

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 095](#): Q+A: Showering & Structure

Phil: Yes, I probably should take a shower, but I don't want to.

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 thank you for joining us. Phil Gutis, Assistant Sherpa, is answering a couple of questions for us today. After listening to a previous episode we'd done, I was curious to revisit showering. My other question is about structure, or lack thereof, in a day. I was shocked when I found out what the transition from working to not working looked like for Phil and others who've had retirement thrust upon them due to Alzheimer's disease.

A quick clarification: This episode starts with Phil saying he'd like to talk about something we've covered in previous episodes. That isn't Phil's Alzheimer's popping up. This episode, number 95, was recorded some time back. It was then promptly mislabeled and hidden in plain sight on my computer. I'm so grateful I finally found it. Now here's Phil.

Phil: That's actually something we should talk about at some point: the word dementia. Remember how that set me off?

Christy: *It was demented, was the word that tipped you over.*

Phil: Yes. *Demented.* Yes, yes.

Christy: *Yeah. We will. I just made a note of it. We'll talk about that in the future. Okay. I only had four questions for today, but we've done one in 30 minutes. This is why it's so fun to have you on the show, Phil. It's so easy. I'm going to go back to this. It's a follow up on showering.*

Phil: Uh huh.

Christy: *This is a quote from our last [episode](#) together: "Tim now knows that the easiest way for him to piss me off is to say, 'You really need to take a shower.'" My question is, in that moment when you're just pissed, do you have an idea about where Tim is coming from? Or, what does it feel like for you? I guess is what I'm asking. And I don't want to put words in your mouth, but when he starts talking about taking a shower, can you talk about that a little bit?*

Phil: Yeah, I suppose I said that with a little bit of tongue in cheek, but he knows I will get grumpy. I don't think he's trying to piss me off, but he knows I'm going to get grumpy. And I'm going to make faces, and I'm probably going to ignore him. You know, he's not trying to make me get grumpy and, you know, he's just trying to get me to take a shower. I think I told you this week that I, I found my own way of forcing myself to take a shower, which was going to plant things in my muddy garden and getting so covered in dirt that there really was no choice. So that may be, you know, *Bring me plants and I'll go take a shower, I guess.* But, and the grumpy does comes from, I'm sure, a place of agreement: *Yes. I really probably should take a shower, but I don't want to.* So...I don't think anybody likes being told what they should or shouldn't do, and especially when they know the other person is correct.

Christy: *I'm so glad you said that, because that's something that I have said to care partners for years. And the way that it's often expressed to me, when people come to me for help is, "I tell her she nee--it's time to take a shower, and she tells me, 'You can't tell me what to do. You're not the boss of me!' And so, what do I need to do?" I'm like, "Well yeah, because no adult that I know likes to be told what to do." And I think sometimes as care partners we can focus on the task at hand, ie, trying to get somebody to take a shower and forget, you know, kind of take a step back and go, Oh yeah, we're talking about another adult. It's going to need to be managed delicately.*

Phil: And yet, I mean, I understand that it's such a normal thing for most people.

Christy: *Mm hmm, mm hmm.*

Phil: You know, you get up, you take a shower. You finish in the gym, you take a shower. You know, there's just these--it's normal. And when it becomes not normal, it's a struggle. And I see Tim struggle with, *Why? Why won't you do this?* It just doesn't make any sense to him. It doesn't make a lot of sense to me, either. But it makes *no* sense to him. And I sympathize with his struggle, but that doesn't mean that he's gonna make me take a shower. I think I described the bedroom, which is, it's an open, big, open box and there is a glass shower sitting in the corner of it.

Christy: *You did. We're getting some feedback on the line, too, Phil. Are you moving your head?*

Phil: Yeah.

Christy: *A-ha!*

Phil: 'Cause I was looking at the shower. So it's a glass box and you know, there's lots of windows around. I mean, our property is private 'cause we don't have any neighbors right on top of us. So, you know, it takes advantage of the light and the openness and all that stuff. I look at it every day and I think, *Hmm. Yeah, that's nice. I'm glad we did that. Yeah. I probably should take a shower, but I don't want to.* And I just, you know, kind of just put it off there. So I sympathize with him. It doesn't make sense to me, but boy, like I started this thing: It's the easiest way to make me grumpy.

Christy: *Yeah. You mentioned in our last episode that the thing was showering started before your diagnosis. In retrospect--and I don't know, you may not really have an answer for this--do you think that that may have been a sign that something was not right? Or do you think they're unrelated and having Alzheimer's has exacerbated the shower in thing?*

Phil: Sure. I, I actually think it was one of the first signs that something was wrong.

