

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
Episode 103: I Can See Why That Terrified You

Christy: So, I can see why that terrified you. I get that. And just a little listener alert: I'm about to hop on my soapbox.

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 today. In our usual fashion, we cover a whole lot of territory. I know we've been talking about driving a lot lately, both on the podcast and on the blog. Phil has some terrific insights; I think it's a really important conversation that too many families struggle with.

I think that these conversations that we've had and the blogs that we've done can be really helpful in getting a better understanding of what's going on with that and, hopefully, help you have a more positive experience with your person when it comes to that issue.

In any case, [in] today's episode we're going to start [with] talking about driving, as far as, does Phil have a plan for when he can't drive anymore? And an experience that I've had with one of my clients, where I thought things went pretty well.

From there, we move on [to] talking about addition before subtraction, which is a terrific tenet of really good memory care, and a technique that's easy to implement. Or, excuse me, I should say simple. Easy is when we do something a lot and have some practice. So you may need to practice it a little bit but once you get into the hang of it, it will make a terrific difference in your and your person's life.

But the bulk of our conversation today has to do with a documentary that Phil watched, and his reaction to it, and then my reaction to it. I think we actually end up in a good place, because we're talking about how to empower families and I think it's a conversation that will be helpful to you, helpful to your person, and I hope you enjoy it as much as Phil and I did recording it.

Christy: Phil, we've talked a lot about your adventures in driving: some various stories about going to Wilmington or going for a dog sitting job and the GPS has kind of thumped you when you were trying to multitask and the GPS is screaming, "Make a u-turn!" And it can be a little overwhelming, maybe, in those moments. And also about the fact that because you and Tim live in a relatively remote rural area, driving is really the only way to get from Point A to Point B. And the importance of driving for your independence and, I got out of it, kind of your overall psychological well-being; not feeling trapped. So my question to you is, do you have a plan for in the future when you're not able to drive anymore?

Phil: I should. But I don't, no.

Christy: Okay.

Phil: My quick thought about it is that hopefully I'll recognize that I won't be able to drive. And I'll also be more comfortable being at home. When I began to feel trapped in my house, I had just stopped working. And you know, the idea of, Oh my God, I'm not working anymore. I have nothing to do. I can't go anywhere. It was a lot to take at once. I think now I'm getting more and more comfortable with the idea that I'm not working. Though some days I feel like I work full-time.

Christy: For everybody who--maybe some new listeners, who haven't closely tracked your story, we don't know why that would be the case because you're fascinating. But you are a full-time Alzheimer's advocate. So, you do the show, The Alzheimer's Podcast, regularly. You write for MemoryWell. You do fundraising. You're on the board of the New Jersey Chapter of the Alzheimer's Association and you're also on the National Early Advisory Board for the Alzheimer's Association. So I don't want anybody to get the idea like, "Oh, poor Phil! He's just sitting there with nothing to do."

Phil: It seems like it's nothing, given what I used to do, but alright. I have a point of clarification: I was on the Early Advisory Council for National, but it's a one year term. So now I'm an alum of that.

There's also--and I'm sure people who retire feel this way too. Who retire willingly, I guess I should say. There is a vacuum. A sudden vacuum. And it is sometimes a struggle, particularly if you tend to be more of a homebody, of what to do with those hours between waking up and going to bed.

If you suffer from any form of depression, those hours between waking up and going to bed can be very challenging sometimes because it's not easy to do nothing.

Phil: And too, we've talked a little bit about identity. You know, when you retire, for many people, you lose a major piece of your identity. I am no longer X, Y, Z at X, Y, Z company. I'm retired X, Y, Z at X, Y, Z company.

So, I was just having a conversation this morning, actually, with someone who had retired. You know, the challenge of looking at that empty calendar can be significant. And trying to find things that you enjoy doing that don't necessarily feel like work but keep yourself occupied.

The worst thing in the world is just laying down. Because you're going to fall asleep, and then you can't sleep at night. And then the cycle starts, and it's really bad. The depression becomes worse.

Christy: One of the things you said was--I can't remember the exact quote, but it was along the lines of you hope that you know when it's time for you not to drive anymore.

Phil: Right.

Christy: And--

Phil: I know how unrealistic that is.

