

The Alzheimer's Podcast: Navigating Rough Terrain with the Dementia Sherpa
[Episode 90: The Inside Scoop with Philip Gutis, a Man Living with Alzheimer's](#)

Christy Turner: I am super excited to have with us today, in his debut, Phillip Gutis, who is an Alzheimer's advocate, a former *New York Times* reporter and a current contributor, and also a person living with early onset Alzheimer's. So, this is a huge treat for us, for the audience, to get to talk to someone who can tell us the inside scoop. Welcome, Phil.

Philip Gutis: Thank you, Christy. I'm delighted to be here.

Christy Turner: Yay! So, I had the pleasure of getting to meet you and your husband, Tim Weaver, on the Inaugural--I know I'm going to blow the name of this--Building Bridges of Hope and Connecting Circles of Care Dementia Conference and Cruise [*It's really the Inaugural Connecting Circles of Care and Building Bridges of Hope Dementia Cruise & Conference. -CT*]. I think I got that all out the right way. So, we got to spend some time together last week while we were cruising around the eastern Caribbean and I'm imagining listeners are jealous of us, but that's okay. We can live with it.

Christy Turner: And I just, it was one of those immediate connections. In fact, Phil, you were the first person that I met on the cruise, when I went to the welcome reception. I saw you sitting there--and I'm naturally an introvert--and there was just something about you. I thought, *He looks friendly. Maybe I can sit by him.* And then from there, I felt like we got on like a house on fire. What do you think?

Philip Gutis: We definitely did, and funny, I'm naturally an introvert also, so it was introverts connecting.

Christy Turner: Yeah. I think people will--go ahead--

Philip Gutis: --anybody. I don't think anybody would consider us introverts, though.

Christy Turner: That's exactly what I started to say. People who know us would say, "Introverts? Are you kidding me?" So, one of the first things that I think we connected on was talking about when other people answer questions on your behalf, as though you're not able to understand the question on your own.

Philip Gutis: Yes. Yes, we did. We did.

Christy Turner: You want to talk about that a little bit?

Philip Gutis:

Well, it's funny. It had been on my mind for a while, and it was going to be the next topic of conversation with my husband, who--I'm sure he's only doing it to help me--would, had started to sort of rush to answer questions that were asked of me, and we already had the conversation of, "Please don't you say, 'Don't you remember?'" Because that was really beginning to annoy me and I had planned to talk to him about the, let me, let me try to answer and if I'm using sign language and clearly can't get words out, then you could jump in. But, you know, I'm most days pretty capable of answering questions and, I did have that conversation with him, I guess that night or the next day. And he, he got me, he heard what I was saying. It's, you and I talked a little bit about the stigma of, you know, having Alzheimer's and you know, even dealing with people who have Alzheimer's. And, you know, I think it's just, it's part of--it's three-quarters trying to be helpful and part of just falling into that, you know, "I'm gonna help, I'm just gonna, I'm gonna take care of this for you. And because I know you sometimes struggle for words and you know, I'm going to make it easy for you." But it can be really annoying.

Christy Turner:

Sure.

Philip Gutis:

Yeah.

Christy Turner:

So I think that's one of those things where there is a really fine line for care partners in wanting to be supportive and then becoming really over-protective to the point where it can create a learned dependence. Like, well, "Why should I even bother? Because you're going to take care of it for me." And that could be answering questions, or it could be any number of things.

Philip Gutis:

Yeah. And I, without naming any names, I think we saw several examples of that last week on the cruise.

Christy Turner:

Um, yeah, we did.

Philip Gutis:

And, and it comes from love. It really does. But, sometimes, you know, it's funny, I--at one point we were, a session was breaking in the conference and I think Tim had said he was going to go lay by the pool, but I didn't really hear him, or remembered that he had said that. So I went to leave and I didn't see him and I looked around and went, *Huh, I wonder where he went.* And then I started to leave to go to the room, to our cabin. And somebody grabbed me and said, "Where are you going?" I said, "I'm going back to my cabin." And they're like, "Well, where's Tim?" And I'm like, "I don't know." And they're like, "Are you

going to be okay?" I'm like, "Yeah, I found it several times already. And I have it written down, the cabin number, and you know, I feel very confident that, you know, I may make a couple wrong turns, but I'll get there."

