, "My, your hair looks nice today," or, "That's a great outfit," or something, and you don't get a response. What? What?

Christy: *Okay. So, typically, if you don't get a response, or--what most people mean by, "I'm not getting a response," is, "I didn't get a verbal response."*

Phil: Mm hmm.

Christy: *So, almost always you're going to get some type of response. And depending on where a person is in the process, it of course, it could be a verbal response, it could be a touch or a tap, a squeeze with a finger. It could be a change in facial expression. And then for somebody who is closer to the end of their life, if they're just able to make eye contact with you, that's a response.*

Phil: Mm hmm.

Christy: *For people who are very close to the end of their life, who have gone all the way through the disease progression, then I wouldn't expect eye contact. But my focus in those types of situations are to speak in a soothing voice, and to let someone know why I'm there. Like, I have a purpose for being here. I'm not being some weird creeper sitting next to your bed. So, in those types of situations where I'm talking to somebody who is very near the end of their life, I would just really focus on, of course, bringing The Good Stuff, bringing that good energy, and speaking in a soothing tone and just doing whatever I could to continue promoting an environment that feels safe and secure and non-threatening. Now, that's not the situation I think that most people are talking about. I think when people are really not sure what to do would be when someone is maybe later in the early stage, or somewhere in the middle stage, where they might be doing something like, let's say, pacing. You walk into a room and somebody is pacing and you say, "Hi," and you don't get a response, and they continue pacing, they might be wringing their hands or doing something else.*

They're involved or engaged in something else and don't seem to be even acknowledging your presence. That's another situation where stepping

into the moment with the person is extraordinarily helpful. For both of you. So, for the person who's approaching, it gives you the opportunity to see what's going on for the person you want to connect with, and shifting your perspective to see what's going on for them. If somebody is pacing, why are they pacing?

Phil: Mm hmm.

Christy: *Are they looking for an exit? Do, you know, do they need some fresh air? Are they maybe, they have some nervous energy to burn off? Maybe they're not sure what to do next? So, there's that. So again, stepping into the moment, figuring out what's going on for them, and then meeting them where they are is really helpful. Prior to that stage would be something probably along the lines of, let's use me as an example and let's make up somebody named Susie.*

Okay, so Susie, let's say, has dementia. So I say, "Hi Susie, really good to see you today. How's it going?" And she gives me a blank look. My next move would be to say something like, "You doing okay?" and making sure we have eye contact. "Oh Susie, you don't seem like yourself today. I'm wondering if everything's okay." And again, giving some pause so that people have time to process and comprehend the words that are being said and to think about what they would like to say next. And I--you know, honestly, Phil, I think a lot of it comes down to just kind of how we communicate as a default. A lot of people struggle with being able to really listen rather than think about what's the next thing they want to say. They're almost waiting for the person who's talking to finish speaking so they can say what they want to say.

Phil: Right.

Christy: *And when that dynamic changes, it of course feels different because it is different. Communication with people living with dementia--I mean, obviously, I'm going to say this--based on my experience, communication with people living with dementia is entirely possible. It feels and looks different, by degrees, depending on where someone is in the process. And*

for the person who does not have dementia, it requires some practice to get the hang of it. You know, some people will feel comfortable with it and go, Okay, this is, this is different now. This is how it is. And other people may always feel some degree of discomfort, or not confident that they're communicating in a way that is making sense for their person or another person. One of the fears that I've heard around that, something along the lines of, Well, why should I continue to go visit? Because he doesn't even know my name anymore. Or, Why should I continue to spend time at the memory care with my mom? Because she doesn't even know who I am anymore. And again, based on my experience: so, number one, for the visitor, it's not about you.

Phil: Right.

Christy: *It's really, it's about the other person, right? And we love the person, so we're going to go spend time with them. So, that's one thing. The other thing, then, is when you are spending time with someone and you're coming from a place of love, you're bringing The Good Stuff, you're making that effort to step into their moment, to see the world from their perspective, and you just accept them as they are right now, in that moment? That's a gift that's received on an entirely different level than anything language could ever convey.*

Phil: Mm hmm.

Christy: *And I promise people feel that up until their dying breath.*

Phil: I just flashed on a memory that, who knew I had? Of my mom's last days. She passed from leukemia when she was, I think, 63, something like that. Very young. And I think I remember just sitting with her at the end. And she was aware, but you know, we didn't need to chat. It was just being there. And I think I was okay--I mean, I'm not okay, obviously--but I mean, I think it was comforting for both of us, just to be there.

Christy: *Right.*

Phil: Me, and obviously I think it was for her. But that's a, that's a level of, you know, that's, that's reaching a stage--the word comes to mind, *acceptance*. And almost a, *There's nothing left*. You know it's almost the end and you don't need to talk.

Christy: *Mm hmm.*

Phil: The beginning stage, at the early stages, and you know, I--so I served on the Early Stage Advisory Council for the Alzheimer's Association. And I don't, I don't think I had--yeah, it was interesting. We had shared purpose, we had shared experience. So there was no, *What do I say to this person?* Because I had things in common with them, you know?

Christy: *Mm hmm.*

Phil: So when I meet somebody living with Alzheimer's, I mean, I obviously have something in common with them, but you don't walk up to somebody and go, *So, isn't your life sucky now?*

Christy: *I would hope people don't do that!*

Phil: Well, I mean, I, you know, so....So, I'm sort of like saying to myself, *I have a shared, I have something in common with a person living with Alzheimer's*. And I still, if I don't know them, can be uncomfortable starting in conversation. Now, that's probably the introvert in me speaking,

and the person who's never been comfortable at a party just circulating and doing, opening, the chat. So, you know, this may be all on me, but I don't think it's just all on me. I think it's a particularly common challenge.

