

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 117: Joining the #ALZResistance](#)

Phil: It can be resisted. It's not easy, it takes some work, but I think it's worth it, because if you can beat this back a year, six months, a decade or two...think about that. If you could beat this back a decade, wouldn't you want to do that?

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 back with us today. As regular listeners know, sometimes we go deep. There've certainly been times I've cried as I'm putting the show together and listening to Phil again. Today, though, we're going in a different direction!

Phil has really been focusing on his health, and it's been paying off...kinda, sorta. In [episode 116](#), Phil reveals he didn't qualify for a study because he did too well on the cognitive testing.

In this episode, we're looking at the flip side of that, talking more about what's going well, how that feels for him, and maybe most important for our listeners, what he's doing! We always want you to be able to do swipe any good ideas for your own person...and yourself!

I've added an explainer into the transcript of this episode, because there are a couple spots where you may not understand the reference unless you're super deeply steeped in Dementia World.

Anyhow, go to DementiaSherpa.com/episode117 for the transcript & graphic Phil mentions at the end of the episode. Meanwhile, we open with Phil sharing what a friend told him after Phil said he didn't qualify for the study.

Phil: Now, another friend, who has some knowledge, said, "This doesn't sound like Alzheimer's to me. I'm not questioning whether you have a cognitive impairment, but it doesn't sound like Alzheimer's. Have you been tested for Lyme, this, that, all these deficiencies and stuff like that?"

And my answer is, "I believe so. I don't know. I would think that to let me into the Biogen test, they would have been pretty certain that I had Alzheimer's, but you don't *know* these things."

But you're left with the--as Tim and I were joking, I'm the first survivor. I should carry the white flower at the Walk [to End Alzheimer's] in November. [*The Walk to End Alzheimer's features a Promise Garden. Participants plant their flowers in the garden. A purple flower signifies the loss of a person dear to you to Alzheimer's or another dementia; yellow is for care partners; orange is for support of the Alzheimer's Association; and blue is for those living with a diagnosis. The white flower was introduced last year with the hope that it will ultimately be carried by survivors. For now, it signifies hope for a cure. -CT*]

But, I don't think that's true, unfortunately. And I assume you, you would agree.

Christy: *Well...*

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Christy: Usually the bulk of the time that I spend with people living with the diagnosis, they are quite a bit further along in the process.

I have been privileged enough to spend a lot of time with you, by virtue of getting to talk to you every week. And, of course, the week that we were on the cruise. Sometimes, I do see a lapse in memory. And then, sometimes I wouldn't know.

What I have noticed as far as recording our podcast episodes is, depending on the time of day, your language changes. Typically, we record at the time we're recording now, which is 8:00 AM Pacific Time, 11:00 AM Eastern Time.

In those episodes, very rarely is there what I call kind of a blip. But, we have done I think three or four episodes where for whatever reason we needed to record later in the day. And so, typically that was 1:00 PM Pacific, 4:00 PM Eastern and I think maybe even once we did like 4:00 PM Pacific, 7:00 PM Eastern. And that's where I have noticed more of a disordered language.

So, if the sentence is [Jill was a stockbroker](#), if that was the sentence that was meant to be said, it might come out more like Jill stock broker was...more like that, before being able to put the words in sequential order. Little things like that.

Based on my experience, some of the little things that I see are consistent with that [Alzheimer's diagnosis], but I'm not a doctor. I'm not as scientist.

You know, the things you describe are consistent with the diagnosis. That said, if I were you, I probably would jot a sticky to myself and say, "Hey, Tim, was I tested for Lyme disease?" Or, "Are we pretty confident that before I got into the Biogen study that they had ruled out other things?" Just to know that.

But, I will say that Alzheimer's, as well as Dementia with Lewy Bodies, or other types of neurocognitive disorders, those are diagnoses of exclusion. Meaning that typically somebody is going to go through a lot of testing for a lot of different things before a doctor is able to arrive at that diagnosis.

For example, and this is especially true of people who are age 70 or better, things like dehydration, urinary tract infection, constipation, depression, thyroid function, upper respiratory infection.

Those types of things will cause someone to present with what appear to be symptoms of dementia. Which sounds really weird if you're outside of this world that I live in, where, like, "Really? Urinary tract infection? That's a problem? That seems weird. Why would that look like dementia?"