Philip Gutis:

And, um, it just surprised me because, um, there, there's a, how do you say this? There's a, there's a, a tendency to baby, almost, people living with Alzheimer's. Now, at the same time, you know, later in the conference people did find some of the attendees wandering the ship, not being capable to find where they were or you know, a little lost. You know, they were able to help them, which is great. Clearly, the person needed help. Um, but in that case, I was, you know, clearly fine. I, you know, I suppose it's okay to ask, "Are you going to be okay?" I guess that's, that's fine. But there was just this, there was this feeling of, "You're not going to be okay. You know, you can't do this on your own." And I'm like, "No, no, I can. I'm really confident I can."

Christy Turner:

I'm really glad that you shared that experience. That brings to my mind a couple of things. So, one is, you and I had an experience. I think it was the night before we were due to come back to Florida, to the US, and you and I had gone for a walk on the deck and we were going to meet up with Tim later. And then we went back to where we thought he was. He wasn't there; he had told someone else where he was going. But that person left without conveying the message to us. So it was like this comedy of errors. And then I couldn't remember where the group was meeting up. And then we were misdirected by somebody, by a crew mate on the ship, about where the place was that we were trying to find. It was this whole thing.

Christy Turner:

But anyway, and it was at the end of a long day, but I said, "I'll walk up to the room with you," and you said--I think I'm quoting you correctly--like, "I can find it." And at that point, I think, you know, I had a decision point, which was either go, "Okay, fine, I'm out of here," or go with you. And, where I was coming from--and I realized later I never conveyed that to you--was I was actually genuinely wondering, *Is Tim okay?* Because to me, that seemed uncharacteristic. So, I was like, "No, I'll go ahead and go on up with you. See, you know, how the upper half lives here," 'cause you were on a different floor than I was. But what was your experience of that? Was that similar to somebody grabbing you, saying, "Are you okay? Can I, you know, walk you to your room?" Kind of like, uh, did you feel like a kindergartner? Or that you were being treated like a kindergartner?

Philip Gutis: No. I mean, and I did graciously accept your offer to walk me up to my room.

Christy Turner: That is true, you did.

Philip Gutis: As opposed to tripping you or something. Which I could have done, you know.

Christy Turner: I know!

Philip Gutis: We had been, we had been in a very long adventure looking for people. So, I understood your concern. You know, it was very late in the day. Um, it had been yet another long day, like they all were, and I appreciated your concern and, you know, I also appreciated the concern of the person who grabbed me and said, "Are you going to be okay?" It's just, you know, it's, you can appreciate something and also sort of say, "Rrrr." You know, I've seen--I'm a, I'm a careful observer, I think. And, I've seen caregivers go too far and definitely baby their person, and also baby other people who are living with Alzheimer's or dementia. And that, watching--you know, it's one thing to, to treat your person that way. It's another, I think, to sort of extend that beyond and to, you know, definitely use a baby, you know, the voice you would use with a baby. And, and I was like, "Ooh, hoo hoo!" You know, but at the same time, you know, they were making an effort, and I think you and I also spoke about--and we could probably have two or three additional podcasts about the whole, you know, how do you talk to somebody who's living with Alzheimer's? And you know, how uncomfortable some people, including some of us who have Alzheimer's, can be talking to other people with Alzheimer's. So you, I think a lot of this is understandable and a lot of it, again, I'm going to say this again, comes from a place of love. But it really is important to watch words and watch language and to encourage. You know, from my perspective as somebody in the early stages, you know, I want to be encouraged to keep doing, you know, to--one of my friends calls it to keep making memories, to keep getting out there and pushing myself.

