

The Alzheimer's Podcast

Episode 138: Laurel & Hardy Throw a Party

Tim Weaver: One of my newly acquired skills, I guess, is I very quickly try to look at it from Phil's perspective. And a lot of times I'm always just glaring at it from my side of it.

And so as soon as I realized, you know, it makes it a lot easier to, once I look at it from where he's looking at it from, to go, *Oh!* It makes it much easier to recognize, as opposed to saying, "What is wrong with him, and why can't he do it my way?"

Christy Turner, CDP: 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!

.....

Christy: So Phil, you and Tim had a team again this year for The Longest Day. Last year, it was the Row2Remember. The year before that, it was the epic Purple Party. This year, obviously, in the midst of COVID-19, it was a different thing altogether. So how did it go? What'd you do? Tell us all the details.

Phil Gutis: Yeah, it was a baby Purple Party. But, it's funny. It started off--well, I originally said it was going to be another Row2Remember. And I pledged to actually row a marathon. And, of course the COVID came along and then the rowing studio closed, and I just didn't have it to sit by myself for four hours.

Then I decided I was going to do a walk, virtual walk five miles a day, basically the length of New Jersey and back. I can't remember how many miles it was and I had to apply 15 to do it. And I think I started on May 15th and then, you know, I just--my legs weren't having it.

So, then I was like, I'm out of ideas. And then I thought, well, you know, I am participating in research and that's really important for Alzheimer's because if we don't have enough people to do research, then we'll never find treatment or a cure. So that was my thing.

And I of course had my first infusion, the Biogen trial, a couple of weeks ago now. Wore my silly shoes and blah, blah, blah. Kind of a cop out, but hey, it worked. So we raised money around that. And we broke our goal, which was \$10,000, and we're probably at 10,600-something dollars.

So I'm very excited about that. Thank you, Christy, for your donation. And Michael.

Christy: Of course.

Phil: And I think for a couple of listeners, to your listeners too, who donated. So, that was good. Then they [The Alzheimer's Association] decided that they want to-- because everything's virtual--they want to do Facebook Live throughout the day of people doing their Longest Day events.

So we had decided to have a little soiree at our house. And Tim, Tim has been working with a Border Collie, one of his clients who turns out to be a Frisbee star. I mean, like amazing for the dog. Having never seen a Frisbee before--he's like four or five years old--he is astounding. So, we came up with this idea that Max--the dog--would catch Frisbees for dollars.

And Max, his mom is in a memory care facility because of a very bad fall from a horse. So, it's supposed to be great [Frisbees for dollars] and we figured we'd have a few people over.

So we're scheduled to go live at four o'clock. Everything's fine. I can't really figure out where the camera is on the iPad, but you know, when I'm moving it around, I just can't get myself in the screen.

But you know, Tim--and I also think my arms are too short, but Tim's arms were fine, blah, blah, blah. So we go out, we get on, we get on and we go outside to do the Frisbee thing and I lose my connection.

Christy: Oh, no!

Phil: So of course I have to log back in again. I'm like, "I'm back! And I'm sorry, guys. We can't show the dog Frisbee because apparently the minute I step out of my house, I had no connections."

Should've tested it before. Oh, well. So then Tim and I go, we go to sit down outside at a table and I sit down and we start talking. Then all of a sudden I feel something crawling on my leg. *That is a tick on my leg!* I'm like, taking off my leg and I'm like, "Sorry, folks. I had to pull a tick off my leg."

This is all, of course, live. So I get the tick off, pick up again, blah, blah, blah, and then all of a sudden, the skies opened up like you would not believe. And we're sitting under this umbrella, which was fine for a little while, until it really starts coming down.

So then we had to move ourselves inside. And I don't know if it's part of the, my brain not working or what, but I could not get how to keep myself, how I could talk to the iPad and keep myself in the image and stuff like that. So I'm pretty darn sure that most of the live shot was my nose.