Christy: *Okay. I was wondering about that and I didn't, in our conversation last time, didn't have the presence of mind to circle back to that. But after listening to the episode, I thought, Huh, I wonder about that. It seems to me too that was probably a sign. And we had talked last time about the degree of difficulty in this, the sequencing, the complexity of it, and whatnot. So if anybody's interested in that, just go back and listen to [episode 92](#). Phil is a terrific guest and that was a particularly great episode. So, okay, final thing--and we may end up diving deeper into this in future episodes--but in passing, in our last episode, Phil, you were talking about the Shiny Object Squirrel and the difficulty with staying on task and you know, whereas you used to be King of Multitasking, you're no longer King of Multitasking. And so you were talking about the challenges with all of that. And in passing you said, "Well, I don't know if it's because of this"--and I don't remember what the first thing you said was--"or if it's because I don't really have much to do during the day." And that was the part that stuck out to me. And you theorized, "It may be both."*

I was really stunned when you, and then also Jeff, Jeff Borghoff, who was the keynote speaker on the dementia cruise and conference that we were on, who also has early onset Alzheimer's. You both mentioned once you stopped working, it was like a black hole. There was, it was like, Wake up and I'm home alone and got a pretty much whole bunch of nothing to do today. And I was stunned that--I guess I was stunned that that happens. I'm wondering, what do you think would be helpful? I have some ideas, but I want to know what you think.

Phil: First thing that occurred to me when you were talking was to recommend the episode of the website Being Patient, which [I did a live chat](#) last week, and this week, they had my friend Pam Montana on. And it was live yesterday and [it's up now](#), and I'm sure Christy can find it and put it in the notes. But, she was an executive at Intel and also basically woke up one day with nothing to do. And she talks about how her advocacy and her participation in a drug trial gave a reason

for continuing and for doing. And I--it resonated very strongly with me. Pam's a great person. So I'm also from the early stage advisory group. But you know, I think what [Jeff](#), Pam, and I all have in common is we were sort of workaholics. She described, you know, the day being finished with her meetings that occupied the full day and she sat down at her desk and, and like started answering emails and suddenly it was ten o'clock. PM. Not AM; PM. And it was time to go home.

So, you know, and that was very much my situation. I mean, you know, there was literally enough work to be done to last 24 hours a day. You know, I mean, maybe there was some slow times, but most of the time you literally could fit 24 hours with answering emails, because every time you answer an email, at least one email is generally generated. And sometimes, if you're responding to a group, you could have five more! You know, so you have that.

Christy: Reply all *is the worst invention ever.*

Phil: Uh, yeah. I don't disagree. But--it also can be very embarrassing sometimes. And you know, now? I mean, Tim asked me, I guess Sunday evening, you know, what was on my calendar for the week. And I looked, and Monday was nothing, and Tuesday was nothing. And today we had our chat scheduled, and you know, maybe I have a couple of other things, you know, as the week draws to a close. Couple of conversations and things like that. You know, there's stuff to do. I know there's stuff to do. And you know, I cleaned my room yesterday, woo-hoo! You know, there's always something I could be doing. But there's usually not something that I *have* to do and that is a challenge for me. I guess I was never one of those really self-driven people that woke up that morning with their to do lists and said, *Vrooom!* Powered through it. You know, mine was, you know, *I got this meeting, that meeting; this phone call, that phone call.* Very schedule-oriented, and in between there, I would squeeze in all the other work. So part of it is my own being, you know? But, uh, there's stuff to do. I mean, I go, I row every day. Pretty much. So that's a thing on my schedule every day, which is good. It's good to give me something to do. And it's also good because I think it helps keep the Alzheimer's monster at bay, somewhat. But I'd be curious to see, to hear what your suggestions are. I'm sure we all would.

Christy: *Well, I'm so oriented to having structure in a day, as a memory care best practice. So structure, routine, predictability. Like the holy trinity. Structure, routine predictability. That makes people feel more secure. It lets people know what to expect. It gives people a sense of purpose. And so I'm thinking of a particular*

memory care--my very favorite memory care--where are our program calendar went from 7:00 AM to, I think, 7:00 PM. And that was seven days a week. Now, that did not mean that people, you know, that it was mandatory that they went to a certain program. Not by any stretch. But people could look in their own room, there was a calendar right there. They could look in the hallways, various rooms; there were calendars posted everywhere saying, This is what's going on. I think that was one of the things that really helped keep people socialized and enjoying life. And when people are doing things like that, it's kind of, it's that use it or lose it theory. So a good thing for people that--you're going to hate this, Phil, 'cause you're an introvert--you know, a good thing to do is to socialize, to be in conversations with other people. Because--and you're actually, you're doing this now, even though you're not doing it in a, like going to any type of social club--but it's an aerobic workout for your brain.

Phil: Mm hmm.