Philip Gutis: And you know, I think it's important that those who are caregivers recognize that and recognize that their person, you know--certainly in the early stages--is gonna want to probably do that. And even if they don't want to? You know, it's really important that they do that. I mean, I've heard from a lot of folks who--you know, I would be lying if I said I didn't sink into the post-diagnosis depression of, "Oh, my God, my life is over! What is going to be of me?" But some people really have a lot of

trouble breaking out of that. And you know, I think having a care partner who doesn't say, you know, oh, doesn't only say, you know, "I've got you, it's going to be okay. We're going to do this. You know, we're going to get through this," but, you know, pushes out a little bit. But it's a very fine line. I recall last year, my car was getting ready to, the lease was running out, so it was getting ready to be turned back in. And there were a couple of incidents where I thought, *Did I look?* I don't remember if I looked, you know, when I was turning. And there was no accident, but you know, maybe horns blaring or something like that. Or not even horns blaring. Just feeling like, "Oh, that was a little too close. And did I, did I look? I don't remember," kind of things. And you know, I said to Tim, "I'm, you know, I'm concerned. I'm, I'm afraid I might not be able to drive anymore." And at first we made the joint decision that we weren't going to replace the car and we were going to become a one car family, but Tim's out all day and where we live, you know, there aren't sidewalks, let alone anything else.

Philip Gutis:

So, you know, I was isolated. I was stuck in the house and if I needed to go some place, and Tim wasn't available, I had to see if I could find a ride. Um, I'm not comfortable on my bike anymore. It was winter, you know, there were all these situations. And, you know, everything had to be, *Can I find a ride to go where I want to go?* And it became untenable. It really, really became untenable. And when we had the opportunity to think about getting another car, I was like, "We have to have another car. I, I'm capable of driving. I know I'm capable of driving. At least in the neighborhood. And I have to be able to get out of the house. I just have to." And the day after we got the car and I got in it for the first time and I drove to the grocery store and I was like, "Hallelujah!" I mean, it was, it bordered on religious experience, from, but just from a non-religious person. But you know, I got to go shopping by myself. It was, it was remarkable. Now, I know there's going to be a time when I'm not going to be able to drive and I'm not going to be able to go to the grocery store. But I don't want it, I didn't want to have it happen too early and become a situation where it was almost a self-fulfilling prophecy. If that makes any sense.

Christy Turner:

It does. I, I think one of the things that you're illustrating repeatedly is there is such a fine line between ending up in learned dependence, or forcing that upon someone, and expressing love--which really underlines the point that, you know, to my knowledge, there's one university in the world that has a dementia degree, and that's in Australia. Most people don't know a lot about dementia until they have to. And I think

that when the word dementia, like when people hear the word dementia, their brain automatically jumps to memory loss, to confusion, and they're not thinking about this long process that is typical for most people. Where we're talking about a process that lasts for years, sometimes decades. And it's, in your case, with the diagnosis of Alzheimer's disease, one of the hallmarks of Alzheimer's is a slow, steady progression. So, getting a diagnosis doesn't mean jumping five steps ahead to, you know, toward the end of the disease process. And I think that, certainly for you, right, as a person living with Alzheimer's, but also for care partners, it's just really rough trying to figure out and learn things that you didn't know you would need to know, in order to continue having just something as simple as pleasant interactions without wanting to, you know, maybe smack your care partner. Right?

Philip Gutis:

I do that anyway, just for fun. But no, I mean, you're absolutely right. And, you know, the word--one of the other speakers at the conference really made me think about this a lot. Well, two of them, actually. One, a poet, talked about dementia and demented, which just stopped me in my tracks because I had never really connected the two. And I'm still not sure what I'm thinking about all that. Chief Saunders--I think I'm pronouncing that right--[with] Project Lifesaver, talked about when he came up with his idea on how to find people who wandered and had gotten lost. He said that--and I guess it was 20 years ago--he said that police departments had no training in how to deal with people with Alzheimer's and--or virtually no--and the little bit they got was an hour long session on mental retardation.

Christy Turner:

Right.

Philip Gutis:

And that also sort of made me go, "Whew!" Because it, you know, and to, to circle back to where we were, you know, how would you talk to a person who is demented? How would you talk to a person who is retarded? Right, I mean, not a politically correct term anymore.

Christy Turner:

Right. But to be clear, those were the words that Chief Saunders used, and--

Philip Gutis:

Right. Right, right.

Christy Turner:

He wasn't trying to be offensive, either. He was saying, "This is how it was 20 years ago."