Christy: You're saying you haven't gone back to take a look?

Phil: Oh God, no! I would never! I hope they haven't posted it. Oh my God. 'Cause then at one point, you know, we're chatting and chatting and Tim takes off. I think he was just done. He takes off and I'm sitting there trying desperately to move this iPad so that I'm in the frame.

Christy: I think one of the little hidden treasures of COVID-19 has been how people who maybe don't use technology a lot in that way, [for] broadcasting and things like that, is if you watch the news at all, you now have an understanding that technology is fantastic when it works and it is not guaranteed.

Phil: No, it is not. It is definitely not guaranteed to work, especially when you have a degenerative brain disease and cannot figure out where to look. Tim's holding it one way; at one point we're talking, next to each other and he said, "Just look at the camera."

And I'm like, "I don't know why I can't!" Every time I start talking, I try to find myself in the camera and I always move my head the wrong way. So this whole film is me going, "Huh? Where?"

Christy: I've actually seen people on TV do that too, where they are looking into the camera, which ends up looking kind of funky. If they're on their laptop, it looks like they're staring off into the distance, up and to the right. *What are you doing?!*

Phil: Yeah, *What are you doing?!* I told somebody I was pretty sure that the entire thing was a closeup of my nose hairs.

Christy: So other than the technical difficulties, it went well?

Phil: Well, we had a very nice little gathering at our house, so that was sweet. Did it rain though! Oh my God, did it rain! And Max eventually went out and caught his Frisbees in between downpours. And, I think one of my friends took some photos for Tim, and some videos of Tim.

But then, of course, let's just say Tim does not entertain without pre-party....

Christy: Preparation?

Phil: No, that would be too soft a word. Hysteria?

Christy: He gets a little nervous, does he?

Phil: Oh my God. Oh my God. He decides that--well, he was up late making cupcakes. I understand that. But he decides that I'm going to go do his eight o'clock [dog-walking] client. And you know, for me to do a dog walk at eight o'clock, you roll out of bed at 7:45. Not for Tim. He's up at seven, screaming at me to get up, get out of bed.

And then, you know, I didn't right away. I snoozed in and then just before he came storming around the corner again, I managed to sit up, and you could just see he was getting ready to go, "Aaaarrggghhh!"

And it just all deflated when he walked in. That happened at least two more times, where he came running around going, "Aaaarrggghhh!" and I was putting on my shoes or something.

The whole day was that way. And I just--we're never entertaining again. Never. Ever.

Christy: Do you say that after every event?

Phil: Probably, yeah.

Christy: I'm just wondering if there are any married couples anywhere that have a spouse who has the same biological clock that they do, the same internal clock. Because it seems like the answer is no.

Phil: Yeah. I mean, I don't know. I mean, maybe it's because Tim's doing it all, but I'm so like, I'm so low key about it, but I'm also just like feeling, look, we have four dogs, two cats, a turtle. It's our lifestyle. Just, you know, there's fur everywhere, okay?

Yeah, we swept it up once today and it's back again. So, you know, welcome to our life. You know, I'm not going to go crazy. This is who we are, right? But no, no, no. It has to be perfect!

Christy: I had a friend who used to say, when people walked into her house, she'd say, "Welcome! As you can see, we *live* here."

Phil: Yeah. We live here with a lot of furry critters, four-legged and two-legged. And, you know, it's just like, you know, welcome to our existence. This is us. That's always the way I felt about it, you know?

And then at one point, the flowers had to be picked up. And I'm like, "Really? Why don't we need flowers?"

"We need flowers!" So he sends me off to get the flowers. Of course, I can't find the place. Of course, he is ready to lose it. And you know, it's like *Laurel and Hardy Throw a Party*, I guess.

Christy: And unfortunately, most of it is not recorded.

Phil: Oh, good God. No. Well, there was enough of the record. If they [The Alzheimer's Association] really wanted to have some fun, they could've had their cameras here all day recording us getting ready for the party.