Christy: *Okay.*

Phil: I assume that's what you were going to say.

Christy: *I was looking for the words. That was not exactly what I was going to say, but I will say that over the years I have had a whole lot of people reach out to me saying, "Christy, my person thinks that it's still safe to drive, and there are scratches and dents in the car from parking lot accidents or sideswipes and they don't seem to be aware of it. So what do I do?"*

And I know a lot of families erroneously believe that they can get DMV involved, get DMV to revoke the license and then, problem solved. But the problem is DMV is not an enforcement agency. It's not like police, right? It's not like a warrant. [But] the police department doesn't show up at somebody's front door saying, "Your license is revoked, sir. Please hand it to me."

Even when a license is revoked--and perhaps the family takes the actual license out of a wallet--for men especially, if they have keys to a running vehicle, that means they can drive.

So, that's what I'm wondering about when I ask do you have a plan for when you don't drive. Is that something that you've really given any thought to? I know you've had so many other pressing things going on that maybe it's just something that you haven't really given a lot of thought to. Or have you and Tim sketched a broad outline of a plan?

Phil: We haven't. It does feel fairly far away and at this point, I think I'm hypersensitive to it. So, I did--I think it was back in October--say to myself once, when I couldn't remember if I had looked and I turned and there was another car coming--that was no accident, but it kind of spooked me, and I said that I shouldn't drive anymore.

So, at this point I feel hyper, hyper, hyper aware. Now, when the time comes, I don't know if I'll feel that hyper aware.

Christy: Right. And so that was October. This is June, as we're having this conversation. In October, you felt like you shouldn't drive anymore. It's June, you're still driving. What happened in the meantime?

Phil: Well, I did stop for awhile. And what happened was that I was going nuts, trapped in the house. And found that I was capable of driving that. That I know...I started driving locally and I felt comfortable and know that I was doing the things safely. And I have not had another experience like that.

Phil: I mean everybody has accidents, right? It's not just people with Alzheimer's or other brain illnesses that have accidents.

Christy: So, you're feeling safe in driving. You're feeling like everything's fine.

Phil: Yes. Just as fine as if I were non-mildly cognitively impaired person.

Christy: Got it.

Phil: I think a lot of people are driving around with cognitive impairment in their hands: their phones. And you know, if I have noticed myself doing anything, it's trying to take a sneak at my phone and I know I'm not unique.

Christy: Philip!

Phil: Yes?

Christy: Noooo.

Phil: You're yelling at me. Yes, I know. But yeah, I mean, who among us hasn't taken a look at their phone, Christy?

Christy: What? You weren't with me when I got that ticket 10 years ago.

Phil: And you haven't done it since. I swear, Officer! I swear!

Christy: No, totally I haven't because I'm cheap, Phil. And the burn of a ticket, I was just like, Seriously? Oh my gosh! So, I do keep it hands-free now.

Phil: Yeah, yeah.

Christy: I promise.

Phil: But even when you're doing hands-free driving and you're looking at the directions and it's telling you to go a way you don't normally go, you look at the map. So, you're taking the eyes off the road a little bit.

And distracted driving is, I think, almost, uh, um, what's the word? Uh, it's, it's, it is driving anymore, right? I mean, you're never sitting there staring at the road. I don't know if anybody ever did. I mean, you're always talking to somebody.

Christy: I was just wondering that, right. Because I remember being a kid--I don't know if it was like this in your family--but you know, You all better knock it off in the back seat. Don't make me pull over this car! And the swinging arm coming at your legs from the front seat.

Phil: Yeah, yeah, yeah. It's always been distraction while driving. And there have always been accidents while driving. So, I think the trick is being hyper aware and then, you know, I think when the time comes, what I'll tell Tim is, "Take the keys away from me, for God sakes. If you think that I shouldn't be driving, then take the keys away. And don't listen to me whine. Just take the keys away. I mean, you don't listen to me about anything else I whine about."

Christy: *I feel like I can see Tim rolling his eyes right now. Like, Oh, okay. Just [inaudible] you out. Oh, okay. Sure. That'll be easy.*

Phil: No, I can see him rolling his eyes now. But my immediate response to [that] is, you don't care [about] whatever else I tell you to do. So, why should you care here? Like, I'm gonna whine. Okay. You're used to that.