Philip Gutis: Right. But would you, would you use a baby voice? Would you baby a person who was labeled as such? As demented or as, um, you know--

Christy Turner: Yeah. Right. I think that that is, that's really important, and I absolutely made a note of it when you said, "Well, we could probably do several podcasts on how you talk to someone with AD like, "Okay, [making a] list for Phil. We will. Okay." But you know, I happen to have a father who was 100% anti-baby talk, period. Didn't matter who the other person was, could be a two week old, you know, a two year old. It didn't matter. And so I have always sort of credited that for my early language development because he'd just talk to me, like I was me, you know, who I consider me. And meaning, in his eyes, from the moment, you know, we made eye contact right after I was born, I was just this, this precious being in his life. The end. And he was going to talk like he talked. And I think that has really, I mean it gets to dignity.

Philip Gutis: Yes, that's a really important thing. But I was going to turn the tables and ask you how you, I mean, not early stage folks because obviously we know how you talk to early stage folks, but how do you talk to somebody in the later stages? Somebody who is clearly, you know, um, not all there, not just suffering from memory loss, but really suffering from a loss of cognitive ability and um, you know, and possibly could really be in mental distress?

Christy Turner: So that's, I think, that's a really good question. Um, I speak to them much the same way that I speak to you, or to Tim, or to anybody. The key difference is I am naturally, I'm a fast talker. So when I'm doing things like the podcast, for example, I try to consciously slow it down. Otherwise I'll just end up with a slur of words that nobody can grasp. And when I'm working with someone who has, or interacting with someone who has, more advanced dementia, I consciously slow it down, and I try to cut a lot of the extraneous out of my speech. So, somebody who is at a point where they are consistently struggling for words and trying to verbally communicate what they need? I'm not going to use a ton of words. I'm not going to um, start describing things with. And I have many writers in my family.

Christy Turner: So, in my family it's like, if, "If you're using five words when you could be using 50, you're just not trying." So it's, it's really shifting the thinking on that to, "How can I best convey what I am trying to communicate, but more importantly, how can I best receive what the other person is trying to communicate to

me?" So it's definitely not any baby talk, but I would say it is more, often more about really reading the energetic signature that's happening there. So I, I think I'm not anything special when it comes to, most humans can look around and see if someone is in distress. So if someone's in distress, to my mind, that is the time that I want to approach them in a way that is non-threatening. I don't want to be threatening with my body language. I want to of course be respectful.

Christy Turner:

But I also want to keep it open so that they feel safe, secure, loved. That's the main thing. And then let's take it from there. So establishing some rapport. I still, I'm verbal, so I still use words. But, um, I guess one example would be if someone is, let's say pacing, wringing her hands, maybe mumbling, um, that's not the time for me to come up and say, "Hey, Betty, how you doing today? I haven't seen you in a long time. Sure is good to see you. It looks like you're going for a little walk, but you keep going in the same place and you're wringing your hands together. Do you need some lotion?" I mean, that's inane, right? So instead it's going to be more like, "Hi, Betty. You look like you're upset." And I want to pause, to see, am I going to get a response?

Christy Turner:

"Are you okay? Let me help you." And for somebody who's advanced like at the stage that I just described, what I'm going to want to do is just really synchronize my walking with her, synchronize my breathing, and try and, you know, communicate on that level first before we get to words. So I don't think that baby talk is ever appropriate. Um, and the other thing is that I know some people call everybody "honey" and it's a sign of like, "You're not important enough for me to learn your name." And then other people call some people honey or sweetie or whatever, and it is a sign of affection and it's a sign of their relationship. And so I think that as humans we need to be seen and heard, acknowledged, validated, as important. And so I use names because in my experience, that's what people living with dementia like it to be called. They like to be called by their name! And then, you know, I certainly have had some client relationships where it was just, you know, we became close and, and um, where I probably have said in, in moments, you know, we're hugging or just that genuine moment of connection. I probably have said, you know, honey or something like that, but never, ever as a sign of disrespect. So I think I probably answered your question and went off on some other rabbit trail. But I think respect is always key when communicating.

Philip Gutis: And you also, you made me realize, you know, from a caregiver perspective, you know, I often don't know, or--that's not the right way to say it. Somebody might see a meltdown coming before I see it.

Christy Turner: Yeah. Right.

Philip Gutis: And their behavior could be, um, such that, you know, they're stepping in to take care of me because they see that, even at the earlier stages, I'm about to lose it. And you know, it was interesting, that last day on the beach. I don't remember where we were, but it was--

Christy Turner: The Bahamas.