Christy: Your effort is even more amazing, knowing the backstory.

Phil: Yes. Ultimately, of course, it's about the fundraising and, you know, I really didn't think we were going to make the \$10,000 this year, but we did.

Christy: Which is amazing in the midst of a pandemic and, essentially, Great Depression 2.0.

Phil: So yeah, I mean, last year we did over \$13,000, and, you know, I was really--you know, you're also just feeling bad about asking for money. I mean, that's a big challenge. I didn't go to anybody and go, "Give me money!" but you know, Facebook, email, and thankfully I have enough good friends and family. And--

Tim: I had to go to my family and say, "Give me money," 'cause we only got 35 bucks until we—

Phil: That's Tim, everybody.

Christy: So only \$35 from Tim's family, but the house had flowers for the party. So let's keep perspective here, right?

Phil: And our deep purple purple cupcakes. I cannot say those two words together. Purple cupcakes were yummy. The place looked gorgeous. Even my sister was impressed. You know what the best part is?

Christy: You raised a bunch of money?

Phil: No. It's done. It's over. I don't have to think about it for a year, for about a year.

Tim: Yeah, no. Maggie wants us to think about it next week. I'm pretty sure she does for next year.

Phil: Yes. She's smoking crack.

Christy: Phil's not having it.

Phil: No, no. I get at least a month off before. I mean, actually, the fundraising season for The Longest Day doesn't end until August 31st, and start again on September 1st for 2021. So we have to get a walk team going, too.

Christy: Yeah, I started to say, where does the walk fit into that?

Phil: Last year was Team Tim and Phil, and we raised \$20 by registering.

Christy: Well, I think your signature event is The Longest Day.

Phil: Yes, we're the co-chairs for the organizing committee. So yes, that is our signature event. And I mean, I know a lot of people hate fundraising. That's not among my favorite things, but one of the first pledges we got was, I think, \$250 from a woman I went to high school with and I have not seen since then, except on Facebook.

And then one of my co-board members [on The Alzheimer's Association-Delaware Valley Chapter]--the goal for individual fundraisers was \$1,600, and that was called Solstice Champions, Longest Day Champions. And one of the board members just donated \$1,600 to our event, which was just, you know, didn't tell me he was doing it.

And I went to look, I think it was the first day, as soon as we started raising money, and I went to look and I was like, *What happened?* The thermometer was so far

along and I went and looked at the donations. I literally almost fell off my chair. \$1,600. One of my former bosses who I did not leave in the the best of places, gave \$250. It's just, you know, it's just, it's always nice.

And I guess the moral of that story is, you know, if you ask you will be very surprised. Some lady who could not afford to give us a dime gave us \$10, which is just remarkable and very, very sweet. It means a lot, obviously, since I'm raising money for a disease that's very personal. So yeah, it's very nice.

Christy: So is Tim still with us?

Phil: No, Tim has left to dog walk.

Christy: Oh, okay. I was going to pull him into the conversation, but that's okay.

Phil: So Tim's come back. He heard, *Ooh, publicity!*

Christy: Well, Tim, I wanted to ask you--because, Phil and I have talked about this on the show before, and it relates back to one of the events you did for The Longest Day, which is the Purple Party. When I first met you and Phil, you showed me pictures from the Purple Party, which you had done in 2018 for The Longest Day.

It was really amazing, and you gave me a lot of the background on it and how you had such a short period of time to pull it together. You just really worked your butt off to make that magic happen. And one of the big disappointments for both of you is that later on, Phil didn't have any recollection of it. Even after looking at the pictures and saying, "Yeah, it looks like it was a great party. I don't remember any of it."

And so my question--I'm wondering, do you think that has impacted how you think about The Longest Day events since then, or has it kind of made you redouble your efforts? Like, *Yeah, I really feel on a personal level how serious this is, and I want everybody else to know.*

Tim: Boy, I think that it's maybe a little bit of a double-edged sword on both sides of that. You know, it cuts both ways. I think one thing definitely you see, you know, all of that effort and all of that work and, and then Phil doesn't remember it.

