

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 106: I Don't Feel Like I Have Alzheimer's](#)

Phil: One of the things I struggle with a lot is this feeling that I generally feel so good, day to day, minute to minute, that I don't feel like I have Alzheimer's.

Christy: *You're listening to The Alzheimer's Podcast with Christy Turner of Dementia Sherpa, where we're all about bringing the Good Stuff --that's respect, kindness, love, empathy, and compassion--for people living with dementia, their families, and the professionals who support them.*

I'm Christy Turner, AKA The Dementia Sherpa. I've enjoyed the privilege of working with over 1,500 people living with dementia and their families so far, including multiple experiences in my own family. In the course of my career, I've transformed from total train wreck on my first day as a professional to local go-to expert, speaker, trainer, and consultant. And if I can go from scared spitless to confident care partner, I promise you can, too.

Good news, Phil Phans! Phil Gutis, our Assistant Sherpa, is with us today. I get the privilege and joy of talking to Phil every Wednesday morning. Often there's emails and texts in between. Since we've met, we've missed our weekly chat just once.

A couple of times, we've needed to talk on Wednesday afternoons. Depending on how full Phil's day was before we talk in the afternoons, you may detect what is for most listeners some subtle changes.

Coming by the exact right word or the exact right sequence isn't a guarantee for Phil in those afternoon chats.

The conversation you're about to hear was recorded in the morning, but it was the day after a very busy day. In fact, Phil's very busy day is the topic of our conversation. It sounds to my ears more like an afternoon chat.

Beyond giving you a little peek inside what it's like to be part of a clinical trial, Phil shares specific things he does that help him feel his best and the effect a busy day has on him. As you're listening, keep in mind that Phil is very early in the disease process and highly functional. He's able to successfully navigate a whole lot of life independently, relying on his husband, Tim, for emotional and logistics

support akin to any marriage. Then consider how your person experiences a very busy day and the effect it has on them--even if they're not able to tell you about it.

Christy: *Phil, when I first met you in, I think it was the beginning of the second week of April [2019], you had just found out, I think about 10 days before that, that the trial you were in [the Biogen trial] was [unexpectedly terminated](#).*

I thought that meant you were completely done. And it turns out you had some follow-up visits as part of that study, and you had your final follow-up yesterday. Can you walk us through why the Biogen study ended so abruptly and unexpectedly, and why you had follow-up visits after, and what the purpose of that was?

Phil: I can try. So, when the study ended back in--when they announced the study ended, back in March, the reason given was that the drug had failed a [futility] analysis, which I think means, in layman speak, that they were seeing no impact on people receiving the drug on their Alzheimer's or cognitive, memory issues--little to no, I guess.

And they yanked the trial. And it caused [quite a bit of consternation in the Alzheimer's community](#) and ripples continue to this day, I think. But they also told us at that point that we would have two more visits. Not infusion; that ended that day. But check-ups, MRIs, blood work, and more cognitive testing. Which, I'm not quite sure why they did that, but that was part of it.

So, yesterday was our final visit and Tim and I had to go to the hospital and we were there pretty much all day. As I told the lady as we were checking in after we arrived, "Yup, we're here for the Full Monty: bloodwork, testing, MRI, and an exam."

She started laughing and then I said, "Yes, if I don't put the hospital gown on right in the MRI center, I will do a Full Monty."

But, you know, it's interesting. It was a very long day. I came home and slept for three hours. But it was also a very bittersweet day. A lot of emotions. Because this was the last visit. And it was such a big part of my life for three years. That's where I got my diagnosis. Every month for the last three years of this journey has been marked by an infusion of aducanumab. I think I got that right.

So, it was sad to really see it end but it was also interesting because--I don't know if we've talked about this or not, but one of the things I struggle with a lot is this feeling that I generally feel so good, day to day, minute to minute, that I don't feel like I have Alzheimer's. And that I'm therefore a fraud in some ways.

I went to the hospital yesterday in one of those spaces, feeling really good. Like, *Nothing wrong in the world with Phil. He's fully hydrated, running on, you know, high test fuel, everything is fine.* Then by the end of the day yesterday, I have absolutely no doubt that I have Alzheimer's.

