

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 101](#): Coming out...with Alzheimer's

Phil: Sometimes I say to my nephew, "I'm done. Uncle Phil's done. There's nothing left." You know, "I gotta go take a nap," or, "I have to go to bed. I can't do this anymore." But often I'm really energized....And I'm *living*. That is the key. And I think if there's any message from this episode, in my mind, it's live, it's tell. Share. Don't be ashamed. Come out. People have to know. Otherwise, it can swallow you whole. The depression is real. The anxiety is real. There's only one way of fighting it. And that's sunshine.

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. Phil Gutis, our Assistant Sherpa, is with us again today. June is Alzheimer's and Brain Awareness Month, and it's also Pride Month. That lead Phil to the idea of doing an episode about coming out...with Alzheimer's.

One of the things Phil and I talk about a lot is stigma and shame, and how the words we use can help or hurt. Unfortunately, those are issues both the gay community and the Alzheimer's and other neurodegenerative disorders community know way too much about from first-hand experience.

I rarely read or watch or listen to content, or observe something in real life, without thinking about how it relates back to people living with a neurodegenerative disorder. What's increasingly caught my attention over the last several months has been trying to decipher the keys to success in the battles for effective treatment for HIV/AIDS and also for marriage equality.

How can we in our community replicate those successes? That's the question I'm asking until my brain comes up with answers. If you'd like to lend your brain

power to the cause, just email Info@DementiaSherpa.com with your ideas. We can continue the conversation in future episodes and, I hope, figure out how to end this scourge sooner rather than later. And if that sounds very pie-in-the-sky, that's okay. I'm old enough to remember when figuring out HIV/AIDS was, too.

Okay, two quick things before we jump in. One, this episode was recorded last week, before *The Longest Day*. So a great big shout-out to listeners of *The Alzheimer's Podcast* and members of the *Dementia Sherpa* tribe who supported our Assistant Sherpa in his and Tim's *Row2Remember* team. I threw in some goodies at certain dollar levels, and I'm super excited I get to work with those of you who took advantage of those deals. But the main thing is, with the help of you and many, many others, Phil and Tim's team raised \$11,100!

And that leads me to the second thing: fundraising is exhausting. And Phil was not just sitting there looking pretty. He was working it--leading up to the fundraising, and then rowing after. So by the time we recorded this episode, he was pretty well cooked just from doing the fundraising. Phil asked me to mention this in the show notes, so you'd understand when he has a couple tongue-twistery moments.

Now, here's Phil.

June is Pride Month.

Phil: Right.

Christy: *And a lot of people, LGBTQIA--am I adding the 'A' on there, or is that really part of it? I don't, I don't, sorry, I--*

Phil: I don't know.

Christy: *I don't, either. I mean I, I feel like I'm with it up until like all the way through the 'Q' and then I get a little iffy. Anyway, the reason I bring this up is because you had an interesting episode idea, Phil.*

Phil: Okay.

Christy: *About coming out with Alzheimer's disease.*

Phil: Right.

Christy: *And when Mayor Pete Buttigieg talked about that, about his coming out experience--not with Alzheimer's disease, but as a gay man--that resonated with you. That's what gave you the idea to talk about coming out with Alzheimer's disease. Can you tell us more about that?*

Phil: I wish I could tell you what resonated with me, but I don't remember. But I have been thinking about coming out, you know, with Alzheimer's ever since I came out with Alzheimer's, I suppose. I remember being struck at one or almost every speech or presentation I've given where somebody comes up to me and thanks me for being so brave and for telling my story. Matter of fact, this morning, one of the researchers thanked me for telling my story of living with Alzheimer's and living with an Alzheimer's diagnosis. And it always surprises me when it happens. And part of me feels like, *Well, of course I would*. I mean, why wouldn't I, right? Why wouldn't I talk about this? It's something that's happening to me. But then I think about people who live their lives in the closet and don't talk about another huge part of themselves, and what that means.

And people who come out as gay--not so much anymore, but where certainly 50 years ago, that was a brave, very brave thing to do. People didn't necessarily do it. 50 years is when Stonewall actually happened. It's the 50th year anniversary of the riots at Stonewall in New York, and those sort of the beginning of the modern gay movement. And you know, *that* was brave then. And I wonder now, although I don't--maybe--that coming out as living with Alzheimer's is also brave. And is it because of the stigma that so many people face? Is it because we're just talking about a private issue? Is it something that people are terrified of? I don't know what makes people come up to me and thank me for telling my story.

