

**The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa**  
**Episode 097: We're All on a Journey**

Phil: So, we're all on a journey. Life's a journey. And you know, my journey through life got a jolt three years ago, when I was diagnosed with early onset Alzheimer's.

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 thank you for joining us. Phil Gutis, Assistant Sherpa, 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. Meeting Phil has been one of the great blessings of my life. I get such a kick out of talking to him, and he's so incredibly open, I feel like I'm getting a master class every time I get to talk to him.*

*One of our recurring topics is the terminology in Dementia World. One of the words one of the words that's commonly used in this world that I really don't like is "journey." After listening to what Phil has to say about it, I've started to think about that differently.*

*A couple other things you need to know before we jump into the episode: What you'll hear in this episode is from part of a longer than usual recording session, recorded later in the day than usual.*

*As a result, you'll notice some changes in Phil's language. There are spots where words don't come as easily or quickly as usual.*

*I'd originally intended to split this episode into two parts, but ultimately decided that would be a disservice. There's a point, around the 24ish minute mark, where we head in a totally different direction than I anticipated. I was a bit shocked when it happened in*

*real-time. Despite that, Phil wraps it all up with a bow at the end, so leaving it as one episode made sense.*

*Now here's Phil.*

Phil: So, we're all on a journey. Life's a journey. And you know, my journey through life got a jolt three years ago, when I was diagnosed with early onset Alzheimer's and I started on a new path, a new piece of my journey. All of life is a journey, in my mind. And we're on a path [from] the moment we're born until the moment we leave. And three years ago when I was diagnosed with early onset Alzheimer's, my journey hit a bump in the road, a fork in the road, maybe. And we started a new journey, a journey of living with Alzheimer's disease. And you know, from what I understand of this disease, there are certain stages that you travel along. So I guess it's the traveling part that you're, that causes me to say it's a journey. Because you know, you're starting at Point A and you're ending at Point Z, and you've got to get from A to Z and there's ways of doing that, I suppose.

One way of doing it is to get to Point A, crawl into a hole and live there until Point Z comes along. Another way to do it is to try to experience as much, and you know, live well as long as possible through all the stages that you can live well and enjoy. And you know, I've started to hear stories, a few, one in particular, of somebody who's really long, far along, but is still managing to have sort of fun, drawing in her eyebrows with green pencils. Being very proud of the fact that she did that. So journey doesn't seem--it doesn't carry a negative connotation to me. Why does it, why does it bother you?

Christy: *I think it's inaccurate, in the sense of it's supposed to be this cushy thing. Like, "Oh, we're going on a journey, and it's going to be fun!" And...no. I don't know, just the journey thing to me--and you know, full disclosure: it may be because of this adoption so-called journey that I was a part of many, many years ago, where I honestly, I did find it the road trip from hell. So, I dunno, I guess journey will be my thing. Dementia can be your thing, and we can agree that words matter and some of them just really tip us over.*

Phil: Right.

Christy: *Even if nobody else agrees!*

Phil: Or I could accept your suggestion and describe my Alzheimer's, living with Alzheimer's, as my road trip from hell.

Christy: *Yeah. Well, I'm glad you pointed that out, Phil, because when you say it like that, I sound like a total jerk. I don't think that anybody should have the attitude, or adopt the attitude of, This is all just so terrible and there's nothing I can do about it and I should just crawl into a hole! like you were saying. That's not it at all.*

Phil: But you know what, it is also terrible and there is absolutely nothing we can do about it. And in many ways, [it] is going to be a road trip from hell.

Christy: *So what, do we need to find the balance? Is that it?*

Phil: Well, maybe we shouldn't use the kind, soft euphemism of a journey. And I don't know how well it works, but finding our moments of joy during our road trip from hell. It's probably more accurate. I mean, it's true, right? I mean, I talk about, and I've written about that day when I sat on the bed crying, because I said to Tim, "It's coming, isn't it? And that was just walking past a local theater where we had seen a show and not remembering at all what the show was and when being told, still having no memory of it. And that is an increasing--that is my number one symptom, actually, right now: is these things just disappear. These events that happened to me, there's just no recollection. I know I was there, but I don't have a memory of it. And that's--yeah, it's not a journey. It is kind of along, like the blips of the road along the road trip from hell. It's not anything anybody would ask for, right? You know, we're not asking for this road trip.