Christy: I think it's a lot of the things you said, which is being an introvert never gives you a headstart in a social situation.

Phil: Right.

Christy: So, there's always that extra degree of challenge right there. And then as far as when you're describing sitting with your mom toward the end of her life, and the acceptance that came from that? I think acceptance might be another hurdle that people need to get past in order to communicate or feel comfortable, feel more comfort in communicating with people living with dementia. And probably thinking about communication in a different type of way. So, we've talked about this before: I'm an introvert also, and when I'm meeting someone new, someone living with dementia, I can't say, "Oh, I have that in common with them. I have dementia, too," because I don't. And I'm an introvert, so obviously I needed to figure out a way to get over it, right?

To get past that, one thing that has really been helpful for me over close to all of my career has been the idea of, I am in service to the other person. Going into an interaction, my goal is to do something that will serve the other person.

Phil: Which gives you a purpose.

Christy: Right. It gives me a sense of purpose. Exactly. And so it might be--and I don't know what's going to happen with the other person when I'm meeting somebody for the first time. And this could be anybody, whether they're living with dementia or not: Do they need my help? Do I happen to be the person that the universe sent to show up when that other person needed someone to actually just look in their eyes and see them? Were they

feeling like, Nobody even knows I'm alive? Did they just need something as simple as eye contact and a smile?

I don't know. I don't know how the whole big picture works. I guess what I'm saying really, at the most basic part, is, if I just focus on the other person, then it allows me to get out of my own way. To stop thinking about, Oh my gosh, what if I say the wrong thing? Oh my gosh, what if I say something dumb? What if I, what if I, I, I to get rid of that and to just say, What can I do for this other person? Or, How can I serve this other person? How can I make this other person feel good?

Phil: Mm hmm. Mm hmm. Yeah. I mean, an opening gambit in a conversation might just be, if you're at a conference or something, "How are you doing? Is there anything I can get you? Are you enjoying the speakers?" Uh, yeah. I mean it doesn't--okay. I fold. It doesn't have to be any different than what you would say to anybody else sitting at a conference, or anybody else sitting in a room. So even though like the person might be wearing a tag that says, you know, *Hi, I'm Phil. I have early onset Alzheimer's* or, *I have Alzheimer's*, or you see my bracelet and it says *Alzheimer's*, you don't have to necessarily start the conversation about Alzheimer's.

Christy: *You don't have to start off with, "Oh! So I see you have Alzheimer's."*

Phil: "What's that like for you?"

Christy: *Yeah, that's freaking awkward!*

Phil: Or, "How did you know?"

Christy: *Right, exactly. So, and to be clear, during our cruise and conference, nobody was identified that way. Nobody had some tag on them that said,*

Hey! I have Alzheimer's, or that, well there were people with different types of dementia there also. You know, all of that said, I think the other piece of that--and this is worth acknowledging--is out of the whole wide world, and there're like, how many people? Like 7 billion, or something like that? And in that whole wide world, there's a relatively small pool of people that are truly comfortable in the company of people who have a fatal illness.

Phil: Mm hmm.

Christy: *Whether that's Alzheimer's disease, or anything else that falls into that category of fatal illness. But that said, I've certainly met people who work in hospice who are brilliant at it, and they're not super comfortable with certain types of conditions. So we all have our thing, our places where we really shine, and then our places where we go, Ugh, that feels awkward!*

Phil: Yeah. I mean, ooh, I can't imagine being a hospice worker. Wow. I can't even imagine working in an animal shelter, let alone....

Christy: *You know, it's funny because I've had the privilege of sitting with 23 people as they passed. I could never work in an animal shelter. At all. Because I can't even watch movies with animals, because something happens to the dog, and I just fall to pieces, you know? We all have our things.*

Okay, to wrap up this piece, Phil, and going back to where I started, which was the article that you texted me last night--and it was talking about Don't say, "Don't you remember?" As the guy in the article is giving this advice, he keeps talking about Alzheimer's patients.

Phil: Right.

Christy: *Which is one of my massive pet peeves. So for anybody who's never heard me hop up on the soapbox, let me break it down. Patients are found in hospitals and doctors' offices. Residents are found in an assisted living, a memory care, a skilled nursing facility. Some place where they would be living, right? So residents are also in apartment complexes, homes, duplexes, what have you. People are found everywhere. Those are humans. And so when we talk about people as people and we say things like people living with dementia versus patients, that's a very different connotation.*

We talked about this last time, about how the words we use really reveal how we think about things. And it's the same reason that we say living with dementia versus suffering from dementia or victim of dementia. It's a very conscious word choice. And so those, those types of word choices, I know there's probably somebody listening who's like, Oh, it's so PC! I don't care. Don't. There're words that we don't use anymore that were probably perfectly fine circa 1900 in the south. Don't use them. So, it's, we're just talking about a basic level of respect for other human beings.

Phil: And I have used it. I have adopted that usage. And I like it. I do. I think because that is true: I am *living* with dementia.

Christy: *Yeah.*

Phil: And you know, I'm not *dying* with dementia. I mean, I am. But not yet. But we're all dying, you know, every day. All time ticks by, we're all dying. So, you know, I'm doing my best to *live* with dementia.

Christy: *And that's our show. Thank you so very much for being with us today. If you have questions for Phil, please let us know. You can send them to me via email, Facebook, or Twitter. All those links are in the show notes at DementiaSherpa.com/Episode94.*

You've been listening to The Alzheimer's Podcast with Christy Turner of dementia Sherpa, wishing you a blessed and easy week ahead. Be sure to

*check out the show notes and subscribe by going to
DementiaSherpa.com/podcast.*