Christy: *You're used to that. It's just one more thing.*

Phil: It's just one more thing I'm going to whine about. So you know, get over it. I mean, talk about being cheap? None of us wants to replace a car.

Christy: *Right. That's true. That's true. I'm wondering, because I did this with a client several years ago and it worked out really well. He had been, I guess, professionally kind of roughly akin to you, as far as [being] a big time player, kind of a big deal professionally. And he was at a point in the disease process where what was most present for him was his time as a CEO. That was what felt like with his daily reality. And so he always wanted to, I mean that was his sense of purpose in getting up every morning, is to go to work. You know, following that routine.*

And that meant driving. But driving was not a safe, viable option. So they got an in home care aid and introduced him as the driver. "This is your driver." And it was kind of a company perk. And that worked really well. They had a lot of fun together. They went out and did things.

And it's funny because a lot of times care partners think, Okay, if a person is thinking that they're, let's say the CEO of this company, then why would they go do things like a scenic drive in the country or go out to lunch, or do things that are fun?

And it's because ideas can be held simultaneously. And so just for this man, it made sense that he had a driver, because he was kind of a big deal. But it also made sense that he would have fun in a day and do interesting things and spend time with his driver. It all worked together just fine, and that was a really good solution.

Do you think for you, is that something you would be amenable to? I mean, I know it's hard to guess into the future. But does that seem like just an idea of beyond the pale that you would ever have a driver? Or like, "Yeah, I could see deserving a driver"?"

Phil: Well, I have had the joy of having a driver, to take me down the Biogen trial. That was exciting. I think what you're touching on is find a way to take the deprivation and turn it into something fun.

Christy: *Right. There's this rule, it's called addition before subtraction--*

Phil: Right.

Christy: *--in Alzheimer's care or other neurodegenerative disorders, where if I don't want you to do something--and, let me just say as a caveat, that should always be because it's in your best interest. And I don't mean what I think is in your best interest. I mean, I'm talking about a safety thing.*

If I don't want you to do something, I need to present something better, more attractive to you first. So that it's a positive affirmative thing rather than a negative deprivation thing.

Phil: I think that makes brilliant sense. But it does not seem to be the state of the art in memory care or old age person care.

Christy: *Well, you're right.*

Phil: Yeah. I was watching a documentary yesterday, the whole time questioning my sanity for watching it. And--

Christy: *What were you watching?*

Phil: It's called...ugh...what's it called? It is called [Carpe Kilimanjaro: An Alzheimer's \[Project\]](#). Which I highly recommend, even if it did gut me. It was a very well done documentary.

But at one point, the wife of the man with Alzheimer's talks about how he's being treated in memory care, assisted living, and that the man had been very musical his entire life. He played, he loved music, blah, blah, blah, blah. And so he naturally just sort of whistled.

And how some of the other people living in the memory care unit or whatever found it annoying, so they punished him for whistling. I mean, it was just like, the story was--it just sort of went on from there.

It was just a horrific story about memory care and assisted living and what it must be like and sort of fed all my fears. But, you know, it struck me as just so wrong. You know, that here is something that this man who doesn't have a lot of joy in his life, yet still finds joy in and they're taking it away from him. It just, wow, you know.

Christy: *So, I can see why that terrified you. I get that. And just a little listener alert: I'm about to hop on my soapbox. So, here we go. No doubt, the memory care staff was thinking, Hey, we want to make sure that other residents that are annoyed by this man who's whistling, they don't act in some type of aggressive manner toward him.*

So, here's the problem with that thinking--and I say this as a former memory care director--number one, music is the last part of the brain that's affected. Music is a way that you can still connect to your person, pretty much all the way down to their last breath. Music is vital, it is crucial, it is like, I think of it as part of a life force. It's a big, big deal.

Second of all, anything that brings somebody joy that is not harming another person, we want to get behind that 100%.

Third thing, when somebody is annoyed by whistling, no problem. We help them head into a different direction and get involved in something else entirely.

As memory care professionals, it is, in fact, our job to make life as absolutely awesome as it can be for every last person who lives in that neighborhood. Because we work where they live. They're not an inconvenience. They don't need to bend to our will or what's most convenient for us. We are there for them. It is, and should be, always 100% about them. That is every last person as an individual.

