

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 116](#): "My memory was too good."

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.

Phil: My journey is so weird.

Christy: We talked a couple of months ago about [the Biogen trial ending](#) as kind of a shock surprise to you, who were part of it. And then you mentioned that you were open to being in another trial. And then, I think it was last week or maybe it was the week before, you were pretty excited. You told me you'd found one, you were going through the process and were going to be starting soon. Then yesterday, another plot twist. So what happened?

Phil: I failed.

Christy: What?! What do you mean, you failed?

Phil: I was too smart. I was too good and my memory was too good. I didn't make the study. So, it wasn't for a drug trial, it was for an observational, long-term, longitudinal study.

Christy: So, hold on. Was it looking to measure disease progression over time, or to look at changes that happen over time?

Phil: Yeah, if I could find what page that was on. I still have the consent form. [It says,] *“Designed to look at the relationship between clinical cognitive imaging, genetic, and biomarker tests to understand the full spectrum of Alzheimer's disease from its earliest stages.”*

Christy: *Okay, so that would seem like you're a perfect candidate.*

Phil: Yeah, wouldn't it?

Christy: *I mean, earliest stages. Okay, they missed kind of a three year window on you. But again, how are you not the perfect candidate? I don't understand. What happened?*

Phil: I dunno. I've got a message into my doctor who happens to be the principal investigator on the study at the University of Pennsylvania.

So, yesterday was the qualification. We went through the consent form at great length. Tim had to be there, which meant that it cost him a day's worth of work. And then they sent me in for quote unquote testing.

And I don't know if you and I have talked about this, but I find these memory tests to be absolutely, ridiculously simple. And I understand that obviously if something's wrong, if something's seriously wrong, you're not going to be able to remember these things.

Christy: *So, what type of test is it? Is it a [SLUMS](#)?*

Phil: I don't remember the name they used, but you know, stuff like: hold up a watch. *What is this? It's a watch.* Hold up a pencil. *What is this? It's a pencil.*

Christy: *Okay, that sounds like a [Mini-Mental](#). Do you have to draw a diagram?*

Phil: Draw a picture; remember the three words. Usually it's *apple, penny, table*. There's something, something flag. I don't recall exactly. What day of the month is it, what day of the week is it, blah, blah, blah. All that stuff. So, apparently I got a 30 out of 30 in that. And then they read a five sentence story and I had to repeat the facts of that story, and then they sent me away for 30 minutes to sit in the lobby and come back and repeat how much of the story you remembered. I remembered it all.

Christy: *So, like a good reporter, did you hear the story, then go out to the lobby and take notes?*

Phil: I didn't take notes, but I thought about it [the story]. Had I not thought about it, I probably wouldn't have remembered. But, you know, I tried to implant it a little bit. And then came back and I answered truthfully and I remembered the story. I remembered all the facts.

Then I went in and I had to remember--they had interviewed Tim, and Tim told them about some things that had happened in our recent past. I happened to remember them this time.

So, like a week ago, and then maybe two or three weeks ago, stuff that happened. Maybe a month ago. So, when I repeated all that, when I recalled all that, the lady looked sort of puzzled and she said, "I need to go talk to [her colleague]." She comes back, and I said, "I did too well, didn't I?" And she said yes.

Christy: *So, again, for the description of what the study is supposed to be, you seem a perfect candidate. The other thing I'm wondering about, Phil, is you have talked about, in the past, particular to you and, we think more common in people like you, who have a diagnosis of younger onset, it's more your long-term memory rather than your shorter-term memory that's an issue. And I'm wondering, if they had asked you about something that happened six months ago or a year ago, how that might have affected your score.*

Phil: I suspect--yeah, depends on the event, but I suspect I would've had more trouble. And it's funny because as we were sitting in the waiting room, I opened *The Washington Post* app on my iPad and kept hitting reload because it kept saying Tuesday, and I was like, *It's not Tuesday; it's Wednesday*, and I kept hitting reload.