Christy: *I appreciate the fact that you spend time with us on the show and that you offer insights into what it's like to be a person living with Alzheimer's disease, to be a younger man living with Alzheimer's disease. Those are the specific things that I really appreciate. Plus, you're my friend and I just like hanging out with you. But I guess the word brave didn't occur to me, in the sense of sharing your story. Now, in the sense of coming out, I think unfortunately, that does apply. And the reason I think that is because there is so much stigma and discrimination. And people hear the word Alzheimer's and start to have questions about can someone still work? Can they still function at work? Can they answer their own questions? Can they use a stove? And so it's not that the questions themselves are from out of left field, but I think it indicates people who are not familiar with Alzheimer's, don't*

understand that it's a progressive condition. Meaning people start at a place of very high function and it progressively causes various impairment along the way. But you as a person are not a totally different human being than you were the day before you got that diagnosis. Rr even the day before you showed the first symptom.

Phil: Right. But you've worked with 1,500 people who have the Alzheimer's diagnosis, or are living with Alzheimer's. Do you sense among them a reluctance to talk about the disease, or to talk publicly about the disease? I know a lot of people aren't comfortable talking publicly about anything, but you know, if you were to say to somebody who still could do an interview, "Would you talk to 'x' outlet to talk about having Alzheimer's?" Would most people say, "No, I don't want to talk about that"?

Christy: *Well, this is a unique privilege for me, getting to have you on the show and to spend time with you and to spend time with Jeff [Borghoff, the face of the Alzheimer's Association young onset campaign. Jeff is 54 and was diagnosed with Alzheimer's disease 3 years ago after almost two years of struggling to get a correct diagnosis.] on the cruise. Because typically I am not involved in a situation until someone has an undeniable--well, sometimes they're not. I started to say diagnosis, but sometimes they still don't even have a diagnosis at that point. In other words, typically when I'm called into a situation, the family calls me and says, "Oh my gosh, I don't know what to do anymore." And at that point, the person who has the diagnosis or the condition is not aware of it anymore.*

Phil: Right.

Christy: *And so even if they were told, "You have this diagnosis," they wouldn't believe that. So, under those circumstances, there's no way to ask that person, "Would you be willing to talk about it?" Because that would be, I guess, like asking you to talk about what life is like as a straight man.*

Phil: Right.

Christy: *It's just, "What are you talking, why would I talk about that? That doesn't apply to me." And so that's what it would be like for the people that I am usually spending time with.*

Phil: Mm hmm, mm hmm, mm hmm.

Christy: *Now, on the family side of it, that's different.*

Phil: Right.

Christy: *I think a lot of families are ashamed. Because the families sort of become the de facto spokesperson for that person with the diagnosis or the condition. And a lot of families are very ashamed of it. It seems to me to be a generational thing.*

Phil: Meaning?

Christy: *Well, I'm seeing people more and more who are very willing to talk about it and whereas a spouse 15 years ago, and the person, let's say, was 85, they would have grown up in an era in which anything outside the so-called norm was considered bad, shameful, a blot on their good character and good name. So that could be anything from having any type of brain illness to being gay.*

Phil: Mm hmm.

Christy: *Anything in between and around that. Just anything outside of a very cookie cutter, white bread existence. And it's not that, you know, people 80 years ago, 50 years ago, 60 years ago, weren't born gay. Of course they were. It's not that people 50, 60, 80 years ago didn't develop a brain illnesses like Alzheimer's*

disease. It's just that it wasn't okay to talk about any of that. It's as though it was some type of moral failing.

Phil: Right.

Christy: *Same with like, alcoholism, for example. Same thing, like it was some type of moral failing because people then, as now, just don't have a great understanding of the complexities of the brain.*

Phil: But there is this sense of, *It's okay to talk about things now.* I mean, maybe it's *The Ellen [Show]* and Oprah and where we're a much more sharing group of people.

Christy: *And social media.*

Phil: Yeah. Yeah. Right. I mean, it's not something to be ashamed about it anymore. It's something that is happening to us, right? This morning, at the event I attended at the University of Pennsylvania, the lead doctor of the Alzheimer's Center there was talking about people who have memory issues but don't carry certain markers of Alzheimer's in their blood. And he said, "They're clearly demented, but they don't have these markers."