Hearing my friend tell me about watching a documentary that scares the bejesus out of him is eviscerating. As memory care professionals, as any type of professional who works with people living with Alzheimer's or any other type of neurodegenerative condition, we have a sacred responsibility and duty to make them feel safe, secure, and loved. Always. That's the core of it, 100% of the time.

And you know, it's just not that hard. It really isn't. It requires learning some new skills, learning some new techniques, but if your heart is there, if you look at a person and see a person, I promise you can learn the skills and techniques. You can wrap your head around this. You can do those shifts in perception. And that is what memory care professionals or other professionals working with this population is called to do.

If it is not your holy vocation, that's okay. The world needs other types of professionals, people who do other things. Go find your passion. Go find what you really should be doing, because it sure as hell should not be working with this vulnerable population.

Phil: Let me ask you to turn that on its head a little bit and say what if you're a family member and you find your person in a situation like the one in that documentary and you've tried other places, and it feels like this is just the way it's gonna be. What do you do?

Christy: Well--

Phil: I took away the easy out of finding a new place.

Christy: *No, I'm not a big advocate of moving people from place to place because that's very confusing for people with cognitive impairment, a continuous change of environment. And you see a significant change in cognition with every change of environment. So, I'm a big, big, big fan of making the right choice the first time.*

And I guess, peeling that all the way back is, I'm a big fan of really doing what's right for your person and so, it's not going to be the same answer for everyone but honestly, and I think everyone knows this about me by now--and I say this as a former memory care director--my bias is toward in-home care and in-home support.

Because I've never met anybody who's like, "You know what? If I could just guarantee that I'm gonna spend the last 3 to 5 years of my life in some place that I've never lived before with people I don't know, sign me up for that!" People don't say that; people don't want that. Everybody wants to be in their home, in a familiar environment. That is people's universal first preference.

That said, there are some people who are highly social and they love memory care. They're great in environments where there's a lot going on and stuff to do and friends and people to talk to and they have a great time.

When I say that, of course I'm talking about decent, good, quality memory care. The fact that we have to have this conversation in 2019? My stomach is churning right now, it's so gross. This should not even be happening.

Which gets to the crux of your question. What about a family that finds themselves in a situation where their person is getting awful care and this feels like this is just how it's going to be? I reject the premise of the question, because I'm one of those never say die people, I'm one of those find a way people, I'm one of those if I don't like it, I'll change it people. So I don't believe there's any need to accept a bad situation as this is just how it's going to be.

I believe in being an effective advocate for your person. Heck, I even developed a free course on how to do that. What typically happens, though, is families feel

worn down and don't know how to do that. Or they're afraid their person will become a target of retaliation.

What's sort of stunning to me, as I've watched memory care as a whole go in the wrong direction, is families accept that. Families don't tend to think of themselves as consumers, but they are. They are paying every month, or cutting those checks on behalf of their person, for services rendered. And when the services aren't being rendered, I hear a lot about fuming to spouses and venting to girlfriends, and certainly a lot of tears of frustration, but not really any action that will change the situation.

I think there's just a really big misconception with families about how much power they have. Unless you're in a remote, rural area with virtually no services of any kind, there's probably at least one competitor to your person's current community. And in this example, Phil's cut me off from the possibility of even suggesting that, but just because you have zero intention of moving your person doesn't mean you can't remind the current community that you understand you have options.

I'm definitely not a proponent of confrontation. But whatever happened to having a conversation? I mean, I go through all this in more detail in the Effective Advocacy course, but in essence, the idea is to hold others accountable. If they tell you implement ABC solution, the next logical question is, "When can I look forward to that?" quickly followed by, "Who's the owner of that project?" And then double-checking you have that person's correct contact information.

We live in an era right now where accountability and consequences can feel like a pipe dream, but I'm certain the only way change happens is for us to work toward that. So I would say to that family, or any family who's unhappy with their person's situation, you don't have to accept that this just how it is. You get to request, push, prod, nudge, give a friendly love tap or playful shove the professionals to get to a place as quickly as possible where your person is getting the care and love they're entitled to.

And that's our show. Thank you so very much for listening. If you'd like a link to the free Effective Advocacy course I mentioned, just head to the show notes at DementiaSherpa.com/episode103.

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.