Christy: *No, you don't.*

Phil: But I guess sometimes we use language--and this, to bring it back to dementia again: We use language to soften the blow.

Christy: *Right.*

Phil: And you know, a journey does sound softer than a road trip from hell or some other term. And I would argue that there's gotta be another term that we could use to soften the word dementia, because it has that other connotation. I know you live in this world at a professional level, and it doesn't have that other connotation to *you*. But most of us don't live in that world. Even those of us who are in the world, you know, have been dropped into the world, still don't live in that world. And it's very hard to understand the language, often, that is spoken in this new land, in this new world, that we have arrived in. I saw some blip somewhere, a blurb about some [inaudible] that seemed interesting to me, and I went to go read the paper--no, not even read the paper, read the *presentation* about the paper. I couldn't understand a word of it! I told somebody I didn't even understand how they used the word *the* and *and* in that thing.

Christy: *Well, I think that one significant problem that we as professionals have is slipping into geek speak. Slipping into geek speak is not helpful for anyone. And it really, if you want to have some impact and reach your audience, no matter who that is, it's really helpful to be mindful of who you're speaking to. Along those same lines, I would never say that because I'm a professional in this world, that my thoughts or ideas are superior to anyone else's who is not a professional. Not true. Do I have more experience than most people have? Probably, you know, talking about nonprofessionals. Yeah, probably. I do. So I may have better insight into some things than someone who hasn't spent the same amount of time in this world that I have.*

Phil: I was just going to ask you if I could tell a little story.

Christy: *Of course.*

Phil: So, I went from the *New York Times* to the ACLU. And I was the ACLU's first media relations director, PR flack--which is public relations flack. And when I got to the ACLU, I began to notice that almost every single time an ACLU lawyer was quoted in the paper, they were calling something outrageous. And you know, the ACLU is there to defend the rights of the minority over the majority. So, when an ACLU lawyer found something to be outrageous, by definition, the majority probably thought it was perfectly sane and

perfectly fine. When we, as ACLU spokespeople, used the word outrageous, it gave the reporter the easy out. There was the ACLU quote: "It's outrageous." No explanation of what was outrageous about it, what violated the Constitution, what violated the rights of the minority. It was just, it was outrageous. So I set off to ban the word outrageous, as a quote to reporters, because it didn't work. And I think maybe that's what I'm reacting to with the d-word. And maybe we can just use the d-word. Maybe that's our term. Alzheimer's and other d-words.

*Christy: This is Christy Turner, AKA Your D-Word Sherpa. Alzheimer's and other d-words.*

Phil: Well, you know, He Who Shall Not Be Named? I think there's some--now, The Disease That Shall Not Be Named.

*Christy: Right? It can slide into people going, "Oh, they're just being so PC!"*

Phil: Right, right, right.

*Christy: Whatever, but calling people "patients" outside of a medical setting tips me over.*

Phil: Right, right.

*Christy: Like there was a really good piece I just read, but it kept saying Alzheimer's patients, Alzheimer's patients. Name the medical condition, slap the word patient after it, and those people are only found in hospitals and doctors' offices. Outside of those settings, they're just people. I wish they were people inside those settings too, but.... So, dogs that live in the wild are not called pets. Dogs who live in people's homes are pets.*

Phil: But what set you off about the word patient? What does that do? Why?

Christy: *Because it--*

Phil: Why is that a negative word?

Christy: *Hello, reporter! Good question. Because in my mind, it reduces you to nothing but that. Phil, the Alzheimer's patient. Not Phil, the former New York Times reporter and current contributor. Phil, the husband of Tim. Phil, the Alzheimer's advocate. Phil, the writer. Phil, the volunteer. Phil, the pet dad. Phil, the homeowner. I mean, what other things am I leaving out about you? Other than that one thing, right?*

Phil: Well, why can't I be all those things plus an Alzheimer's patient? There's something about the word *patient* that set you off.