Christy: *Did you let him have it?*

Phil: No, I just giggled quietly. Um, but, uh, the reason I bring it up, not just to rub it in your face, is to--

Christy: *Please don't say rub it in my face, because I do not say demented. I don't. I never have.*

Phil: I know, but the whole dementia conversation. But, we live in a time where we *don't* say, you know, a person who has Alzheimer's, a person living with Alzheimer's, even an Alzheimer's patient? We don't say they're *demented*. And as we have talked about, language matters, right?

Christy: *Mm hmm.*

Phil: And, you know, if it was commonly described as, *You have Alzheimer's, you're therefore demented*, I don't think people would be as willing to talk about it because being demented is not a good thing. You know, that's, that's a--

Christy: *Right.*

Phil: That's a crazy mental illness. And not that there's anything, you know, I'm not saying that there's something to be ashamed about, by, about having a mental illness. Matter of fact, more people need to talk about their challenges with, uh, uh, other types of brain diseases like depression, and like anxiety and stuff like that. But it's just interesting how words matter. And you know, we've talked about senility, and how dementia was often just in a basket with senility, right?

Christy: *Mm hmm.*

Phil: Am I, or am I sort of, making any sense about what I'm trying to say here? I do feel like, I feel like I'm not tying it all together.

Christy: *Yeah, you're, you are talking about why words matter. And I think there was something about the statement that the doctor made at the meeting this morning because he was saying--he used the word demented.*

Phil: Right.

Christy: *He said this, the statement was, he said something about people with, not everybody with Alzheimer's shows signs of being demented? Was that what he said?*

Phil: No, they said "they were clearly *demented*" but they didn't have Y, Y or Z markers.

Christy: *Oh, the markers. Okay.*

Phil: So, "they were clearly *demented*."

Christy: *Okay. Was there a different point about the markers being absent?*

Phil: Yes, the markers were absent. So it's like something called "non-Alzheimer's something something something." Apparently, it impacts up to a million people and isn't Alzheimer's but has memory illnesses. But, but that's, you know, it wasn't so much that he said that. I'm just saying, Would it be as easy to come out with Alzheimer's, or come out as living with Alzheimer's, if it was, *I'm coming out as demented*. That's what I was trying to say.

Christy: *Okay, gotcha. Yeah, sorry. It was hard for me to stay with you there on exactly when, when you said, "Well, is that making sense?" I'm like, I don't know, because we both have such hot button issues about the words and are so adamant about the fact that words do matter and language is so important. That's such an*

interesting question, because I've been anticipating recording this episode, and thinking about it since you sent me the email with the idea. And looking at something like, for example, the Stonewall riots happened 50 years ago. Marriage equality happened not that long ago. And the attitudes and the changes that have happened in 15 years is astounding. It's the biggest shift in the public's attitude about any type of civil rights issue in forever, basically. Since anybody's been tracking these things. In 15 years, the numbers flipped entirely, from opposed to accepted.

Phil: Right.

Christy: *And so my question is like, What can we, in the world of Alzheimer's and other neurodegenerative neurodegenerative disorders, what can we learn from that? What can we copy to help destigmatize, to create awareness, to help change the conversation about that? And one of the interesting things I read recently, and this was going back to marriage equality, is one of the things that they thought was a successful part of that campaign was focusing on love. As in, Love is love. And I was like, Great! That's what we talk about here.*

And then the second thing was they focused on was older adults. And I was like, Okay, you lost me there. 'Cause that's usually the focus here, too--is you know, Alzheimer's and other neurodegenerative disorders typically do happen for older adults, like, elderly adults, people in their mid-80s and beyond. So...it feels to me like I should be able to pick up some kind of clue. Or maybe I'm just hoping so much that there's some kind of clue because being able to copy success is really important.

So, I'm 49. In my lifetime, there has been significant difference in how various groups of people are talked about, are welcomed or included into society, and stigma attached to it. And I think something that was really significant was the AIDS epidemic and how organizations like ACT UP sprung out of that and got really serious about saying to the government, You're allowing our tribe to be wiped out. Like this is, you can call it epidemic crisis, whatever. This is ravaging our community. We're going to far too many funerals were losing far too many people. And so I think that activism made, obviously, a really significant difference in the government response to that crisis. Unfortunately, it took way too long and--but I'm wondering, is it going to take something like that to change the conversation about Alzheimer's and other neurodegenerative disorders?