But, in the process of arriving at an accurate diagnosis, they need to look at all of those things to make sure, if they are present, that they're addressed. And often that will improve symptoms of cognitive impairment, even if someone ultimately does go on to get a diagnosis of Alzheimer's or another type of neurodegenerative disorder.

That was a really long way of saying, yeah, probably they were looking at everything before they came up with that diagnosis.

Phil: I would imagine so. I mean, they spent a gazillion dollars on this study. You would think that they would have done a good screening job, but you never know.

Christy: You never know. [Kris Kristofferson that was diagnosed with Alzheimer's disease and it turned out to be Lyme disease.](#)

Phil: Right.

Christy: Are you curious about, if the fact that you failed to qualify for this study, if that means that you're looking at a disease progression that is very slow, what that would mean? The implications of that?

Phil: I'm laughing, because also in the car on the way home [when] we joked that I was the first survivor, I looked at Tim and I said, "Does that mean I'm stuck with you for the rest of my life? If it's really long?"

And he goes, "Yup!" And then I said, "*Man Declared First Survivor of Alzheimer's Kills Himself Later That Afternoon.*"

I have had indications. So, when I agreed to be a little bit of a lab monkey for some professor at Penn and I went down and sat in front of his class. And he asked me a bunch of questions. He did test, a memory test, a more complicated one, and I did very well. And he turned to the teaching assistant who had brought me in and said, "Does he really have Alzheimer's?"

And she said--I can't remember the exact words, and it kills me because I really would like to remember the exact words--I think she said, "MRI is consistent with diagnosis," or something to that effect.

And he said, "Well, if that's true," he said, "You're going to live for 20 years." And I was like, "Oh, okay."

But I'm about to hit, I'm a hundred thousand meters away from rowing a million meters since December of last year. That's a lot of meters.

Christy: *Yes, it is.*

Phil: So, I have really been working hard. And, you know, maybe that's what accounts for the improvements. And, maybe everybody else who has Alzheimer's should get on a rowing machine. Maybe not do a million meters, but do a thousand meters a day and then build up from there. Or whatever.

Christy: *I think that's probably a hard sell in an 85 year old body.*

Phil: Yes, I know. But, there must be some form of exercise. And I know there are exercises for the elderly, but it depends on when it hits. I mean, obviously, that's early onset [for rowing]. Everybody with early onset could get on the rowing machine and do a million meters.

And, you know, maybe they will experience the same thing I am, which is, generally, I feel pretty good. Definitely have episodes, but day to day, week to week, not so bad. And maybe that's what science will tell us is, *We can't figure this out, but if you do really vigorous exercise for you early onset people, you can really keep this at bay.*

Christy: So, this is consistent with what they're telling us, which is exercise, weight management, good nutrition, keeping your brain active, staying involved in things you enjoy. And these are all things that you do. Oh, and I didn't say water, which you're also very good at drinking your water.

Phil: I have become better at drinking.

Christy: I would say you're probably better than most. Seriously. I just met with a client family last night and one of the big issues is the person drinks less than 24 ounces of water a day, because of fear of not making it to the bathroom in time. And that is pretty common with people who have some type of mobility impairment and it certainly doesn't help anything cognitively.

Phil: No. It wouldn't.

Christy: At this point, it seems to me, you're kind of the poster boy for following the guidelines for brain health, and it seems to be working pretty well.

Phil: Which is great.

Christy: Yes.

Phil: So, you can resist. You can resist this. I mean, you know, if it's caught...Actually, this is an important message. If you catch it early, as early as possible, and you apply yourself and not dive deep into depression and, *Oh, woe, my life is over, blah blah, blah*. Maybe you can resist this. And it's not a cure, it's not a proven treatment yet, but maybe you can resist it.

And that, to me, should be a message you start to hear more and more. But, getting back to the start of this show, if they're [scientists] not letting people like me into tests, then they're cutting their nose off to spite their face. As you said, they should have welcomed me into this test with open arms, because maybe they would have learned something.

Christy: *For sure they would have learned something.*

Phil: Maybe they would've learned I don't have Alzheimer's. That's important, 'cause somebody gave me an Alzheimer's diagnosis. I don't think that's what they would've found, but maybe they would've found that this is the secret to prolonging quality of life. Maybe not life itself, but quality of life.

