

*The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa*  
[Episode 114: The Incidents are Coming Faster and Faster](#)

Phil: The incidents are coming faster and faster and you know, even though I often say that I feel just fine, you know, I'm clearly not just fine.

And no matter how many times it happens, at this point I think it's going to devastate me because it's just yet another smack in the face that I am sick. And...no matter how much I feel like the old Phil, I'm not the old Phil. And I guess that's the hardest thing.

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! In this episode, Phil and I continue the conversation we started in episode 113, where Phil talks about getting on the wrong train in Philadelphia and the rising panic he initially felt in trying to figure out how the train ended up at the wrong stop.*

*As he says in that episode, it took 16 hours before he realized that he got on the wrong train in Philadelphia, rather than the train going to the wrong station. Here, we talk about the aftermath of that incident, and what it means to Phil.*

*Well, can I ask you, what did Tim do? Like, when he came to pick you up, what, if anything, did he do that made the situation easier for you, or more bearable, or helped you feel, you know, safe? Or...?*

*I'm not trying to put any words in your mouth...but, can you share a little bit about what he did that may have been helpful, or if he did something that you didn't, that you found less than helpful? Other than the obvious, of coming to pick you up.*

Phil: Right, right. He came to pick me up...

Christy: *Which was a very big deal.*

Phil: Which is a big deal. And he managed to get lost, not get lost, but to miss turns and have to turn around, like, three times going out, leaving Trenton, which was, I guess, fun.

Christy: *Did it help you feel like, "Okay, this happens?"*

Phil: No. Truthfully, I was quite annoyed about it. Kept saying to him, "Do you know where you're going?"

Christy: *Oh, Phil.*

Phil: Not annoyed. I mean, we were caught in rush hour traffic and schools were letting out and yeah, it was, it was, it was kind of a cluster.

Christy: *Uh-huh.*

Phil: In retrospect, it was kind of funny. We didn't talk about it. I mean, I guess I just talked and he didn't, he didn't fight me.

Christy: *He listened?*

Phil: He listened, and he kept getting, you know, lost. And so he was focused on driving. The interesting thing he did do, which, so when we got to the parking lot, he found the car and you know, let me out of the car. And, um...

Christy: *So for those wondering or not remembering immediately, Phil and Tim have several dogs, and Tim has a dog walking and pet sitting business. So, those are their dogs, you hear in the background and they're also very good guard dogs too, some of them.*

*So, sometimes you might hear those noises in the background when I'm talking to Phil, because that's called normal life. And you might also notice that when Phil is in the middle of a thought or trying to give an answer and there's a little commotion going on around him, his train of thought gets off at the wrong station. And it takes a minute.*

*So, that's just normal life. It's not some weird, like we blew it in the editing process. That's just how it is. So, go right ahead, Phil.*

Phil: And the other part of the issue is that I have a little bit of an Amazon addiction, so I'm sure that was Amazon dropping off a package. And actually ringing the doorbell, heaven help them.

So, oh, so he dropped, you know, found the car for me, which of course was not where I thought I left it, but he found it. And I got in my car and I drove away and I left the station and I kept thinking to myself, *Gosh, why, where could have Tim have gone?*

I mean, I put my GPS on even though I knew where I was going, but I put my GPS on. *Where do, you know, he didn't leave that far before me. Why can't I see him up ahead?*

And he told me when we got home that he actually followed me to make sure that I got home okay. Which I thought was very sweet and thoughtful. Obviously, I must've appeared shaken to him.

I haven't asked him and I, I'm going to, because the minute I, he got on the phone with me, he was in caregiver mode. And I don't know what he heard in my voice. Obviously [he could] hear the panic, but yeah, I didn't necessarily feel like I was panicking at the time.

And calling Tim is not unexpected. I mentioned that, you know, when I got there and found a parking lot that was full--and no signs for additional parking, by the way, none. Who does that?

You know, I called him and he said, "Oh, there's another lot," you know, so he's my, obviously, my backup. But you know, there must have been something in my voice.

*Christy: Well, yeah. Right. When you say Tim immediately went into caregiver mode, what does that mean?*

**Phil:** There was never any question about he was going to come get me. I didn't even have to say, "Can you come get me?" He was like, "I'll come get you."

*Christy: Okay.*

**Phil:** You know, I don't know if I said I don't know what to do, but I don't think, well maybe I did. I don't know.

*Christy: And he just immediately offered.*

**Phil:** I think he just said, "I'll come get you." You know, I'm sure I said something like, "I don't understand how I got here." And then he said, "I'll come get you."

*Christy: Okay.*

**Phil:** I mean, I know I was pretty close to crying. It was funny, when I called him, it went to voicemail. And I get this text, you know, like, "Can I call you later?" And

I wrote back, “No.” And then the phone rang. And he said, I didn't, he didn't mean to send that message of “Can I call you later?”