Christy: *Because you're processing what the other person is saying. You're formulating what you're going to say back, and that--it is very use it or lose it. For people who--where I really worry is for people who are sitting at home by themselves with nobody to talk to. They don't have someplace they need to phone in for an interview. And I think, you know, what you and Jeff, and now you're saying Pam described, as far as like, Okay, so I, not only was I at work, but I was kind of a big deal at work, and now I wake up one day and it's the, you know, "Congratulations, you've won a retirement! At home. By yourself." What? Are you kidding? I don't know about Pam, but for you and Jeff, you both have spouses that work. So it's, it's not like there's, there's not really, it's not like hanging out with somebody during the day. And I think because you all are so young, this is one of the things that is really overlooked. So, I had never really given it any thought, but once you all, once you and Jeff said this was an issue, my next thought was, Really? The Alzheimer's Association doesn't have some type of transition program for people that are newly diagnosed and like, "Okay, now what?"*

Because there is that initial rush of getting documents in order, right? Or, re-looking at an estate plan, or those types of things. Looking at appointments with financial planners, those types of practicalities. But after that, I mean, you don't, you know, run around with those appointments all the time. After that, what happens? What's the plan? And from what I'm hearing, it just didn't seem like there is one. So, you're kind of left to your own devices to figure it out?

Phil: I mean, I think that's... Anybody that is suddenly retired has to cope with the same sudden lack, loss of structure. And depending on the person, where they are in their lives, they may welcome the loss of structure. It may sort of drive them a little crazy. I've, I've heard that.

Phil: I see a lot of people, older people who, you know, you would think should be retired working at grocery stores and things like that. And sometimes I think it's because their Social Security can't support them. And other times I think it's because they were bored sitting at home. So it's probably one of the two things. And you know, they need that socialization. You know, it's particularly challenging in a semi rural area, where there's not a lot within walking distance. And, you know, we've talked a little bit about, you know, not having a car in this kind of setting.

Christy: *Right.*

Phil: It was truly, truly, truly, truly, truly, truly, truly a problem. But, you know, there's gonna come a time when I can't drive anymore.

Christy: *Mm hmm.*

Phil: And, wow! And you know, on our list of things that we should probably talk about is driving because--

Christy: *Oh, it's on the list!*

Phil: Last week, [I was on NPR](#). A segment I had taped a long time ago finally ran on NPR, and I happened to be in the car. When driving in the car, when it came on. And I was desperately trying to find it on my radio, which, you know, it's Sirius and--not serious, but Sirius, S-i-r-i-u-s--and is still a mystery. Actually, they should call it Mystery, because trying to figure it out, sometimes I feel like it needs a higher education degree that I obtained. And you know, I finally did find

NPR and the local NPR was broadcasting another show. And I was like, *Argh!* They weren't doing *All Things Considered* here. They were doing another show. And I was like-- and suddenly I--you know, I had my GPS on 'cause I was driving someplace that I didn't know how to get to.

And all of a sudden the GPS is telling me, *Make a u-turn*. I'm like, *Why should I make a u-turn? I haven't missed any turns*. Well, apparently I did. And promptly managed to get myself lost. But getting--that's multitasking in some ways and it's bad--

Christy: *Mm hmm.*

Phil: Bad, bad, bad distracted driving and I apologize to the world for doing it. And you know, I'm very aware of what I did, and very aware that I shouldn't have done it. And if it becomes something that becomes an ongoing challenge, then you know, I can't drive anymore. Um, but I don't know where I was going. I completely lost this train of thought. Where did it start?

Christy: *Well, we were talking about structure, or lack thereof.*

Phil: Right. Right, right, right, right, right, right, right, right, right.

Christy: *And then you were talking about being on, an interview you did on NPR that you recorded actually quite some time ago.*

Phil: Yeah. Yeah. But just, just that...I mean...ah, shoot...You know, it was interesting. So the reason I was in the car was because I was driving to do some pet sitting at one of Tim's client's house. (Phil's husband Tim has a dog walking and sitting business.) So I was going off to do something structured and something else came in, which in my old life would have been fine. I multitasked all the time, could handle both things at the same time. And this time, you know, it just came at a very inconvenient moment and I couldn't do that. So structure can go very quickly from good to a bit overwhelming at the same time, right? I mean,

you know, it was great when I did that NPR interview, and it was great that I had that job I needed to do for Tim, but suddenly the two of them collided and in the past, it wouldn't have been a problem, but it was a bit of a problem.

Christy: Mm hmm.

Phil: If that makes any sense.

Christy: Yeah. Again--and this is something we've talked about and I imagine we'll continue to talk about--is things that were formerly taken for granted are more of a big deal now.

Phil: Yeah.

Christy: Yeah.

Phil: Yup, yup. And the other thing I'd love to put on the calendar, which you mentioned earlier in the broadcast: predictability.

Christy: Okay.

Phil: Boy, that is, that's a--I don't even know what to say about it. It's such an increasing issue for me. Predictability.

Christy: Well that sounds like a tease for the next show, if ever I heard one, so we'll leave it there.

Phil: Okay. Perfect.

Christy: *Thanks a lot, Phil.*

Phil: You're welcome, Christie. As always.

Christy: *And that's our show. Thank you so very much for being with us today. Send your questions for Phil, or for me, via email or DM on Facebook or Twitter. Contact links are in the show notes at DementiaSherpa.com/episode95.*

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.