

The Alzheimer's Podcast

Episode 135: “Where isolation and solitude comes in handy”

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And I needed to do that several times, like big moments like that where I would say, *Give this up. This is not what you're supposed to be doing. You're supposed to be loving him, you know? That's what you're supposed to be doing.*

And, so then I would say, *Stop listening to other people. Let's just listen to each other.* And that's where isolation and solitude comes in handy.

And the comparison, like, *How good of a caregiver are you?* And you know, so much of the language of caring is about the battleground. You know, “you got this;” “you can beat it.” And I'm supposed to be like a warrior all the time. *No! No! No!*

Let's go to the garden and feel the sun on our faces and look at the same view holding hands. And that is perfectly perfect.

Christy Turner: 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.

This week, I got author and blogger Donna Thomsen to [come back](#) to the show. She has so much wisdom to share about solitude, a timely topic in this time of Covid-19. Although many states are “reopening” right now—and we’ve got more on that in upcoming episodes—Donna’s thoughts on solitude and isolation are relevant to care partners no matter what’s going on in the outside world.

Christy: Donna, thank you so much for coming back to the show. I really appreciate it.

Donna: Thank you for having me. It's a pleasure to be here.

Christy: It's a pleasure to talk to you. So, before we started recording, we were talking about the idea of solitude, and I was saying how much safer I feel being around some solitude these days.

And you mentioned [you've written a book about solitude](#) actually, and it's something that you've sort of developed a comfort zone around over time. So, I would love to talk to you more about that.

Donna: Mm hmm. Well, you know, as caregivers, we really, really have to do a crash course, I think, in isolation and solitude. And it's such a timely topic, right now during the pandemic.

And I think it's what you were saying in the introduction, it's so ironic that being alone right now is what is keeping us safe. And so I think we, in our culture, have traditionally thought that safety in numbers, [and now] we feel, we don't feel safe [in numbers].

I don't think, culturally, when we're alone. It's an anomaly to be alone, and to be happy alone is even stranger. I think, you know, we crave distraction a lot of the time and it is hard work. And I think many of us try to learn how to make friends with solitude and be at peace in our own heads, by practicing meditation, practicing mindfulness, practicing gratitude, and finding a way just to be at peace.

I've really thought a lot about what it means to be a caregiver and to be very isolated in that role. And that really came from my personal experience of being the primary caregiver for our son, Nicholas, who is now 31 years old. But for 23 years, he lived at home and we ran what I would call a home ICU for him.

His needs are very, very high. And now he lives in a nearby care home with 24-hour, one-to-one, awake nursing care. So, we provided all of his care, largely without very much help, for all those years. And you know, it was interesting. So, so many days, so many years, it was very difficult to leave home, to leave our son's bedside.

You really couldn't ever leave him alone. And many times he was—he is—very medically fragile. So many times, he wasn't well and he needed me to be very, very close by or with him, and we would be home alone. And sometimes light bothered him, so we'd close the curtains. Sound bothered him. So, I disconnected the telephone and we would be alone together.

And I began to—I think that this big part of caregiving that involves isolation is interesting, because at first it feels like kind of water torture, particularly if you're like me and you're a naturally social person. And I would crave the company of others, I would crave a conversation.

And I would be wondering, *When can I leave? When can I, you know, escape this isolation?*

Christy: I just want to make sure that everybody understands your son, who is medically fragile, is also nonverbal.

Donna: Yes. But, you know, I think the thing is, I began to think about this process of settling in to care and settling into this reality of the two of us together.

Christy: And how long did that take, Donna?

Donna: It was a slow process. That happened over years. I would say.

Christy: I can see that, because I would imagine when you have a newborn infant with a lot of medical diagnoses, that may be you're trying to figure out, or conditions that you're trying to manage, everything feels sort of life-threatening right out of the gate.

Donna: Yes.

Christy: So that each particular thing gets your total focus until—how long was it before you realized like, *This is sort of the zone that we live in, where we have a son who's medically fragile, so things might not ever really feel settled as far as like, 'Oh, we can lean back and exhale that everything's okay'?*

Donna: Well, I think it's an interesting learning curve, or at least it was for me. I don't know that we could ever exhale and say everything is going to be okay.

Christy: Right.

Donna: Our son now, the latest even was that now that he lives in a really wonderful—we're so blessed, thank God—long-term care home, the latest is that, he's, we think, he's going to be tested for Covid, and I wasn't sure how that would work without sedation.

I was afraid that actual swab would break in his nose or in his throat—wherever they're swabbing; I'm not even sure—and puncture him somehow, because he wouldn't understand and he would struggle.

Christy: Right.

Donna: And I could see this potentially happening with someone, you know, with Alzheimer's or dementia, as well.

Anyway, the nurse reassured me that the swab is flexible and it's very, very quick, and she didn't anticipate a problem, but I mean, even something like that was potentially something to keep me awake at night. So, we don't, I don't ever feel that my husband and I can truly think that there is not a potential threat in the offing for our son. But—

Christy: So, it really has been a process. Just something that you've built on over years of coming to—

Donna: Oh yeah.