It certainly makes for a stark reminder that you don't do this, have an event, raise money for it, and then it's all over. It doesn't make it all better. And so it instills it more in your being, to become a cause. Because that requires a much longer investment. Just like our journey in being Phil's caregiver is the same way.

You know? I mean, I didn't know what to expect when I started. And I had--as I learned more, I had greatly more fears and misgivings, but then as I learned even more, you know, you become better prepared to deal with it and you become better equipped to handle what comes your way.

Christy: What do you think has helped with that, Tim? Like, are there a few things where you can point to and say, "Well, that was really helpful. I'm really glad I found X, Y or Z," or has it just kind of been a cumulative thing over time?

Tim: think it's been more an accumulative thing over time. I don't think there's really been one thing that I have found, any X, Y, or Z that I could point to and say, "Oh!" I mean, it's just been the cumulative effort of watching Phil's journey and watching others' journeys and then my own shortcomings.

Because one thing that this whole journey has definitely exposed is many of my shortcomings and the things that I have to learn about this disease. One of the things I have to learn is how to deal with this disease and how to deal with Phil's responses, and Phil's responses to the disease, and how important it is that I process those from some other perspectives and not always from my own personal perspective, which is hard to do at times.

Phil: You never know what you're going to--not even just wake up to, but any minute, you know, along the way, something can crater.

Tim: Yeah, I guess that's been one of the biggest things I've learned, is that you can be like Phil just mentioned. You know, at any given time, this thing can rear its ugly head.

Christy: With no warning.

Tim: And it does, with no warning. And we can go from being--having the best, most fabulous day in the world to being in some really deep and dark places in one moment or one sentence, in one unthoughtful sentence said, in a begrudging look. I mean, there's just so many, you know, I mean, it's, it's--

Phil: I wasn't even going there. I was thinking, you know, just everything's going along and then something, like one shirt--

Tim: You know, a tee shirt that Phil doesn't remember. I mean, it can really be so many different things, like an event or whatever, but it could be something as simple as something said. But it's usually a little bit more than that, but it can trigger a

rollercoaster of events. And you just never know what those triggers are, what those events are. And that's one of the things about this disease that's so difficult.

Christy: Right. Phil has said many times that you are in a thankless role, Tim. That--

Phil: A no-win situation.

Christy: Right, a no-win situation. That is, as you've just described, you guys can be having a fantastic day, happy, laughing, everything's great. And then something comes out of left field and when Phil is telling us about it, he's saying, "Tim was in a no-win situation, because there's really nothing he could have said or done. Once that kind of thing happened, that pothole appeared, there was no way for him to win. And so he was left in the position of sort of just dealing with the fallout with absolutely no right answer." So I'm wondering in light of that, Tim, how do you process that?

Tim: Well, you know, I process it by trying--, you know, there's, there's one thing that, a go-to, I guess--I don't want to say mechanisms or defenses or whatever, but one thing that I'm learning, one of my newly acquired skills, I guess, is I very quickly try to look at it from Phil's perspective. And a lot of times I'm always just glaring at it from my side of it.

And so as soon as I realized, it makes it a lot easier to, once I look at it from where he's looking at it from, to go, "Oh, it makes it much easier to recognize," as opposed to saying, "What is wrong with him, and why can't he do it my way?"

The big recognizer is that we know what's wrong with him and he has to do it his way. And even though it may not always be what we would--and I don't, I'm not saying doing anything any particular way--but somebody's responses to, or reactions to, everything aren't always controllable and aren't always--what's the term I want to use?

Phil: You did very good last night. You very much wanted me to get in that glass box and I did not want to.

Tim: Yeah.

Phil: And you didn't lose your stuff.

Tim: No, no. Yeah. You know, you pick your battles.