*Christy: Oh, yeah. It has that auto thing on your phone.*

Phil: Sometimes our phones do these things we don't quite understand. But you know, it's...it's another...another reminder that, that it's coming, right? Or that it's here.

It just, it's clear to me that this is, you know, and this was probably also cause for the tears yesterday, but it's coming and it's coming faster.

The incidents are coming faster and faster and you know, even though I often say that I feel just fine, you know, I'm clearly not just fine.

And no matter how many times it happens, at this point, I think it's going to devastate me because it's just yet another smack in the face that I am sick. And...no matter how much I feel like the old Phil, I'm not the old Phil. And I guess that's the hardest thing.

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*Christy: When you talk about, you feel like the old Phil, but then you're not, is it because of situations like this, do you feel that there's a gap? Because it sounds like inside, you feel like yourself, and you feel good about that. And then if a situation doesn't go the way that maybe it would have 10 years ago or 15 years ago, that it's the situation that makes you feel really bad. Not that you're feeling like a different person, is that right?*

Phil: No, it's what the situation signifies.

*Christy: As a signifier. Okay.*

Phil: Yeah. It's just, you know, when I didn't remember what show we had seen at the playhouse, you know, and the next day sat on my bed and said to Tim, "It's coming isn't it?" And that was like, you know, in some ways my first real...

So you know, that, that first reality moment of not remembering the show and you know, since then...I mean there are definitely things I don't remember.

And Tim tells me stories and you know, I'm like, "Oh, that's interesting. That's why I got fired. Oh, okay. That's a fascinating story. Thank you."

But, some of these things just really kind of...and I, I think [I described it in the piece](#) as like, you know, slapping me in the face, you know, and I got slapped in the face again this week and it just happened a week after I got slapped in the face.

So it feels like the--and I think we talked about this last time, the stages of the journey. And I feel like I've crossed into another stage and things are moving fast. And that's really...upsetting.

*Christy:*       *Yeah. Have you thought about enrolling in the [Safe Return Program](#)?*

*Phil:*            You mean the thing that Gene Saunders...?

*Christy:*        *No, that's [Project Lifesaver International](#). The Safe Return Program is partnered...it's through the Alzheimer's Association and it is partnered with MedicAlert. So it's like those bracelets, or necklaces.*

*Phil:*            I actually do have a bracelet I wear. It was right after diagnosis. My first dream about having Alzheimer's was walking Abe on my block and my block suddenly getting longer and like turning into something I didn't recognize.

The next day I went on Amazon and I ordered a bracelet that says “Alzheimer's, Phil Gutis, if lost, please call Tim” and his phone number. So I've worn that for three plus years.

But yeah, there was a video that I hosted on my Facebook yesterday--somebody shared it; I think Jeff Borghoff shared it--about if you see somebody who's clearly struggling, be a friend and go over and ask if they can help.

And...it struck home yesterday when I saw it. Because I was in need of help.

*Christy:*        *Right.*

*Phil:*            You know, at that train station. And I don't know, you know, it's impossible to stand outside of myself and know what I looked like. You know, was I really panicking that anybody would've seen? I don't think so. I mean, I guess if I hadn't had my phone...

*Christy: Right, right.*

Phil: It would have been...I mean, if I had left my phone on the train? Like, good God! I mean, that's-

*Christy: Okay. We don't, we don't need to dwell in the house of scary thoughts. Right?*

Phil: That's a nightmare. Right? I mean, I so rely on this phone, I want to attach it to myself. I want to plant it on my head because everything is in it. Really, everything. Now, the GPS, the phone numbers and the this and the that. It is my lifeline. You know, how easy is it to lose this?

*Christy: Okay. Now, now let's talk about Project Lifesaver, which is where you could wear like a little bracelet, and be enrolled that program.*

Phil: Yeah. Yeah. Unfortunately, it's not used in...

*Christy: Bucks County?*

Phil: -in Bucks County, and made a note to start pestering people about that, but we haven't done it yet. It is actually used in Trenton, I believe, and that... But, yeah, I mean it was all kind of theoretical, right?

*Christy: Right, right. It always is until something happens.*

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](#).

*Christy: Which luckily in this case, I mean you're, you were again, easily able to problem solve, but you had a crucial piece of technology that allowed you to execute on that.*

Phil: Right, right.

*Christy: And so that's why we're talking about Safe Return or Project Lifesaver, is what if the phone had been left on the train?*

*Or, what if something might happen down the road? Because, you just don't know when the first time something happens is going to happen until it's in progress.*

Phil: 'till it happens.

*Christy: Right. So-*

Phil: Well, the other thing of course was when you use your GPS on these phones batteries go [drain].

*Christy: Right, exactly.*

Phil: You know, my battery was in the red when this all happened, so...

*Christy: Oh, boy.*

Phil: Yeah. 'Cause I had been on it all day, right.