And, at one point I looked at Tim and I said, "What day is it?" And he said Wednesday, and I was like, *Oh, that's why*. No, no, he said, "It's Tuesday." And I was like, *Oh, that's why* The Washington Post *app won't reload, because it is showing today's news. It's not Wednesday*. So, had I not gone through that and had I sat down in that room, I wouldn't have known what day it was.

Christy: *So, this experience sounds like pretty much the polar opposite of the experience you had the last time you went in for the Biogen study, because even after the study was stopped, you still had some follow-up appointments.*

Phil: Right. And, no, it's not the polar opposite. I mean, they told me, it was either the ABC study or the Biogen study, it all begins to blend in my mind. There's another longitudinal study that I'm part of called ABC.

So, it's once a year. You go down and you do testing and they said I scored slightly better in that.

Christy: *I remember you telling me about that. That was around the same time you went for that final Biogen appointment.*

Phil: Yes. I don't recall what the Biogen stuff was, but it's the same test over and over and over again. And I realize if I was further along in the journey, then having the same test over and over again would be challenging because I wouldn't remember.

But, I'm reminded--I had dinner with [Jeff Borghoff](#) and his wife, and another couple that live near us, with the guy who has early onset, and his wife, and Tim and I, and it was right after the testing where I did slightly better and we were all joking about the *apple, penny, table* test.

So, everybody at our stage in the disease memorizes this.

You know, you'd think that all of these smart scientists would understand that. And, if they're truly trying to capture people in the earliest stages, would modify their tests. I understand there has to be a baseline, I understand there has to be something, but you know, it's got to be more challenging.

Christy: *It's funny you say that because 15 years ago when I was a Social Services Director, I had to administer that as people came into the rehab so that I could get a baseline on their cognition, because these folks were often post-op. And, so, of course they were there for rehab and physical therapy, of course it's going to measure that progress.*

But, I needed to look at how were they when they came in as compared to, Okay, it's closer to discharge. So, is there a cognitive issue beyond the knee replacement or the hip repair or whatever? And, I thought to myself, I need to memorize this 'cause I might need this information 50 years down the road.

And then, I can't remember, I think it was somebody from the VA I saw administer it, and she didn't say apple, table, penny. She chose three other random words. And she's like, "The point is, can people remember the words that we're giving them? But you don't want to--because you're doing repeat testing, you don't want to keep giving the same words."

I was like, Oh, that makes sense. Oh, shoot. Maybe memorizing it isn't going to help me 50 years from now. But, I understand your point, and it seems there's not a standard way of administering.

Phil: But, there has to be a test that better captures this. I mean, after we got home--well, in the car on the way back, Tim and I were joking that I'm the first person to be cured of Alzheimer's 'cause you know, I got a perfect score.

Then we were standing there, we had to drop the puppy off at a friend's house, and we went to pick her up, and the friend was telling us about how she took her to a dog park in New Jersey. And I was like, *Oh really? What one, and can anybody go blah, blah, blah.*

And she's telling us about it and Tim looks at me and he goes, "We've been there." And I looked at him and I went, "I don't remember ever going to a dog park."

And on our way back from picking up the puppy to the way home, I was trying to sort of capture my feelings of failing to qualify for the study, and I could not come up with the words. I just couldn't.

And, I'm sitting there and I'm going, *The irony here, of testing perfectly and then an hour later being reminded that not all is well with Phil.* And the thing that truly rubs me wrong is, there is a crisis of pretty large proportions, because they can't find people to participate in these studies.

And this was no-joke study. I was going to have a lumbar puncture, three PET scans, MRIs, genetic testing, extensive memory testing--which, I was sort of looking forward to, to see where I rated--and it was, I think, four or five visits in the first month, and then it went to once a year for five years.

You know, sometimes Tim had to be there with me, so again, because of his work schedule, he would have had to find somebody to cover for him, lost income. But, we think it's important.

Christy: *It is.*

Phil: And we made--you know, my sister covered Tim's walks yesterday. He lost all that income. We had a friend take care of the puppy; now we owe her. And the time, we were down there all day, even with the abbreviated thing, we were still down there pretty much all day and it's not easy to do.

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Phil: And for them to say, "Nope, sorry, you passed this really silly test so you don't qualify."