Christy: *It seems like you are living with a good quality of life. Is that your assessment of it?*

Phil: Yeah, I mean with the bumps. Yeah.

Christy: *Right.*

Phil: Yeah, I definitely feel--it's funny that you mentioned the time of the day thing, because, yeah, in the mornings I can be flying. By four o'clock, five o'clock, I'm generally napping. And sometimes I fall asleep really hard.

Sometimes I just relax and rest and read, but sometimes I'm sound asleep and Tim can't wake me up. Which means, then, that I wake up at nine and lay in bed

forever 'cause I can't fall back asleep, which is not good. Tomorrow, I think we need to be up at six to go speak somewhere. So, hopefully that won't happen today. I'm going to try like hell to stay awake.

But, you know what, I have also found that when I feel tired, if I hop on my home rower, do a couple thousand meters, I can generally beat that back.

Christy: *So, you get the blood flow going again.*

Phil: That blood flow going again. Important lesson, possibly.

Christy: *Right. Well, I am glad you mentioned, so we wouldn't do any of those types of afternoon recordings anymore and we haven't for a while now, because that nap time strategy has become more ingrained. And I do call it a strategy because you seem to be functioning really well.*

Sleep, rest, relaxation are so crucial to good brain health. And a lot of people, they have that kind of, I don't know--it is a weird thing. I've always thought it was kind of weird. Like, I'll sleep when I'm dead!

What? Are you trying to get there quicker? Like, stop. Study after study has shown it is really bad for your brain. It's like trying to drive an electric car without ever charging it. You're going to get so far and then that's it. You're done.

Phil: Right.

Christy: *People, after so many days--I don't have the study right up in front of me, but--will start to show actual psychosis from missing sleep. And there is no such thing as catching up on sleep on the weekend. It doesn't work that way.*

Honestly, anybody who can hear my voice, if you're not already sleeping seven to nine hours a night, make that your goal. And if your person is past the point where Phil is, which is probably the case, understand that they need even more than that. And a nap is a great strategy. That is helpful to let go of whatever stress may have built up prior to that point, to get a recharge, to not have to take in all

of the sights, sounds, smells, things going on around them. It's a gift to anyone's brain.

Sponsor: Hey, care partners, just a reminder: you don't have to go through this alone. Dementia can last up to 20 years, which is a very long time to fly by the seat of your pants, struggling through trial and error.

If you don't have a strategy, or if you're not sure what the next "right" step is, please book your complimentary [Dementia Caregiver Strategy Call](#) with me.

Just go to [DementiaSherpa.com/call](#) and you'll see the link to book your complimentary [Dementia Caregiver Strategy Call](#). You just put in your name and email, pick the time that works best for you, and that's it. It's really that easy! Again, that's [DementiaSherpa.com/call](#).

Phil: And it shouldn't be shameful.

Christy: *No. No, no, no.*

Phil: I kind of feel somewhat ashamed that I take these naps, 'cause you're not supposed to nap during the day, right?

Christy: *I think it's that weird American thing, because how many cultures have siestas, right? I mean it is a very, I think, uniquely, weird American thing where it is shameful to sleep.*

Is it shameful to use the restroom? No. Why do we use the restroom? 'Cause it's something our body needs to do. Likewise, sleep. Likewise, drink water. Likewise, eat food. Likewise, move. Breathe. These are just things that our body needs to do in order to continue functioning, period.

And why sleep was singled out as shameful...somebody has, no doubt, done the research and written a book on it. I don't know what it is, but it's like this weird competition thing and it's like this little macho thing too, I think.

And I know there's a globally famous politician who brags about only sleeping three to four hours a night. I think we can safely say that the whole world has seen the effects of that. And it ain't pretty.

Phil: No, it ain't.

Christy: *Whether you want to talk about the judgment or the decision making process or lack thereof, the language capacity, the...I mean, yeah...Sleep, folks. Sleep!*

Phil: Sleep, sleep, sleep. Don't be ashamed of it. I mean, that should also go into the stay active, exercise, eat well, watch your biomarkers--sleep should probably be part of that.