Philip Gutis: Right, The Bahamas, the private island. And I was, it was really hot, and all the shade chairs were taken. And I did find myself a shady spot. And I was up there, and I felt it was going. And you know, I was, I was about, I was on the trail to losing it. And one of the folks in our group came over, saw me standing, you know, it was, I think it was a beer vending stand that wasn't being used. And, "Would you like me to get you a recliner? We can put it up there and you can lay in the shade." And it was the perfect thing to do. And because I was otherwise about to run for the boat, for the ship, because clearly, I couldn't stay in that sun. It was, it was really beginning to get to me. And I asked him at dinner, I said, "Could you tell I was about to lose it?" And he said, "No." He was just, he was just being a nice guy. But I wonder, you know, sometimes do folks see that in a person, you know, living with Alzheimer's or any other kind of disease that causes distress and know that it's time to step in and take a little more control? Um, or offer a little more assistance as opposed to, well, there's even times when you have to take control, but you know, at least offer assistance. 'Cause you know, I'm perfectly capable of going and getting my own lounge chair. But I couldn't have done it then. You know, all I was thinking of was, *I have to get out of here.*

Christy Turner: Right. And I think that's a great point. So yes, like certainly, I have, you know, I'm coming up on 20 years of experience. So yes, I'm pretty good at seeing something coming down the pike. But sometimes, and it depends on the type of dementia, the cause of the dementia, also. Because, where I find Alzheimer's as a disease tends to be more predictable than some of the other causes or types, where things might change on a dime. Of course, you know, every person is different.

Philip Gutis:

Right.

Christy Turner:

And, and so with that in mind, some people are just more tuned into the people around them, as with the person who said, "Hmm, it looks like you're kind of getting over-baked there. Can I move a chair up for you in the shade?" So, it's yes and. I think--I'm glad you made that distinction between taking control of the situation and offering assistance there. I think that the more we as care partners lean on the side of offering assistance rather than seizing control, the better off everybody is. There are situations, and I'm thinking really specifically when it comes to safety, where seizing control would be appropriate because there's just no time to do anything else. If somebody seems confused and disoriented and they're heading into a street, I will seize control. And I'm going to try and do that in a way that, of course, protects someone's dignity and is respectful. But if push comes to shove, I'm not going to let them get hit by a car. When we offer rather than try to direct, um, sometimes that can go too far the other way. For example, I was with a client yesterday, um, and he said that he was wondering what the best way was to get his wife to remember where he put information for her. And I was like, "Okay, this is going to be a very long conversation, because we have some work to do!" But, so his idea was more about like, asking her a lot of questions in the offering of, like, "Do you want me to write this down for you? Should I--?"

Christy Turner:

Throwing a barrage of questions at someone who has expressed that they have a need for information, but maybe seem like they're kind of confused or haven't really fully woken up for the day, that's not going to be helpful, either. So again, like with so many things, we're looking at a fine line. And one of the things you said toward the beginning of our conversation, Phil, made me think of this when I was talking about most people don't have experience with dementia until they are in a situation where they need to learn more about it, is I think as professionals, we as professionals, do a really poor job of making sure that care partners, number one, are aware that there's help and assistance out there for them, so that they can be the best darn care partner they can be. And number two, that when we're looking at most types of dementia, most causes of dementia, it's a process that has some distinct phases. So not everyone--and again, 'cause we're talking everybody who's living with dementia is human, right? So when humans are involved, people are going to be different, because everyone's unique. So there can't really be a hard and fast rule about if somebody has this diagnosis and they're this age and

live in this state or whatever, then you do this. Um, there are certainly best practices. There are ideas that are better than others, but it always comes down to what's happening right now in this particular situation, and getting a read on that. Rather than grabbing someone and saying, "Where are you going? Are you okay? Do you need me to walk you to your room?" Or something like that.