Phil: Certainly if people in their 20s, 30s, 40s started getting Alzheimer's on an epidemic level, yes, the conversation would definitely change. Even in their 50s, the conversation would definitely change. I mean, you know, I'm an oddity. There's what, 200,000 of us in the country suffering from early onset? Something like that. I mean, that's not very many. I'm an interesting oddity from a research perspective, because they want to understand why it is that those 200,000 people have, carry the biomarkers. The tau and the--oh, what's the other stuff? Tau...

Christy: Amyloid?

Phil: Amyloid, thank you. But I have another answer for the, did the AIDS--and actually for Alzheimer's too. And I do think it is, it does come to coming out. I think the more people that are public with this diagnosis, that they are living with Alzheimer's at a younger age and as science improves and can start to say earlier and earlier, *You have this. You're going to get Alzheimer's.* You know, I think that begins to change the narrative and begins to--it's not something that's just locked away in a nursing home. And that the rest of us don't have to look at. It's something that is real every single day and....

I've been very struck--so I'm in the middle of fundraising, right? 'Cause we're doing this event for The Longest Day in a week. Thank you for your contribution. But I'm very struck--you know, you hear people say, "Oh yeah, my grandmother had that," or, "My mother-in-law is dealing with it right now." But it doesn't seem to translate to people willing to, more people willing to open up their checkbooks and say, "I'm going to make an investment in making sure I don't get this," or, you know, "Making an investment so that my children don't get this."

Um, it's in your family, right? You would think you would want to make it stop. And I just think there's too much of a, too much distance. It happens to people 40, 50--I think about 50 years from now! But I bet you could think about 20 years from now, or 10 years from now. Or, oh, holy crap, they've now improved the diagnosis to the point where they're saying, "Your brain is showing symptoms in your 30s and if you, if we can't stop this, or if you can't change your lifestyle, you're going to develop, you're going to be living with this disease. And I think that might be the answer. But I also think that we need people to tell their stories and we have to, you know, sometimes I feel like all I do is talk about this anymore. I mean, I look at my email and it's all Alzheimer's-related. I look at my Facebook feed, it's all Alzheimer's related because, you know, that's what I'm engaging with.

Christy: *Yeah, I know. I know, Phil.*

Phil: Yes, I'm sure you do. And...what was my? You know, it's, it's, it's, it's, it's, it's, it can be exhausting. Just, you know, I, I joke now that I'm a full-time Alzheimer's advocate, like I used to be a full-time environmental advocate and full-time civil liberties advocate. I wonder if--although it pays *much* less--I wonder if I felt that way with civil liberties and the environment, if I sort of got tired of just thinking about those, or if this is somewhat different because it's much more real to me. I, I don't know. I don't know. Civil liberties was real to me too because gay rights was part of the ACLU, is part of the ACLU's agenda. Amazing, incredible, incredibly big part of the ACLU's agenda.

Christy: *Right. I think--*

Phil: So, I--g'head, g'head.

Christy: *I think you hit it right on the head: more people need to tell their story. And I think what stops that from happening, or historically has stopped that from happening, has been the stigma attached to Alzheimer's, where people have the idea--and this then goes to the stigma of mental illness. The brain is our really most essential organ. If the brain isn't working, nothing else works. But for some reason, because our brain is associated with higher thought, it gives it this weird alternate status where, "Oh, it's all in your head!" right? "Oh, mental illness!" like that's some type of awful thing. And depression is awful, but that doesn't make you an awful person.*

Phil: Right.

Christy: *You know, years ago, families would take care of a person who had some type of brain illness, be it untreated schizophrenia or bipolar disorder or Alzheimer's*

disease or frontotemporal degeneration--conditions where people can act differently than what is the norm in society. And when the people around them don't understand how to support them, or there aren't effective treatments available, obviously that can make for very challenging situations. So, those people historically have kind of been kept out of sight and families have experienced a lot of shame around that. And so people have not been as willing to get an early diagnosis. And now I think there's so much more information out there, about Alzheimer's in particular, that people understand, you know, certain symptoms can be associated with that. It's still an extraordinarily hard sell to get people to go to the doctor. It's very well known it's a fatal condition without any effective treatments and certainly not a cure. Versus, let's say, bipolar disorder where it still may be challenging to persuade a person to get a diagnosis. But one part of the appeal may be there are effective treatments.