Christy: *Yeah. Because it reduces it to that one setting, to that one thing.*

Phil: Well--

Christy: *People live--it's the difference between saying, and here we go again, demented and person living with dementia.*

Phil: Mm hmm. Mm hmm.

Christy: *You know, it's just a big difference.*

Phil: Right, right, right.

Christy: *And the words we use inform how we think about things, right? And if we're looking at a whole population of people and saying they're patients, then, I don't know. I feel like we're missing a lot to them. And why the way we do certain things, the way we talk about certain things, are important.*

Phil: Right. Which is why there are groups of people sitting around tables today in many places having heated discussions about ad language and tag words and all matters. I love your--and I'm pretty sure you taught me this on the boat--"people living with," "a person living with." "I'm Phil, I'm living with Alzheimer's." And I love that phraseology because I'm *living* with it. And that is key, for me. Is I'm living with something. I'm a husband who's living with Alzheimer's. I'm a dog dad who's living with Alzheimer's. I'm a former *New York Times* reporter who's living with Alzheimer's, you know, all these things. But I'm *living*, and I think that's the key. Now, I would never say, "I'm Phil, and I'm demented."

Christy: *Right. Would you say, "I'm Phil and I'm an Alzheimer's patient"?*

Phil: Umm, not anymore.

Christy: *Okay.*

Phil: I probably did before. But you know, when you say the word *patient* to me, I imagine somebody in a hospital gown. And those are just not attractive things.

Christy: *Right, okay, yes. Great point on both. Two great points. That's what you imagine. That's where your head goes. And no, they are not attractive. Who did that?*

Phil: I mean, even when you try mixing them with kinky red boots, they're still not attractive. And I have proof of this.

Christy: *But that does make for a great picture.*

Phil: You know, I think we're getting, we're, we're diving down here. So, patient is "unattractive, hospital gown." Dementia is, in my mind at least, and we would need to do at least a series of six focus groups and probably a poll, which is the way we do it in the real world, to understand if my connection of dementia-demented is shared with a large population. And you would ask them, you know, "I'm going to give you a list of words. Tell me, what is your first thought when you think of it?" So patient, my first thought is hospital gown, unattractive. "Dementia, what is it? What does that word, what is that term, that comes to mind? When you hear the term dementia, road trip from hell? Brain illness? Brain disease?" I'm sure the Alzheimer's Association's done this. And other groups. [I'd] be very curious to get somebody on [the podcast], talking about the terminology of dementia.

Christy: *I'm guessing it would be like a lot of other things, where there's a group of people who shrug their shoulders and say, "Who cares? It doesn't matter."*

Phil: Right. Until it matters to them.

Christy: *Right, exactly. When you say patient and you think hospital gown, unattractive? I hear patient, I think, hospital gown, vulnerable.*

Phil: Mm hmm, mm hmm, yep. And we're terribly vulnerable, mostly.

Christy: *Right? And everybody has moments of vulnerability in their life. But you know, the hope is always that you get to make the choice about when you're going to be vulnerable, not that it is thrust upon you; that that vulnerability is thrust upon you. I think that*

*Alzheimer's, like so many other types or causes of dementia, thrusts a certain amount of vulnerability upon people that they never chose. Obviously. So I guess, saying all of this out loud, for me, it just comes down to dignity. And I think that's maybe your larger point about the word dementia, also. It just always, whatever it is, it leads back to dignity and the words we use. Are they protecting or honoring somebody's dignity as a human being or are they attempting to strip that away?*

Phil: So, yes, absolutely. And I think, you know, after a bunch of dancing around the word, we're getting to it. When you get diagnosed with an illness, you lose your dignity. You often lose your dignity. Last October when I had my baby heart attack, all of a sudden--and they put me in the hospital for testing--you immediately lose your dignity. You are in a hospital gown. You are, your groin is being shaved. They may need to run a--what's that test where they put a camera into your heart?