Christy: *What is it that changed in the course of the day, where you went from feeling like a million bucks and, Everything's great, to, by the end of the day, feeling like, Yep, this was a correct diagnosis! ?*

Phil: So, it was interesting. They did the blood work first. They did an exam, and then they sent me down for an MRI and it's 40 minutes in the tube.

Christy: *Oh, I didn't realize that.*

Phil: Yeah, 40 minutes in there.

Christy: *That's a long time.*

Phil: It's a long time. And I have this habit of falling asleep in the tube, and they don't want you to fall asleep in the tube. And--but it's really loud in there, so you would think I can't fall asleep in there, but every single time, I do. And yesterday was no different.

I was feeling great, feeling great; staying awake, staying awake; listening to them; listening to them. And then next thing I know, we're done and they're pulling me out, and I had obviously been sound asleep. So when you're sound asleep, and awoken that way, you're disoriented. You know, it takes a couple of minutes before you can stand up, get off the machine, and all that stuff.

But then I went up for testing. And I don't know if it was the disorientation of the machine, or what, but--I don't know the actual results; they don't tell us. But I--you know when you blow something. I blew that testing.

I definitely had trouble. I had trouble remembering the long list of words, list of words, you know, which words was it, which word wasn't? Reading backwards. And then we got to the part where they asked me about stuff Tim has told them about my life, and what I, what we've done together for the past couple of months.

And I have to tell you that if the lady had not prompted me--like, she's like, "So, I heard you and Tim did something fun a couple of weeks ago. Do you, can you, do you have any idea of what it was?"

I said, "Well, we went to the movies. We went to dinner." And she's looking at me, and I'm like, "Guess not, huh?"

And she goes, "Nooo," and I'm like, "Hmm. Well, I can't remember anything else."

She said, "Did you go see a play?"

I'm like, "Oh, the play! Yes, we went to see *Mama Mia!*" If she hadn't provided that prompt, it wouldn't have been there. And when she did provide the prompt, it all came back, so that was fine. But without that prompt, it wouldn't have been.

And then she said to me, "What did you do in May? You celebrated a holiday, a pseudo holiday.

"Holiday?"

She said, "Yeah, with your family."

I'm like, "I don't know." And there was nothing, absolutely nothing.

And she said, "Mother's Day."

And I'm like, "Oh yeah, we went to dinner. Or yeah, we went to brunch for Mother's Day. We went to the steak steakhouse, blah, blah, blah, came back." Again, had she not provided that Mother's Day prompt? Nothing. There was nothing.

So between the words, and the memory recall issues, I went home thinking, *Yeah, there's not a doubt in my mind that there's something wrong. Something is going on. And something good. Something not good is going on.* But I still, I can't shake that 'I'm a fraud' feeling.

Christy: So what is it, specifically, that makes you feel like a fraud?

Phil: I feel so good day to day. I feel my day to day interactions are just fine. I mean, you know, I get tired in the afternoons. Even if I've been drinking my water, I still will nap around 4:30, 5 o'clock. But other than that, I generally feel like Phil.

Somebody, some head hunter, sent around the job description for a position in San Francisco for director of communications. And I'm sitting there going, *I can do that!*

And you know, I know I can't. And I'm not moving to San Francisco, and you know, there's a thousand things why I would not be qualified for this job. But there's such a feeling of being okay that, you know, I do have this little propensity of, *Yeah, I can do that. I could be a director of communications for a climate group.*

Christy: Do you--so, when you say you feel like a fraud, do you feel guilty, or--

Phil: Very guilty. Because I'm out there constantly, as you know, doing things like this--talking about what it's like to live with an Alzheimer's diagnosis. And if you feel like a fraud; you know if you feel fine--people say to me all the time, which of course, is somewhat annoying--"You seem fine."

Yeah, I know I do. My standard line now is, "I present well, but I do have issues." And I think that's true. I do present well. You know, at this stage of the journey, I do present well.