Phil: Right, right. When I got diagnosed, one of the first dreams I had was of walking on my street and getting lost. And right after that happened, it was such a scary dream, I went out and bought myself sort of a medic alert bracelet. Made it myself and it says Alzheimer's with my name and says if I'm lost, call Tim and gives his phone number. And people look at, looked at that and I'm sure some still do, as radical. I mean, like, *You're labeling yourself! You're outing yourself!* It never, ever, ever occurred to me to keep this quiet, not once. And I wonder if that's because I went through it--actually, I came out twice. I went back in, um, after seeing my mother's reaction to it.

Christy: *Really?!*

Phil: Oh, yeah. Yeah. I said, "Oh yeah, I, yeah, yeah, yeah, I'm fine." 'Cause she went--I had just seen her, how she dealt with the death of her parents and she was in mourning, of course. And she went into mourning. I recognized it. It was the same exact mental status that she had just experienced. So, I couldn't take that and I sort of went back in and wasn't for many years after that I came out again.

Christy: *Oh, wow!*

Phil: But I never, ever, ever... You know, the other thing that strikes me is the minute I was diagnosed, I knew I was going to use whatever tools I had to, you know, search for a cure. And the biggest tool I had was my ability to write. So like my

first phone call was--maybe not my first phone call, but among my earliest phone calls-- was the Alzheimer's Association's PR Department, because I knew I wanted to write about it, because I knew I had to tell the story. And I think that, that has to come from being in the midst of another social revolution.

And I really hope....And you know, frankly, there are days when being a full-time Alzheimer's advocate is exhausting. And that, you know, you feel like you talk, and you talk, and you talk, and you talk. And I assume--and actually, as I'm saying this, it's the same as being a full-time anything advocate. You know, people who are into, you know, reproductive freedom. I'm sure there are many days when they feel like, *Oh my God, if I say reproductive freedom one more time...!* But you know, that's what we need to make progress.

And you know, I think it is, it's interesting. Another interesting thing--and I'm sorry, my brain is all over the place today and these things are just popping out like popcorn--but June is also, it's Pride Month, but what else is it? It's Alzheimer's and Brain Awareness Month. So, interesting coincidence.

Christy: Oh, I don't believe in coincidence.

Phil: All right. Then, how do you explain it, ma'am?

Christy: What do you call it? A synchronicity.

Phil: Kismet.

Christy: Yeah. There is--for reasons surpassing my understanding, and unfortunately, they're just so many of those things out here in the universe--but there is stigma attached to having a brain illness and, in way too many places still, stigma attached to being LGBTQ. I don't really think we're taking the show in a political direction by talking about any of these things. Because I think if you listen to the beginning of the show where I say, "We're all about bringing the Good Stuff: respect, kindness, love, empathy, and compassion," you kind of already have an idea of where I stand on things.

Phil: Mm hmm.

Christy: *Until we can talk about what's happening for a person in a compassionate way, in an empathetic way, in a respectful way, then we don't create an environment where it is safe for people to admit--even if it is only to themselves--Hey, I think something's going on here. This doesn't--whatever it is that's happening right now for me--doesn't feel right. It doesn't feel like it used to. Maybe I need to go to a doctor, maybe I need to get checked out.*

And the thing is, because of people like you who said that and went, Okay, there's a study? Yeah, sure. I'm going to pursue that. Absolutely. Yes, I'll go through all the testing. Then you ended up in this study and you've said many times before you've quoted--I don't remember who it is--saying, "The first Alzheimer's survivor is going to be in a clinical trial."

Phil: Mm hmm.

Christy: *And so how do people find that path? How do people spend the time being in a clinical trial, an intensive clinical study, like you were if they can't openly disclose that they have a condition.*

Phil: Yeah. I mean, how...? right. Acceptance. I mean, we often say that coming out is a self-acceptance situation. And having memory challenges or cognitive challenges and accepting them is an acceptance situation. And you know, even though it's a fatal disease and there is no effective treatment, all the things that you said, there is increasing belief that you can take steps--exercise, eating healthy, blah, blah, blah, blah--to perhaps delay the onset of some of these things. So, it's not even--I would even argue that it's not even just knowing that something is wrong that should send you to self-acceptance school. It's knowing it's in your family. It's a willingness to perhaps get the genetic tests and say, *I'm not going to put my head in the sand about this. I'm going to be out and open about carrying this genetic predisposition prep prep--* ugh, I always get this word wrong!