Christy: *Angiogram?*

Phil: Angiogram. And now they use the vein in your arm, or the artery your arm. But if that doesn't work, they're going to have to go in through your groin. So to be ready, they had to shave my groin and the tech who was doing it even said, "Okay"--after that was done, he was like, "Okay, the embarrassing part's over. Now you're just going to go sleep." But my God, you lose your dignity. You're attached to, you know, monitors left and right. You know, you've got the IV in you. You can't go to the bathroom anymore. You have to use the old--what are those things called?

Christy: *The urinal, or the bed pan?*

Phil: The urinals and the bed pans, right. So your dignity is stripped from you. So you know, when I hear the word patient, it goes beyond, obviously, the hospital gowns, but it's all of those things. But Alzheimer's is an illness. So, in some ways--but it's a long slow illness, you know, and it's an illness with many points on its journey. Many points of the road trip from hell. But fundamentally, at its heart, it's an illness and we are patient[s]. When I go down for, or when I would go down for my drug trial, you know, I went to the University of Pennsylvania Hospital. I went to a doctor's office. I was a patient. I had the little arm ID thing too.

Christy: *Yeah, and I would say in those moments you were a patient, for sure.*

Phil: Right.

Christy: *Yes. And outside of any of the settings, you're Phil, a guy living with Alzheimer's. And lots of other things being true about you. I guess to me it's like the difference between--well, here are two great words, two great examples. And this still happens; these two words are used way too often, still used in reference to people living with Alzheimer's: Alzheimer's victims--*

Phil: Mm hmm.

Christy: *And people suffering with Alzheimer's.*

Phil: Mm hmm.

Christy: *Are there moments that you suffer? Undoubtedly. Is it because of Alzheimer's? I don't know, but I would pin it back further in your life than that and say it's because you're human. Just like anybody else on this planet. We all have moments when we will suffer, in that moment. Does that mean we are sufferers? Should we call humans sufferers? Because we all will have that experience at some point in our life? Many times in our life, most likely. Where we're suffering something, in that moment.*

Phil: Mm hmm.

Christy: *Victims, let's say, of anything. But you know, what most readily pops to mind now is assault. Victims of assault prefer to be called what they are, which is survivors.*

Phil: Right. Right. Yep. Victim is a very heavy, heavily loaded word also.

Christy: *It is.*

Phil: I don't, I've never thought of myself as a victim of Alzheimer's. A survivor? Yeah. I think I could make a case that I'm surviving with Alzheimer's. And that there are times when I'm not surviving very well, but I am surviving. And there are times I'm sure--I mean, I've had those times, when I didn't want to survive. And if I wasn't such a chicken, I probably wouldn't have survived.

Christy: *What does that mean?*

Phil : Well, you know, you have your very dark moments when, what's life living? What's life, what, what is worth living for--

Christy: *Mmm.*

Phil : --when you have Alzheimer's? And you know, I've, I think one of my articles for the *New York Times* said, I understand assisted suicide much better right now than I ever have. Because you know, at a certain point, is life worth living when you have advanced Alzheimer's, you know? And sometimes when you're in your dark, darker moments, where you're, all you're thinking about is losing your mind, and losing your memories, and losing your ability to do almost everything, what's... Yeah, you're living. But why? What, what for? You know, what? You don't recognize anybody and you see all these strangers and they're coming at you and....

Christy: *I always wonder, How much time do people spend with people in the later stages of, let's say, Alzheimer's disease? I do understand that most people look at people who are in the later stages of Alzheimer's disease and don't see anything of worth. I think that also people conflate individual moments with an entire existence.*

Phil : Well, what about when the bad moments overwhelm the good moments? You know, when you're suffering from hallucinations and you think people are trying to kill you and you know, on and on and on.

Christy: *That doesn't happen for most people!*

Phil: Okay. All right. That's good to know.