And you know, if I take care of myself, if I stay hydrated, if I get my exercise, if I stay engaged, I don't find myself struggling for words. I don't generally find myself overly exhausted. Again, I do need that afternoon nap. But you know, I'm driving, I'm shopping. I'm doing this, I'm doing that. I'm bouncing around with thousands of project ideas in my mind. It's, it's this weird dichotomy, and I've felt it for a long time.

Christy: Yeah. It's a weird dichotomy for me, hearing you talk about that. Because on the one hand, I can point to lots of evidence, I guess you would say, about why I, as a

professional, I can see why I think, I believe this diagnosis is certainly accurate. And that you are very early in the disease process. So there's that.

And then the other side of it is the thing that we always want to do, that professionals always want to do, you know, people who, who do get to interact with people living with Alzheimer's or other neurodegenerative conditions, is reaffirm and validate when they're feeling great and feeling like, You know, I feel like myself. I feel good. I feel confident. I feel like I can take on X, Y, and Z. And that's when you step up to encourage people, to validate them and say, "That's great."

Later in the disease process, where I've seen many, many thousands, probably millions, of instances where it can be a major source of conflict for the person with the diagnosis and their family care partners or even professional care partners, [is] where the person says, "You know, I'm feeling great," or, "I want to do this," or, "I have this idea," or whatever, where the person is not validated and it looks like the care partner is really raining on their parade.

Like, "Oh yeah, that would be great to be a communications director, Phil, but don't you remember you have this diagnosis? And what's happening in your brain, blah, blah, blah."

And as I'm saying that as an example, you can hear how condescending it is coming at the other person and really pitying, I guess. It just serves no good purpose to try to contradict someone or to contradict them.

I mean, and feelings are subjective, right? So, if you're feeling great and feeling full of energy and you want to do this and you have ideas, great. I mean, really. Sincerely. Wonderful. Pursue that. Do that. I'm rooting for you, no matter where you are in the process.

Phil: Right. But as a care partner, I would imagine there are times when you have to say, "Umm, probably moving to San Francisco and doing a high level communications job isn't in your future at the moment."

Christy: *Well, I can definitely imagine that people would have that response to it. And you know, one of the best practices in memory care is to reframe. So, I always want to say yes, because just looking at it on a human level, no matter whether somebody has any type of diagnosis or not, most people, definitely myself included, do not like hearing the word no.*

And that happens very, very early in our lives, right? By age two, we're over that word like, "Oh, okay, I know what the word means now. I don't like it." And then if you're in some type of field like me--and I'm sure there are people in many other fields that feel the same way--I don't like hearing the word no, and I don't like saying the word no.

So, instead we're always looking for the yes. How can I make this affirmative rather than negative? So, instead of, "Hey, bad news, we're not moving to San Francisco because that job isn't going to happen for you!"

Instead, asking something like, "What do you think that would look like?" Or, "What really excites you about the idea?" Because a lot of times people, will start talking about whatever the thing is, and as they're talking about it, realize like, "Oh, maybe that's one of those things that looks like a very pretty package. But once I open it, it has some other things that...maybe not so much."

And that can be something really big, like what formerly would have been a dream job, or something really small. And again, it doesn't even have to be exclusive to someone having a diagnosis.

People get excited about things all the time that may not be realistic, but they feel some excitement in the moment. And I don't see the benefit to putting a fire hose on that excitement. If somebody's feeling good, I think, why wouldn't we want to be affirmative?

Which is--of that emotion--which is not the same as saying, "Totes magotes! Let's get the airline on the horn and get a Realtor and make this magic happen!" You know what I mean?

Phil: Yup, yup. Yeah, I do. I do. And I've seen, you know, examples of redirection and how good caregivers can redirect somebody and get them on the right path. And I--you know, and it gets to driving, which we've talked about, you know. Or right now, I feel fine. Although I did have a little bit of an experience on Saturday to talk about.

You know, now I'm the one that's sort of autocorrecting or self- or redirecting. And you know, maybe it is just because the disease stage, the stage I'm at with the disease. But I could see myself at some point saying, "Hey, I got this email, Tim! There's this job open. We should go for it. You know, I really want to apply for it!" And having him try to walk me down or redirect me from it. Isn't that part of life in some ways?