Philip Gutis:

Yeah. Yeah. It's, as we were talking, as we talked last week, and as I've lived for the three years now with this diagnosis, it's, it really does change, even in the early stages, it changes everything. Because obviously, you wouldn't have the diagnosis if things weren't happening to you. So, you know, all along things have been happening. Care partners have been looking and going, "Hmm, that's not right." The person themselves may be thinking, *That's not right*. And you know, this idea that it's this constantly evolving, you know, almost minute-by-minute....And I'm thinking in the airport on our way home. Tim was very careful with me. And yes, it's true: I do get anxious when I fly now, more than I ever used to. I used to be on an airplane every, every week, virtually. But now I definitely get more anxious about it, and I need to move slower and more carefully through airports and things like that. But I guess I was feeling fine the day we left and everything was going smoothly and I almost began to resent the extra care that was given to me because I felt, I can do this. I'm fine. Now, it's not fair to Tim because, you know, if there had been a delay, like many of our cruise mates had experienced, it wouldn't have been fine. And you know, airports are crowded places and I don't--and most people living with Alzheimer's don't--like crowds and they're noisy. And you know, there's all these reasons that you could say, I need to be extra careful, as a care, caregiver, care partner. I was feeling fine and you know, it's a no win situation, isn't it, for him? I guess that's what it comes down to. He's never gonna, he's never gonna get it right. It's never going to be perfect.

Christy Turner:

Well, I feel like this is a great time for me to say, number one, no human's perfect. Number two, to pipe up and say, I've met Tim. I love Tim. Tim is a really gentle guy. He's got that--it's funny, 'cause we didn't talk about this, so I don't think this is part of his past, but who knows? It could be. Um, but he's got almost like that California surfer vibe, real low-key kind of energy. That's, um, and he doesn't, you know, he's not looking like Spicoli from *Fast Times* [at Ridgemont High], but, he has that kind of really mellow energy. So I'm wondering, can you, do you have an example that comes to mind, Phil? Where during

that airport experience where you were like, *It would be okay if you backed off!* to Tim?

Philip Gutis:

Um, we were getting ready to board and somebody had told us that if you go to the flight, go to the desk before and say, you know--and Tim does this--and say, "I'm traveling with somebody, you know, where the person who has Alzheimer's. May I board early?" And they always say yes. And so we were sort of in front and it was getting a little crazy and Tim was being, you know, 'cause a lot of people were jockeying for position because Lord knows you've got to get on that firm phone plane first, otherwise you might miss it, right? So it was getting a little crazy and I could feel Tim's energy was changing and you know, he was being extra careful, but I felt fine, you know, and I was prepared to knock over whoever I needed to knock over to get on the plane. I didn't need any extra care at that moment and you know, but, but again, I could understand why he would think that maybe I did. Because people were pushing, and was getting crowded, and you know, we were all jockeying for position. So yeah, I could, I could see that, you know. And other times, I might have gone a little catatonic on him, um, and he would've needed to, to take care of me a little more. So.

Christy Turner:

Okay. So, interesting, because he didn't, it sounds like he didn't do any particular thing. But you felt a shift in the energy; that's what you said.

Philip Gutis:

Yeah, I think that's it. Yeah.

Christy Turner:

Okay. Interesting. So, I have a couple of other questions for you, Phil, and I know you're being super generous with your time. And as you know, I can talk to you for hours and hours, and--

Philip Gutis:

Yes, we can. I can talk right back [to you].

Christy Turner:

Which is why I'm so excited you're going to be a regular. But, um, so a couple of things that came up during our conversation today is, one thing that you mentioned when you were talking about a meltdown and asking, Can other people sense it, maybe, before I can? You wrote a piece about the holidays and how you were going to try and do it different. I think this was for the 2018 holidays, and described an experience that you had had, I think it was the year before, where everyone around you, or the information that you had, was kind of indicating it's better to keep it a small gathering. And so basically you said, "Nah, that's not what I want to do. We're going to do it my way. We're going to have a blow out! It's going to be awesome!" And

unfortunately, yeah, it didn't go the way you would have hoped. And in that article, you mentioned that Tim did sense that it was probably time to wrap it up and you waved him off.

Philip Gutis: 'Cause I didn't want him to not experience, to not have the experience of the party.

Christy Turner: Yeah. And I wanted you to say that in your own voice, so nobody thought I was putting words in your mouth. I think that, and to me in reading that--and I will definitely link to that piece in the show notes--that was, I think, one of the most tender things that I've read about anything related to dementia. Is that level of care and concern for the care partner, is a two-way, it's a two way street, really, from the--

Philip Gutis: Yeah. It really is.