Christy: *That's another one of those big myths that's out there. People living with Alzheimer's do not automatically become violent. They don't automatically have so-called behaviors, they don't automatically live a life of misery. They don't automatically have hallucinations, delusions, any of that stuff. That's just not true.*

Phil : So what do you, so what is late stage dementia in your mind? Is it a time of peace for most people?

Christy: *It really depends on the environment people are in and the people they're surrounded by. Those are two critical, crucial factors. So if someone is at a place where they are not able to attend to their own care needs, but they have helpers who are able to do that on their behalf, then--and in a loving way, not in a task-oriented, Oh, gotta do this, then do this, and have this list of stuff, but actually understand and recognize the fact that, This is a human being that I get the privilege of caring for and assisting--that is extraordinarily helpful. And then the environment. Is it a--are we promoting and creating a peaceful environment, an interesting environment?*

*People who are at the end of their life with a chronic illness, they naturally turn inward. Interacting with people and things around them is not as important or compelling as it*

*would have been 20 years ago, or maybe even a year ago. It's just not part of that process. And this is, certainly, another point of vulnerability for people where they are to, I would say, a 100% degree, dependent on the people around them creating that environment and providing for those needs in a way that is kind and compassionate, empathetic, respectful, loving, and peaceful.*

Phil : Mm hmm. Yeah, it's a very hopeful description of a future that I would think we would all aspire to, no matter where we are on our life journey.

Christy: *Yeah.*

Phil: Um, because I have said over and over again, you know, if you're born, you're going to die.

Christy: *Right.*

Phil: So wouldn't it be nice to say that, you know, as a society, we are going to do everything in our power to bring someone's--anyone's--closing act one toward, to make someone's closing act a time of peace. But, and this could just be the stereotypes and these make the best stories, you know, quote unquote better stories, most dramatic stories. So this is what you're going to see, you know, when you see documentaries about Alzheimer's and things like that, you're going to see horror shows. Of people suffering incredibly. So, you know, maybe again, it's a question of what we choose to tell ourselves about various possibilities and futures. I mean, seriously, if I had any reason to believe that my days would go from forgetfulness and mild confusion to a place of peace and quiet, Alzheimer's wouldn't be such a terrifying disease. But that's not what I understand is likely to be facing me.

Christy: *And what is your understanding of what's likely to be facing you?*

Phil: Um...uh....

Christy: Not peaceful?

Phil: No! Pain, you know, um, a horror show. A road trip to, from hell.

Christy: *I think where that comes in, Phil, honestly, is it is so dependent on the people around you. So, for example, if you are confused about something, maybe you're getting a little anxious about it, starting to show some signs of anxiety? You know, too often the approach--and this is for people who just, I think, genuinely don't know any better--we blurt out unhelpful things like, "Just calm down, everything's fine! You're fine! It's all good!" Things that in fact raise one's blood pressure rather than creating any type of soothing effect. So that is definitely going to exacerbate the situation, going to make you feel worse. Versus if you have someone near you who says, "Hey, I can see you're getting upset. I'm going to help you. I'm here to help you."*

*And so it's in the approach. It's in the energy that we bring. It's in the tone of voice. It's in the words we use. And it's then in what we do next. And in either case, whether somebody initially handles it poorly or somebody initially handles it well, the next action may be the same thing, which is, "Let me help you look for the thing." But that initial approach kind of determines whether the next thing is going to go well or not. Because if you're already upset, anxious, confused, and somebody thinks they're being helpful by telling you, "You need to just pipe down and chill out," and they're going to get it handled and find the thing for you, you're pretty likely to get even more pissed off, more upset, more angry, more anxious. Or maybe if you weren't angry, if you were only anxious, now you're likely to get angry because somebody just spoke to you really disrespectfully. Versus if somebody approaches you in the second way I described, they are more likely to inspire confidence in you that this is going to turn out okay. Because now you have somebody in this with you, you have an ally right there, you have a cheerleader. You have somebody on your side, on Team Phil, who's like, Yep, we're just going to figure this out together.*

*So I think the more people that have that second approach, the better life is and can be and continues to be for the person living with Alzheimer's. Does that make sense?*

Phil : It does. But then I think of things like, you hear stories of people turning violent, often when their families say, *I can't handle this anymore*. Maybe understandably so; nobody likes getting punched in the face. Or the hallucinations, you know? Is your point that with

proper education care partners and caregivers can avoid people turning violent and people turning, or people having bad trips?