Christy: *It is, it really is.*

Phil: You always need to redirect people if you think that the latest brainstorm, like, "We should get another puppy!" isn't a great idea. Although, suddenly we're getting another puppy.

Christy: *I cannot believe that that was Tim's idea.*

Phil: He bought in.

Christy: *Okay. That sounds closer to reality. Bless his heart.*

Phil: I found it. I showed it to him like I've shown him many, many, many, many other dog pictures. And he melted. And I had him trapped in the car on the way down to the Biogen appointment yesterday. So I filled out the application.

Christy: *Okay. So, I think that's a great illustration of, you know, kind of talking someone down: a lot of times that's just, we just call that part of marriage, right? Like, "That's great, honey, but that's not exactly the direction we agreed we were going." So, there's that.*

But then the other thing too is like, you know what you're saying in the future, of you saying, like, "Oh, Tim, I got this email and we should do this!" And you said, kind of leaving Tim in the hot seat of navigating through like, "Well no, that's not really going to happen," which is certainly one way. But another way is to go, "Oh, okay," and this--

Actually, I have a driving example about this too, because these are so parallel--where a family will think, Okay, my person should not be driving anymore, so I'm going to notify, and or have the doctor notify, the DMV.

And then the DMV sends a notice saying that the person needs to test, they need to go for retesting. And the funny thing to me is, at that point, right, then the family needs to let go of it.

But what happens instead is the family is frantically flipping through the mail. "Where's the notice? Where's the notice? Here, Dad. Did you see this notice? Okay, I took some time off work so I can take you."

And I'm like, "No, no, no, no, no. That's kind of missing a big chunk of this, which is the person has to recognize what that notification in the mail means. And then can they take action to follow through on setting up an appointment? And then how are they going to arrange transportation for it?"

And all of these things need to happen. And if the point is to see if somebody can actually do the thing, whether it be take a driving test or get a job, then that's up to the person, not the care partner to do it for them. Does that make sense?

Phil: No, it does. I mean, you know, if you want to prove to somebody that they can't do something, let them try to do it.

Christy: *Okay. That seems kind of mean when you say it that way, and that's not how I mean it.*

Phil: Well, but that is the bottom line.

Christy: *I think the bottom line is there are certainly times where the care partner is taking on more than is necessary or required of the situation, and it's ultimately not helpful. Because often--and again, going back to the driving example, often what happens is then the person who does not pass the test is completely infuriated, which is understandable. But do you know who the target of that fury is? It's not the DMV.*

Phil: But that's why I'm saying in some ways that the bottom line isn't let them find that they can't do it. Because if the notice comes from the DMV and the care partner,

the person living with Alzheimer's isn't gonna say, "Oh, I know you're behind this." Probably. Unless they're me. And I'd say, "Tim, you're behind this. I know you're behind this."

That notice comes and you say, "Okay, great. You know, let me know if you need my help. But otherwise, we'll deal with it, whatever comes," maybe. And then the first struggle to make the appointment to get the truck, you know, get the, all the transportation, maybe they're learning a lesson. Maybe they're not. Maybe they're too far gone, in which case you probably should take the keys away. But maybe that struggle to make the appointment and all that stuff is actually a lesson.

Christy: *Is instructive.*

Phil: Right.

Christy: *Yeah. I guess it really, it does depend on where the person is in the process and probably the time of day they check the mail and what's going on in that moment. I've certainly been part of many experiences, or heard many stories, where the family says, "Hey, Dad, did you get a notice from the DMV?"*

"Oh yeah, I put it in the junk mail."

"Well, why junk mail?"

"Well, because they're saying my license is going to be suspended if I don't come retest."

"Okay, well that seems important."

"Nope. I've got keys. I've got a car, I'm fine." So, it is kind of all in how the person perceives what's going on.

Phil: You know, there's no one answer for every person and that's why you still like doing this, preparing loved ones. Could you redirect for a second?

Christy: *Go ahead. You're redirecting me?*

Phil: No, redirecting our conversation.