It all seems so short-sighted to me and therefore it frustrates me greatly. 'Cause I really do want to do my part in helping further the research, and I haven't found another clinical study.

The one that I supposedly qualified for, I just felt very uncomfortable with the facility, so I didn't want to go back. And, the big tau test that's here, that's not being run anywhere near me. I don't remember who's doing it, but the next sort of wave, the big wave test, I guess it's [a phase three, the tau test](#).

So, this was my opportunity. This was my chance to keep giving back. And...[it's] frustrating. Frustrating. But, on the other hand, I have been doing a lot to take care of myself and to try to, I guess, slow the progression of the disease and maybe I am sort of

gaining cognitive ability. You know, maybe it's true that you can restore some cognitive ability.

Certainly, I think, science believes that you can delay the onset of further symptoms through watching blood pressure, cholesterol, weight, stuff like that. And doing exercise. And I have been doing that like a crazy man. But again, yesterday, the ups and downs, the ups and downs, not knowing what day it is, knowing what day it was, not remembering stuff, not being able to come up with words. You know, I just came back from rowing class, so, I feel great right now. Absolutely, great.

Yesterday, I did row before I went down there. Maybe that was a mistake. I actually rowed 8,000 plus meters before I went down to Penn and maybe you know, the blood in the brain made it to do better. Tim's like, "You should've just forgotten a fact or two." And I'm like, Yeah, I know. I know. But I feel, then I'd feel guilty about that."

Christy: Right. It makes it hard for me to wrap my head around why you wouldn't have qualified for the study, because this too seems like really valuable information to be recorded for the record, for looking at, Is it that Phil's brain, specifically, responds to all of this stuff? Or is it, Phil is yet a another example that doing these things that we recommend, meaning the scientific medical community, really work?

I mean, clearly, you're feeling better. That's a good thing. I got a sneak preview of your next article. I always feel very special when that happens. And, you mentioned in that that you've lost 20 pounds. So, congratulations. It seems to me that, again, that just more enhances you as a test subject.

Phil: I guess, because these protocols are so rigid.

Christy: Yeah.

Phil: I guess they have to be in some ways.

Christy: I understand that, but, it seems like you should be able to just play the Phil Gutis Card, right? Don't you know who I am? I'm kind of a big deal!

Phil: Like I said, there is a message into my doctor who happens to be the principal investigator for the trial at Penn.

Christy: *I do hope that you let us know what he has to say and what the explanation is.*

Phil: I'm looking forward to that. But it might be that he just says, "Look, I don't have any kind of flexibility. That's what the protocol determines, and that's what the protocol determines."

There was a question of whether my sister was going to be able to cover Tim's appointments in the afternoon. So, I wrote to them and I was like, *Is there any way that Tim doesn't have to be there? And that you can review the consent form over the phone. We've consented to these things many, many times now.* Nope. There's nothing in the protocol that allows for that.

Christy: *So, it's very rigid.*

Phil: It's very, very rigid.

Christy: *Which, again, you would want in a scientific study. But that seems kind of outside that scope.*

Phil: What do you mean?

Christy: *Well, I mean it's before even being in the study. So, how about a little human flexibility?*

Phil: Yeah. Well, apparently science doesn't do *human* well.

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Christy: The test that you've been describing sounds like what's called an MMSE or Mini-Mental State Exam, which used to be very popular. And then, I'm not sure who originated or designed that, but it fell out of favor, quite some time ago actually, because they wanted to start charging for a Copyright. So, it was gonna be a dollar per test. And so, just speaking from my long-term care experience, a dollar per test is not financially viable every time you use it, considering the volume with which it's used. And then also around same time, what's called the Mini-Cog became more popular and was also adjusted for English not being the first language, and for educational level.

Then the SLUMS became kind of the standard and is now. And that stands for the St. Louis University Mental Status, I believe. And that goes kind of in a completely different direction. And it does say, What state are we in?