Christy Turner: And I think that gets overlooked.

Philip Gutis: Well, I don't know if it was you who mentioned it, or somebody else, but the loneliness of the caregiver. And, you know, Alzheimer's is an isolating disease, certainly for the person who's living with it. But I hadn't thought so much about the caregiver. Obviously, it makes sense because they can't go out and party like they used to. And, um, you can't leave your person alone. You can't, you know--can you get assistance, blah, blah, blah, blah? So, you know, I am aware of my limitations, but I hate the fact that it's going to stop Tim from being in a situation where, you know, this one event, that Thanksgiving dinner that we're talking about, he loves it. Um, so yeah, and I tried--this was, okay, so I've tried three times. The first year, I started to cry in the middle of dinner, for no apparent reason. The second time, I had a strategy, which was god-awful stupid, looking back on it: to plant myself in the football room. Um, yeah, not the smartest thing, huh? And this year, I had a strategy. I went back again, and I had a strategy that I was really going to stay in a quiet space. And it turned out to be the space where a lot of moms with toddlers were hanging out, and I had the best time with the toddlers.

Christy Turner: Really?

Philip Gutis: You know, and I didn't go to the main dining area, you know, where the long tables are lined up. I got food myself and I went back to my quiet space where, you know, there were moms and toddlers, and, or just by myself. And Tim was off being social butterfly and carving 600 turkeys, and wearing silly hats, and stuff like that. And it was fine. And now I know, I feel more

comfortable that next year I have a strategy, that I can make this work. Now, this Sunday we're supposed to go to an Easter egg hunt and blowout, but I've not been to before and I'm a little worried about that, but I'm going to try.

Christy Turner:

Yeah. Well I, I love that, that you pointed out in the Thanksgiving example: "So here are some ways I know that it doesn't work." And you kept trying to refine it. Like, "I'm gonna come at this with a different strategy," until you hit on something that works. And I think that's a really important thing for care partners to hear, that just because something didn't go well one time doesn't mean it's forever a no-go. If it's something that is important to people in the household, how can we make some adjustments? How can we devise a different strategy that is going to make this a good experience? And that's worth trying.

Philip Gutis:

And that really comes down to the whole notion of living with Alzheimer's, not just having Alzheimer's. You can very easily sink into the spot of, *My life is over. It's not worth moving forward, blah, blah, blah.* But you know, it's so critical that you not fall into that, because your life isn't over. And you know, um, everybody dies. Sometimes, sometimes the parting is more painful than others and more extended than others. But, you know, we're all gonna, we're all gonna--the time's up for everybody at some point. And, you can, you can try to make the best of the awful situation you've been handled, handed, or you can, you know, disappear into depression and sadness and misery and probably leave earlier.

Christy Turner:

Right. Right. And, and we'll definitely delve deeper into that in other shows. Another thing that I want to come back to again is--and I think it's really important for care partners to hear this, whether you are an adult child of a person living with dementia, or an adult grandchild, or a spouse, whatever the nature of your relationship, that when you love someone, it's that two-way street. And so in talking about that Thanksgiving story, Phil, where you're saying, "I waved Tim off because this was an important event to Tim." So, just because you have a diagnosis of Alzheimer's disease doesn't mean that the part of your identity that is husband of Tim is stripped away. You still, that's still a role in your life. And I think that a lot of times, again, going toward that, "But I want to help! I want to help!" is people kind of forget that those are other roles. Parents still want to act parentally, they still--you know, spouses still want to be spouses. So those roles still exist. And I think as care partners we would often do better if we took a giant step back and gave

our person the room to be who they are in whatever capacity they are,

Philip Gutis: You know, as long as they can. I mean--

Christy Turner: Right.

Philip Gutis: There are going to be times when they can't, you know, and--

Christy Turner: Sure.

Philip Gutis: And knowing what's, what's the, the song knowing a hold them and hold or fold. I don't know. I'm, I'm messing this up.

Christy Turner: Kenny Rogers, yes.

Philip Gutis: Right. What is the, what is the song?

Christy Turner: It's called *The Gambler*. I think.

Philip Gutis: Okay. Okay.

Christy Turner: "You gotta know when to hold 'em, know when to fold 'em, know when to walk away."