Christy: *Oh, sure.*

Phil: Where we were before we got diverted by something I'm sure I did. But we were talking about how I, you know, came out of the MRI tube feeling kind of goofy and not all there anymore.

And you know, two weeks ago or three weeks ago, I was down there [at University of Pennsylvania] for another study where, you know, I did apparently better than I had the year before in the memory testing. It was basically got down there, did the memory test and then left. There was no way, blah, blah, blah. And, and I did really well.

And here [at yesterday's appointment], there's an MRI and bloodletting and you know, blah blah blah. They wanted so many tubes, I'm surprised I still had blood left. But the--and I did not do well in the memory test. And you know, two weeks apart, there's not going to be that much deterioration in my memory skill.

And it strikes me that, you know, so much of what we call cognitive skills and cognitive abilities depends on other things that are going on, you know? When I took the Social Security, when I took the memory test for the Social Security Disability, I did not do well, you know? I did so bad I got disability because I did not do well.

It's the same test over and over and over again. And sometimes I knock it out the park, and sometimes I don't. And I've almost memorized it, though. That tells me something about my memory.

Christy: *That's a great point, though, because what you said was when you did well, it was not a long day. There wasn't a whole bunch of other stuff going on. When you pointed to a time when you feel like you blew it, there was--it was a whole day. There was a whole bunch of other stuff that had happened before that.*

And I think that is something that too often, families just aren't aware of. Or they end up learning the hard way, is that that energy level and managing that is so crucial to what kind of day they and their person ultimately have.

Like, you're talking about, you need that nap at 4:30, 5 o'clock. That's a necessary thing. I would imagine if you're out and about for whatever reason and miss it, you feel it later. Tim feels it later, I would guess.

Phil: Right, right.

Christy: *And so that, that's a really important thing. And it's a great strategy, because you're saying you feel great, you feel like Phil. And part of that strategy is taking a nap every day.*

And so just little tweaks to a usual pattern can have a really significant difference in how somebody feels and the kind of day that they're having. Right? Both on the positive and then on the negative, where you're talking about a full day doing all of these things and you felt wiped out, needed to sleep for three hours after you got home and it felt like you really blew it.

Phil: Right, right. So, one of those thoughts that I had was that memory is not a straight line. And we know we all have good days, and we have bad days. But how...how do I say this? I'm not sure how to say what I'm trying to get to, but it's.... You can't sit there and look at this disease and say, you know, "In March, I'm going to be here, and in August, I'm going to be there."

Or even, "2019, I'm going to be here, and then August, 2019, 2020, I'm going to be somewhere else," because there's going to be a lot of peaks and valleys. There's gonna be a lot of other things that impact day to day where you're going to be on that scale.

It would be fascinating to, if they could come up with like, a changing memory test that you could almost take every day that wouldn't be the same thing, so you memorized it, but would be, you know, various tools that you could just kind of like, "Okay, you know, today, with this experience behind me, I felt like this."

It's almost like a blood pressure thing. Take your blood pressure three or four times a day, you know, after you've done something, blah, blah, blah. It would be

interesting to see what a person's progression is like, detailed. You know, so detailed... it would be interesting.

I always criticize these memory tests, because they're always the same. And I sort of, I've taken it now so many times that I feel like I know them, but I also, on the other hand, know that that means my memory's not so bad because otherwise I wouldn't remember the test. Catch-22.

Christy: But you're not remembering the answers.

Phil: Well, if I, if my memory had deteriorated to the point where I'm not remembering the answers, or not remembering the answers from the three times ago that I took the test.

You know, I can now count backwards from a hundred by 7s without thinking about it because it's part of every memory test. Exactly those numbers. "From a hundred, subtract seven and keep going until I tell you to stop." I can do that now!

But you know, at some point, even though I've done it fifteen times, I'm going to struggle with it. And that's going to be a change, right? I'm too with it for these memory tests at this moment. But at some point I won't be, I imagine.

Christy: And that's our show. Thank you so very much for being with us today. Links to resources or programs mentioned in this episode are in the show notes at DementiaSherpa.com/Episode106.

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.