So the SLUMS actually looks at word problems. So, for example, I know I'm probably not quoting it exactly from memory, but, something like, You have \$100 you go to the store

and buy two dozen apples, which cost \$3 and a tricycle, which costs \$7. *So, it's like that. And then the question after that little story is, How much, and you pay with the a hundred dollar bill, how much change did you get back?*

Phil: Right.

Christy: *So, it's quantifying objects, right? And, for me, I always think that's a really tough question, because I think in pictures. And so, I'm trying to picture two dozen apples and I'm thinking 24 and then...but it costs this other amount of money and then how much money did...and so, there are a lot of numbers that are thrown at you, but not specifically as a one, two, three, four, five. But more like two dozen or tricycle again, which is looking at how many wheels does a thing have.*

So, questions like that. And then there's also some shapes. Identifying shapes or redrawing a shape. So, I think there are like three shapes, and then you're asked to identify which one is a triangle or to draw one of those shapes, but it uses the word, and that seems to get better results.

That again, is adjusted for educational level, and English not being the first language, and it seems to be more accurate. The final story in it, this is where it really seems to separate out even people who have done pretty well up to that point, the final story in that test is where I see more people struggle than at any other point in that test.

Phil: And it's more than five sentences long?

Christy: *I'm going to look it up real quick. I don't think I have a copy saved. Oh, PDF. And the VA uses it.*

What I was just saying is, "You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20. How much did you spend? How much do you have left?"

Oh, and then this question I'd completely forgotten about. It's been a while since I've done one of these. This is a great question. So, "Please name as many animals as you can in one minute." And you could do animals or you could do ingredients in a salad. That question is also very telling.

Okay, so here's the story. "Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She

married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children when they were teenagers. She went back to work. She and Jack lived happily ever after. What was the female's name? When did she go back to work? What work did she do? What state did she live in?"

And, of course, in administering the test, you pause and let somebody answer the question.

Phil: Right. Don't remember her name, she was a stockbroker. Don't remember when she went back to work. Maybe after her kids were grown? And she lived in Illinois.

Christy: *Do you have a barfing dog?*

Phil: Oh, he's got a heart condition.

Christy: *Oh, is he okay?*

Phil: He coughs like that. He's unhappy because he can't go to work with Tim anymore and the puppy goes.

Christy: *Oh, poor guy.*

Phil: Yup. Yeah.

Christy: *The female's name is Jill. When did she go back to work is, "when the kids were teenagers." But the answer you gave is usually the answer people do give, which is, "when the kids were grown." What work did she do? Stockbroker. And people usually do get that right.*

And then, "What state did she live in?" This is where people will often say, "Chicago." And you, of course, said, "Illinois," which is the correct answer.

Phil: I saw where that was going. And, you know, it's interesting. I think I did something much closer to that for the Social Security Disability test earlier last year. And I failed miserably. It was much more complicated and there was drawings and I had to draw them and then they took the papers away and I had to--and they were complicated drawings--and I had to put down what I remembered.

I was nervous. I will admit that. So, that probably impacted my score. I did not cheat even though it was oh so tempting because the stakes were so high. But, the woman at the end of it said, "Well, I don't see any problem, you did miserably." I was like, "Oh, well, thank you."

Christy: *Right. So, in any test, there's always this, you know, you want to do well, right? To say, Okay, I'm okay. But, then you need to do poorly to get whatever the benefit is of the thing you're trying to accomplish.*

Phil: Right. That's why when you wrote, when I told you yesterday via text that I had not qualified, you wrote, "My first instinct is to say, 'Oh, bummer.' And then my second instinct is to jump up and down and go, 'Yay!!!'"

You know, that's what's going through my mind, too. And of course, we've talked about the *Do I really have Alzheimer's, am I a fraud?* And, every time a [Randy Rainbow](#) or a [train going to the wrong station](#) happens to me, then I am reminded that something is seriously wrong.

Christy: *And that's our show. Thank you so very much for listening. Head on over to the show notes at DementiaSherpa.com. And if you feel like you need to clone yourself to get it all done for your person, be sure to visit our sponsor, Home Instead Senior Care-[East Portland](#) and [Clackamas County](#), and let them know that The Dementia Sherpa sent you.*