Philip Gutis: Right, right, right. And that, that's kind of the challenge that we're putting on a caregiver of any type. And you're not going to get it right every time. Nobody is. Nobody could ever get it right every single time. But, you know, I think it's really important that you try to find that balance.

Christy Turner: Yeah. Okay. Final question for today, Phil. And I think you're the perfect person to ask because, well, for several reasons. One, because you're a person living with Alzheimer's. Number two, and maybe more importantly, you trained as, you got into a training program after you graduated Penn, you got into a training program at the *New York Times*, you were promoted to reporter. You are a careful observer. Words matter to you. So, you've used both the word "caregiver" and the phrase "care partner." As a person living with Alzheimer's, as a former *New York Times* reporter, do you have a preference? And do you see the distinction?

Philip Gutis: I think I learned the term "care partner" last week, um, and I, uh, definitely, definitely, definitely prefer it. I think it is a partnership, and it has to be a partnership. And you know, it gets back to everything we've been talking about today. You know, if it's not a partnership and if it's, you know, all one way,

either way, I don't think it can be, I don't think it will be as successful as it would be if it's a partnership. As any relationship, right? I mean, most relationships need partnerships, not just givers. Some, I guess, people need just givers, but I think most relationships are better if you approach everything as partners, um, including, you know, chronic, fatal diseases. And, yeah, it's an interesting--you know, I hadn't necessarily--well, I did realize that I was using the terms interchangeably at one point, as we were talking today, and kind of like, *Huh, where'd that come from?* And I think it was last week, where it was, you know, somebody used the term--and it could have been you--that sort of opened my eyes. I had my eyes opened a lot last week. I thought it was a really valuable experience and kudos to Lisa, who's name I'm blanking on. Of course.

Christy Turner:

Lisa Marie Ciricco.

Philip Gutis:

Yeah. Um, for pulling together such an amazing group of people, you know, the faculty for her conference. You could tell she gave it a lot of thought and really nailed both the topics that were presented and the quality of the people that were there to offer their perspectives. It was educational and it was affirming and it created community. Like, all of us who were there, you know, definitely felt like as we left and you know, the conversations are continuing, and I think they're going to, they're going to continue. Some people who aren't on Facebook aren't seeing them *ahem*.

Christy Turner:

Really?

Philip Gutis:

Yeah. Yeah. Those of you who aren't on Facebook missed me in tall red stiletto boots yesterday.

Christy Turner:

Oh, no! Did you have another MRI?

Philip Gutis:

Yes, I did.

Christy Turner:

Oh, okay.

Philip Gutis:

And I did it. I wore them.

Christy Turner:

Yeah. Okay. So, we are referring to the shoe challenge. That's #shoechoallenge, that Phil created, on MRI days while he was part of a study. So, and that is something, of course, that we will be covering in a future episode also. So, wow. Well, I echo your sentiment that Lisa did an amazing job pulling together an amazing group of people. I was blown away that I got invited to

be a part of that speaker faculty, because I mean, seriously, you take a look at the people who were, who were part of that and I thought, *Oh my gosh, this is, this is going to be tough to be to a, you know, run with these wolves.* But, to me, I mean it was one of the most enjoyable weeks of my life, but it was the quality of the participants. I just, I, my two feelings, the overwhelming feelings coming out of last week were joy and love. And that was, that was just the experience that I had. So, um, yeah, it was terrific. And I got you out of it. So, yay!

Philip Gutis:

Yay, there you go. And I hope you'll be back next year, and I hope I'll be back next year, 'cause I think it was incredibly well worth doing, and doing it again.

Christy Turner:

Absolutely. Well, thank you, Phil. We look forward to having you back and covering so much more territory.

Philip Gutis:

Yeah, I look forward to it. This has been, again, eye-opening and enlightening. Just as a last thought, I mean, I also think there's a--which gets into the stigma, which I hope we'll talk about a lot more, but--

Christy Turner:

Of course!

Philip Gutis:

You know, you know, "We can't talk about this! You know, we're, this is not meant to be talked about. This is meant to be, you know, held close to the vest and suffered in silence." And that's the exact wrong way to play this. We have to talk about this now, and I'm glad you have provided an opportunity for folks to listen and to talk about these issues.

Christy Turner:

My pleasure.