Christy: *Predisposition?*

Phil: Um, yeah, something like that. I think that is also possibly very important, that we should be thinking about. And, you know--

Christy: *I'm going to go one step further on that because I think--*

Phil: Okay.

Christy: *Whether you have genetic markers or not, look at all of the things--and we've talked about this before--*

Phil: Yes, we have.

Christy: *All of the lifestyle choices, right?*

Phil: Mm hmm.

Christy: *And if you don't want to develop Alzheimer's, if you don't want to develop vascular dementia, if you don't want to have a stroke, if you don't want to develop heart disease, all of these things, right? There's Type 2 diabetes--all of this, these risk factors are the same. We don't know enough about Lewy bodies. We don't know enough about that at this time to say what risk factors are for developing that. We just don't know. Likewise, frontotemporal degeneration, but we know enough about the other stuff to really make different choices as soon as possible. Because if you're shrugging your shoulders and saying, "Hey, I don't have the*

genes so I don't have to worry about Alzheimer's," that doesn't mean that you can do whatever you want and not wind up with vascular dementia or Type 2 diabetes or a massive heart attack or stroke or what have you.

So, I think just looking at everything through a different lens, of just health. Part of heart health is brain health. The two are very, very closely linked. And helping people be more aware of that. The other thing about the stigma though, and not changing our way of thinking, is that window of opportunity closes. Because we talked about this recently: about anosognosia, where people who are living with Alzheimer's or another type of neurodegenerative disorder, typically at a certain point are not aware that they have that condition.

And it's not a matter of saying, "Oh, hey, here's your diagnosis." Because the diagnosis itself often means nothing to the person. They don't understand the implications of it. Their brain is, for whatever reason, telling them, "You're good. No worries, it's all fine." So, if that's what your brain is telling you, it's very difficult to go out and share a message like you're doing. It's difficult to be an advocate like you are doing. And we lose that window when we attach shame and stigma to somebody having a certain condition. We lose that advocacy. We lose that voice.

Phil: Mm hmm. But what--I'll push back on one thing you said, which is, you know, we all know the lifestyle, you know, smoking, eating too much, and not exercising and all those things? That generic warning doesn't work. All too often it doesn't work. Sometimes it works, but all too often it doesn't work. And you still see people in convenience stores like crazy buying cigarettes. In this day and age, why would you smoke? But people do, a lot of them. And I wonder if it would be different if you were to say to somebody, "You have the genetic predisp--predispose it"? No! Oh, whatever! Um, take, take a, make a note of this for your show notes.

Christy: *Predisposition?*

Phil: *Phil's struggling with words.* But I wonder if that was, you know, more widely known, if people would take the actions necessary to delay the onset, or if they would say, "Oh, you know, even if it happens, it's not--". It's the same with smoking, right? It's, "Yeah, it might happen. I might get lung cancer, you know, but it won't happen for a really long time, and you know, they'll probably cure it by then."

Christy: *I don't know that people even think they'll probably cure it by then. I mean, no person with the ability to use Google is going to be thinking that. But what if the surgeon general's warning on a pack of cigarettes said, "Smoking can lead to Alzheimer's"?*

Phil: Mm hmm. Would it make a difference?

Christy: *I wonder because looking back historically, I mean, we've seen the rates drop.*

Phil: Yeah. But there's still a lot of people who do it!

Christy: *Not nearly as many.*

Phil: Right, everybody used to.

Christy: *Yeah, it's pretty significant. Oh, sure. I mean, people used to drink when they were pregnant too. Like, you know, "Have another martini!" Heck, I stood in the front seat of the car without a seatbelt on the way to see my sister when she was born. I was holding my dad's beer. I mean, you know, people do a lot of crazy stuff before they know any better, right?*

Phil: Right, right.

Christy: *So, change--I think for us warriors, change never comes as quickly as we'd like to see. But that doesn't mean it doesn't happen.*

Phil: Right. And that's possibly what's happening with Alzheimer's now, too. Change is happening. You know, that's why I didn't have any problem talking about it. There wasn't a stigma that I saw in my life, but I still think it has probably more to do with my coming out experiences as, "Eh, I've done that already. It's not a big deal. I did it twice. It was so much fun the first time I decided to do it again."