*Christy: Uh-huh, right, right.*

Phil: Yeah. So I'd used GPS three or four times, you know, so, yeah. And it was funny, I went to get a battery pack before I left, and Tim said "Oh, those aren't charged." And I was like, "Well, that's a fail."

*Christy: That's true.*

Phil: But I guess the--I mean, a lot of lessons I learned from this week--and I hope this week ends soon, and it will--but, back-up is the clearest lesson, I suppose.

Because I don't think, and we probably could type another...tape another episode about this. I don't think I was wrong to do what I did, in terms of trying the train and trying to...push my...you know, it would be all too simple to just stay home.

And wallow in my disease and...just, all too easy. I mean, so simple. I mean, even like yesterday when I said all I wanted to do was crawl into my bed and just go back to sleep.

And I wouldn't let myself do it, because I knew it wouldn't have been good for me. But, you know, then I did my retail therapy. But I think at least for me, I have to keep pushing. I have to keep pushing the envelope and that's maybe just me

and my strange make-up. But I think it's really critically important for care partners to let their people try.

*Christy: I wholeheartedly agree. And I would say not just let, but encourage, support, assist if needed. I think using the train was a great idea. Continuing to be involved is a great idea.*

*You are an advocate. You use many different platforms in your advocacy: your column at [MemoryWell](#), being on [The Alzheimer's Podcast](#) with us, [your writing](#) gets picked up in various publications.*

*And then also on the Board of the Alzheimer's Association...I always get the name of it wrong, is it the Delaware Valley Chapter?*

Phil: Mm hmm.

*Christy: Yeah. Which is why you were, had the meeting in Philadelphia? Yes?*

Phil: Yes.

*Christy: Yeah. So you're a very important voice in Alzheimer's advocacy and continuing to do that--number one, thank you. And number two, keep going! Absolutely.*

*And that's a really important message for people to hear too, because you know what? For all of us--as Phil has said many, many times--no matter what you do, you are going to die. If you were born, you will die.*

*So making the most of the time that you have here is so important and can really make a positive difference for everybody else on the planet too.*

Phil: But even if you're not an advocate-

*Christy: Yeah you, you know, you don't have to be an advocate.*

Phil: Yeah, you don't have to be an advocate. You don't have to be out there shouting, you know, but you do have to keep pushing. And you do have to keep doing. And not everybody's an advocate. I understand that, not everybody's comfortable blabbing their entire life story to the world. And I understand that too.

*Christy: Well, I think it's worth noting that you're not always comfortable blabbing your life story. But you do it anyway.*

Phil: I seem to do it a lot...

*Christy: On that pushing theme.*

Phil: Yeah, I mean, I do it. It's important, and I encourage as many people in this situation to do it as possible because it's really, really important.

And it's really the only way-- and this was actually what the meeting ended up being about down at the Alzheimer's Association--was, you know, we were talking about communications and marketing and I was like, "You know, look, if you asked me to pitch the fact that there's a walk in a community? No, thank you."

"If you asked me to tell the story of somebody who's going to be at that walk, in the [Promise Garden](#) holding a flower? Yeah. Then I'll get on the phone and talk to reporters."

And you know, I said to them, "You should set a goal," and I volunteered to write them--"a story a week of a person dealing with either having Alzheimer's, being a caregiver, you know, memory of a person who's passed."

I said, "That's the power. And, if you could post a story a week with a photo or video of somebody," I said, "you will see your media impressions skyrocket."

And I volunteer--like I said, I volunteered to write them. So hopefully, they'll take me up on that. And you know, I hope we can find people. I know we can find people.

They do seven walks and four or five people are at each memory garden for each walk, different people. So, that's 35 right there. If I'm doing the math right, which I often don't... That's 35 stories right there that need to be sort of captured and told.

*Christy: You're right. I mean, stories are powerful and studies have shown this, that stories help us retain information.*

**Phil:** And they, they capture your attention, you know, as, as opposed to, “Oh, somebody else is having a walk,” or something.

*Christy: I love stories. That's one of the, to me, one of the major benefits of doing the work that I do, is getting to hear people's stories. It is such a privilege to get to hear people's stories and realizing how many really awesome people are within our community and their unique life stories and experiences and the lessons that they've learned and to really, truly understand in one's bones why this fight is so important. These are real people. This is, it's you.*

**Phil:** It's real people. Yeah. It's us. I mean, it's everyone. And increasingly it's going to be *more* of everyone. Not to go to statistics, but the statistics are not pretty.

*Christy: Thank you so much for being willing to share your story and the scary, rough spots that eviscerate you. I so appreciate the vulnerability in you doing that and really honor the importance of it too. So, thank you so much.*

**Phil:** Very welcome. And it's, it actually makes me feel better talking about this stuff.

Christy: *And that's our show. Thank you so very much for listening. Head on over to the show notes at [DementiaSherpa.com](http://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.*