Christy: Right. For clarification, for anybody who didn't catch it, the glass box Phil is referring to--I'm almost certain--is the shower.

Tim: Right.

Phil: No, it's just a glass box. He puts me in it, everyone, just to make me go away.

Tim: Ha! If only it was that simple!

Christy: So what I'm getting from what you're saying, is one of the key things is you don't seem to take it personally.

Tim: You can't!

Christy: Or even if you do in the moment, you let it go very quickly.

Tim: You have to let it go. Because if I took this disease personally, if you took the effects that this disease has on a relationship personally, the response, I think, would be a hundred percent of the time you would walk away from--I'm not saying this is a correct response, please--but I think a hundred percent of the time most people would be, if they took everything personally that goes on as a caregiver, if you take everything personally, you're going to walk away as a caregiver very quickly. You cannot do that. Because it's just, you can't, sorry. Rule number one, you can't take it personally as a caregiver.

Christy: Do you think that's always been a strength of yours, or is that something that you've had to develop since Phil's been diagnosed?

Tim: It's definitely gotten much better since Phil's been diagnosed because I've had to draw much more--fortunately for me, I have had in my past some caregiving experience. In much different roles, but in some hospice care roles for people in later stages of their lives, but which are still caregiving roles. And I had been put in situations to do things that were uncomfortable and people--things were said that I could have taken very personally and you just, you have to learn that that is never meant personally. So I think I have a little more to draw upon than everybody else does.

When I was presented with Phil's diagnosis, I was maybe a little better prepared to deal with it, but that doesn't make it any less stressful or any less devastating, particularly since it's the man I love.

Christy: Right. Right. So do you have any tips for people about how you get to that? 'Cause it sounds like it is something that you've developed over time, based on past experiences that you've had, also. But I'm assuming now, as years have gone by in your life and from the experiences you talked about prior, that you're able to get to a place of not taking it personally and letting it go much more quickly than maybe you previously were able to. Is there anything in that process where you could point other people to, *Hey, this is what really helped me get to shortcutting that?*

Tim: don't know if there's any one thing I could point to. Other than, when it came home. And when I say that, when it came home, when it came to Phillip, and then that was, you know--when it came to Philip and then it came into our relationship. So it became very personal.

Christy: right.

Tim: You know, it was one thing when I was dealing with it from somebody else's perspective of--even when they were loved ones--of, I don't know, it just, it became much more personal with Phillip's disease.

Christy: Well, sure. It's different when it's your husband.

Tim: Right. And because of that, I think, it forced me to reassess how I approach everything and look at the big picture. And I think some of it has been the sad self-education of the realities of this, of dementia and Alzheimer's and stages of it. And as I've learned, one of the things that I think I have learned to grab onto and hold on to, if you were looking for a caregiver tip that I could offer, would be it's particularly more important to learn in the, obviously in the early, at the earliest possible stage, is remember that this is going to be a long journey.

It's going to be very difficult. And so it is best that you can't take it personally, so that you can get to the moments when it's really good, because you don't know when that ugly monster is going to rear its head.

So one of the things I would say is it's all of those situations when you're struggling with taking it personally, regardless of what the situation is, or all of the bad situations that the two of you face, you never know when they're going to happen. You never know how bad they're going to be. But they're coming and they're going to happen.

So you can't take it personally because you can't get back to the good spaces you're going to be able to be in without letting go.

Christy: Absolutely true. That is great insight.

Tim: So that is my that's my tidbit of advice, before I run off with a 85 pound silver lab for a dog walk.

Christy: Well, thank you so much for taking time to talk to us. Really appreciate it.

Tim: Thanks for letting me join into the conversation without ruining it. And I would love to come back and do it again sometime. And we can talk about anything you want to talk about anytime.

Christy: Our pleasure. Thank you so much.

Tim: Thank you.

Phil: Bye. Don't melt.

Tim: I'll try not to.

Christy: And that's our show. Thank you so very much for listening.