Christy: *So, was there anything from those experiences that you feel like it gave you--like, there wasn't a fear of the unknown because you had had a similar experience or do you feel like you'd have more courage? Or also, you were a real grownup, right, by the time you came out with Alzheimer's, versus being a puppy when you came out as gay.*

Phil: Right. I think I have largely learned that shame is a really bad thing.

Christy: *Mm hmm.*

Phil: And there's nothing to be gained from--well, let me put that in a positive. There is everything to be gained by being honest and open and telling the truth about what you're living with, and through. We have to do that. We can't survive unless we are willing to tell the truth and to--there's nothing worse than suffering in...in...silence is not quite the word I'm looking for, but suffering alone. Because you know, if you're feeling it or if it's important to you and it's important in your mind, I'm almost 95,000% certain that others are also feeling it, feeling that emotion, and have dealt with it, live with it, possibly figured out a way to move forward with it.

Yesterday, my sister and I went to meet our childhood friend who is in home hospice, Stage IV colon cancer. I misunderstood the situation. I thought she now had Stage IV colon cancer. She was diagnosed with Stage IV colon cancer years ago. So, she has defied the odds so many times now, in terms of her survival. And when they told her that there was nothing else they could do and sent her home from the hospital and put her in home hospice, they told her that her life expectancy was two to four weeks and she's now two weeks later. And showing no signs of, you know, of dying anytime soon. And I think it's because her spirit, there's a spirit there, a willingness to fight, a willingness to reach out. And you

know, she's the reason my sister and I were there yesterday. I haven't talked to this woman since I left for college when I was 18. So, that was long ago.

And my sister hadn't been in touch with her for a very long time too because, you know, people move apart, blah, blah, blah. But she reached out. She wanted to see us. It was an appointment we made. It was, you know, we went to lunch, we talked. We talked about our families, we talked about what's happening to us. She was very honest about her situation. And I think that, that willingness to, to confront, to share, to talk--you know, she and I, we were talking and you know, she could have sat on the couch when she got that first diagnosis of Stage IV colon cancer and said, "I give up." Right? "The odds are so against me, I'm going to die. I give up." And she wouldn't, she wanted to see her son graduate from college, which she has, and you know, all these things.

I guess it was three years ago or four years ago, she was diagnosed and that's an eternity with stage four colon cancer. And you know, she refuses to give up now. And my sister and I were talking in the car on the way home, when our mother had leukemia, was diagnosed with leukemia. My sister reminded me that she had just had, like two or three months before the diagnosis, had both of her knees replaced after, you know, years and years and years of pain. And you know, was now facing a diagnosis of leukemia and chemo and you know, so much more pain. And while she fought on, and while she had the chemo, she gave up. And she was gone fairly quickly after that.

And I think there is something to be said for fighting as long as you can, for sharing your story as long as you can, for *living* as long as you can. You know, I'm living with Alzheimer's, I'm not dying with Alzheimer's. Yeah, I'm dying with Alzheimer's, but we're all dying. We've talked about this. But I'm living with Alzheimer's and I'm increasingly determined to live with Alzheimer's because there's stuff I still want to do, places I want to go, people I want to see.

My nephew and I have really gotten engaged in our vinyl toy collection and reached out to one of the gods of the vinyl toy world and to talk about our idea of opening a museum based on our collection. And, you know, it's exciting, right? It's exciting. My nephew and I have been sitting here cataloging toys and going through boxes and, you know, getting dupes [duplicates] out and selling them so we could buy more [Dunnies](#). And, you know, sometimes I say to my nephew, "I'm done. Uncle Phil's done. There's nothing left." You know, "I gotta go take a nap," or, "I have to go to bed. I can't do this anymore." But often I'm really energized by it. And I'm *living*. That is the key. And I think if there's any message from this episode, in my mind, it's live, it's tell, share, don't be ashamed. Come out. People have to know, you know, otherwise it otherwise it can swallow you whole. The depression is real. The anxiety is real. But boy, there's only one way of fighting it. And that's sunshine.

Christy: *And that's our show. Thank you so very much for listening. Be sure to check out the show notes by going to DementiaSherpa.com/episode101. 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.*