*Christy: People living with Alzheimer's have this reputation as often turning violent when they get to the middle part of the disease process. That's just not true. It doesn't often happen. But like any other person, if you feel threatened and you're trying to defend yourself, you may do something that is considered violent. So it doesn't matter if I have great intentions, what does that person perceive in that moment? If they perceive a threat, I'm going to get hit. Self-defense. I've brought all of this on. It's not the person's fault.*

*We don't talk about this enough, because just this--I guess this is where words really, really matter. Because in the old days what happened was people living with Alzheimer's got put on drugs that they didn't need because they hadn't done a damn thing wrong. It was the people who supposedly were there to help them who did not have the proper training. And now, boom! The person with Alzheimer's is paying the price. And you know, I tell this story from my very first day as a professional. And actually when I'm telling the story live, I say my very first day as a so-called professional because I was such a train wreck. Nobody had given me a list of Do This, Don't Do That. So, I was walking very fast. I came up on this guy who I found out later was blind on his left side. But that was the side I approached him on, so he couldn't see me approaching. And I talked a mile a minute, which made it very confusing for him. I was too close to him and I know that because how he finally shut down my motor mouth was punching me in the jaw. And he had a terrific right hook. But I didn't think at the time that I was too close to him, but I know that I was because his fist connected with my jaw, therefore I was too close to him.*

*Was it his fault? Hell, no, it wasn't his fault! It was 100% my fault. He got put on a behavior monitor. He got medication because he was being violent. That's how it was back in those days. That's disgusting. And I'll feel shame about that until my dying day. I did that to someone because I didn't know any better. To be clear, I wasn't the one who put him on a behavior monitor; I wasn't the one who gave him drugs. But that is the way that kind of crap was handled back then. And that kind of crap? When I say that, I don't mean what he did. I mean what I made happen. That was 100% my responsibility. That was not a violent man. I scared the bejesus out of him. He wanted to defend himself.*

**Phil:** Do you think that things are very different now in those places where people are living with Alzheimer's at the end?

Christy: *I think that they're better. And...and not 100% where I would like to see them, no. No, not 100% where I would like to see them. At all. Because the fact of the matter is--and I talked with Dr Tia Powell about this when we were discussing her book and her ideas about what needs to be different--you know, too often communities will hire somebody with a pulse, versus someone with the heart. Someone with a pulse can sit through training. They may become technically proficient and I guarantee you, they will never be a resident favorite. Versus somebody with a heart--you hire somebody with a heart who has never had a moment of experience with anybody living with any classification of dementia?*

*Those people are brilliant! They are magicians. Because they have the heart for it. They soak up the skills like a sponge. They are a joy to work with, a joy to train. A joy to have as part of your team because they make the residents so happy. Because you know who they see when they walk out on the floor and they see all of these residents? They see people. The condition, the disease, is always secondary. The person is always first and foremost. They just need a little tweaking, a little knowledge so that they know those skills and techniques. Somebody who's there for a paycheck? It's not that they're out to hurt people or to harm people, but they walk out on the floor and they see tasks. They see, This one needs a shower. That one needs medication. That one needs help with changing their clothes. That one needs help to the toilet. That's what they see. So there's an extraordinarily different vibe. Now imagine if all the places were filled with people with heart. That's, that's when you see a big change in how things are done.*

Phil: Hope for the future. We traveled a really long journey today.

Christy: *And that's our show. Thank you so very much for being with us today. Send your questions for Phil, or for me, via email or DM on Facebook or Twitter. Contact links are in the show notes at [DementiaSherpa.com/episode97](https://DementiaSherpa.com/episode97).*

*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](https://DementiaSherpa.com/podcast).*