Christy: *For sure. Absolutely, but the other thing I would also like to point out, kind of as part of this larger discussion, because this is something that we also know is super duper helpful for your brain, is doing something that really engages your brain.*

So, the recommendation is 15 minutes per day, minimum, of concentrating on something. Sudoku is kind of the recommendation, rather than a crossword. And it's because of what happens inside your brain. It works differently in figuring out a Sudoku puzzle.

And you can [start with the very easy](#) and work your way up from there, but the point is, for 15 minutes, you need to be concentrating only on that. And if your brain kind of starts to drift and you realize you're thinking about your grocery list or your chore list, then you reset the clock and go back to 15 minutes. So, 15 minutes of concentration.

The other thing is, do something every single day that brings you joy, that makes your brain happy, that gives you that feeling of, Yeah. And I see you do that, Phil, with writing.

That is such a great outlet for you in not only expressing things that you think the world needs to know, but also in working through things where you're trying to figure out, Where am I landing on this? Or, How do I feel about this? Or, How

can I express how I'm feeling about this? *It requires concentration and it also makes you happy to be doing something that you've loved doing for so many years.*

So, I think it's important that people know about that too.

Phil: I agree. I very much agree. Yesterday, when I came home, I sat down and I started writing, because that's my outlet. Even though I was tired from the day, and I was tempted to go lay down, I said, *You know what, I need to capture this.*

Yeah. I do believe, and I actually had Tim design a little graphic for me, a resistance movement for Alzheimer's, ALZResistance, because I do think we can resist it. And I'm going to start trying to use Twitter more and I want to use that hashtag.

Christy: *#ALZResistance.*

Phil: Yup. Actually, I have a tweet drafted somewhere and I was just waiting for the graphic, so, I have to have to find it and put it out there.

But, I do think that it's incredibly important that everyone, not just people living with this, but their care partners and people who are afraid of it--which is I believe everybody over the age of 50 in the United States--needs to learn that it can be resisted.

It's not easy. You know, it takes some work. But I think it's worth it, because if you can beat this back a year, six months, a decade or two...think about that. If you could beat this back a decade, wouldn't you want to do that?

And that is, I think, where I'm increasingly coming out on living with this disease. *Can I push it back a decade?* When I first was diagnosed, I'm sure I've told you this story, but [Pat Summitt, that basketball coach, had just passed and she lived with early onset for five years](#). And that was the timeframe I put on myself: *I have five years.* And now I'm being told by some doctors that I could have 20 years. That's a big difference.

Christy: *Huge, huge. And I will say, when Pat Summitt died, I was stunned at how quick her progression was. That was super quick, because she went from working to like, Oh, there are problems at work, to boom. It seemed like the blink of an eye.*

Phil: Yeah, it was. Five years is.

But, particularly for even those who are just afraid, wow. If you could change some habits. And I'm not on any--I think I've told you this--I'm not on any crazy diet. I'm just using an app and I'm logging what I eat.

Which therefore means sometimes I have to weigh what I'm looking at to get the calorie count correct. But, you just learn so much about what it is and how much of what it means to grab a handful of chips. That handful of chips could mean half of the calories that you're supposed to eat for lunch.

Christy: *Ugh, that's an ugly trade off, isn't it?*

Phil: Right! And did you really get that much joy out of that handful of chips? Or did you just do it without thinking? Often it was, I did it without thinking.

Christy: *Immediate and very fleeting gratification.*

Phil: Yeah, like, *Oh yeah, just have some; Tim's having some.* So, I'll go by and grab a handful and then I'll finish those, and I'll go by and grab another handful, and suddenly you've eaten a third of the day's calories in just mindlessly having some chips. That's--that's--talk about head exploding! When I saw how many calories that handful of chips was, I was like, *oh, yeah. I don't know if I want to do that anymore.*

Christy: *I know how that translates to meters of rowing.*

Phil: Yeah, exactly. Gosh, do I hate Tim for being able to sit there and eat the bag!

As with everything that I've experienced on this journey of mine, and that I've had the opportunity to talk to you about, there's a lesson in this. And, yes, I definitely want to get more information out. But, even if I don't get any more information and things are status quo, I think ALZResist, ALZResistance is the way to go. #ALZResistance.

Christy: Love it! 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.