Christy: Or understanding like, *Okay, this is reality.*

Donna: Yes, it's reality. And also, it's so beautiful so many times and it is delicious to be that intimate with another person.

Christy: I feel like I know what you're talking about in the sense of—and if you could see my face, I'm grinning ear to ear from the way you're describing it—my experience, obviously,

quite different than yours, but where I'm relating to it is spending time with people living with neurodegenerative disorders who are at the end of their life, or coming near the end of their life, where they're not going to be ambulatory. They're not going to be making conversation.

And so it's more—they are maybe in a chair or in bed, and being present with them.

Donna: Yes.

Christy: And I've had the privilege of sitting with 23 people as they passed.

Donna: Oh, wow.

Christy: What would I consider the highest privilege, because of what you're saying and how you're describing it. So please talk more about that, because I would love for people to really understand what it is you're saying and what you mean.

Donna: Yeah. You know, it's a state, and I don't think you can achieve this if you don't have any experience of solitude with another person who is as you describe. And my mother, at the end of her life, was—she was always verbal until she died, but sometimes because of dementia, we would sit in silence. Very in companionable silence, for a long time, maybe looking at the same view and that kind of, I guess I would call it sometimes, you know, like, think about it as the sacred ordinary. Or—

Christy: I love that description!

Donna: Yeah, I do too. And sometimes when you're with someone who is, you know, very diminished but living life very richly, the ordinary does become extraordinary. It becomes touching, like giving a massage, giving a foot massage to my mom, or just holding her hand, and kind of looking at her wedding ring, which was the same hand that I remember holding when I was a little girl. I had this vision of her ring through her lace gloves, holding her hand, walking to church, and I felt so safe. And that hand and that ring on her finger, the same hand, the same ring, it really made me feel close to my mom and really kind of feel that circle of life with her.

Christy: Right. Do you feel like being your son's mom helped prepare you to be your mom's daughter at the, at the last stretch of her life where you were able to be in that, you know. sacred space in that companionable silence in just being together.

Donna: Yes, I do. I do think that our son, Nicholas, really taught me a lot about how to be together without a to-do list that determined our value. Like, he doesn't—he is never going to be employable. He is a very beautiful person with lots of capacity, but he is non-speaking. He has low vision. You know, he's tube fed.

He spends most of his time lying down because of chronic pain, but he's quite comfortable in his bed. But, you know, being with him is so fun and so interesting. And, I did learn a lot about deep listening from him. And communicating in different ways, communicating by touch. Communicating by very close observation of what his body is doing, where his eyes are, even though he has low vision.

I'm always looking at him for signs of what he might be thinking. And I did that with my mom too, 'cause he taught me how to do that.

Christy: So, when you were stepping into your role of becoming Nicholas's mom, of figuring that out and how that needed to work for you and Nicholas, this is where you started to understand the solitude. And I'm wondering, do you know, was there a point when you realized, *This is okay?* Or, was it more of a, in retrospect, you understood, *This isn't just okay; this is something that's really special?*

Donna: I think I began to understand that it wasn't going to fundamentally change. I mean, nothing about the reality and the implications of the reality, for me personally or for Nicholas, was going to change. I think for years, maybe 12 or 14 years, I kept thinking there would be some breakthrough.

There would be—if I worked hard enough, if I loved him enough, if I used my advocacy skills enough, we would have some fundamental change in his possibilities, his life possibilities. That I could somehow make that happen. And I began to accept that that wasn't going to happen. And so, I—you know the, the title of the book that I wrote about Nicholas and about the meaning of caring for someone with his level of needs over years, the title of the book is *The Four Walls of My Freedom*. I sort of borrowed a quote from the Christian, the Catholic philosopher, Thomas Merton, who wrote in a book that he wrote—it was a very popular book in the 1960s called [*The Seven Storey Mountain*](#).

And he wrote about becoming a monk in a cloistered kind of order of non-speaking priests, or monks. And he entered his cell, which was his room, and the door closed, he said, and he discovered the four walls of his freedom. And I thought about that, you know, with respect to being alone, being isolated, really, from the world; that's what it felt like.

And then sort of waking up one day and saying, *Okay, this is, these givens are my givens. And what can I do to be free, to exercise choice and to make this beautiful? Because I'm not leaving, you know?*

Christy: Yeah. So, I think in the way you described that, like you saying, for 12 to 14 years, you were just feeling like if you would just do more, if you would be more, then the outcome would change for your son. And I think so many dementia care partners can relate to that. And unfortunately for a lot of them, that 12 to 14 years is the entire disease process.

And it's only after they lose their person that they realize everything they missed. And that always just—I feel eviscerated when people share that with me because, you know, I always want to make sure that I'm doing everything I can to help people understand how they can connect and how they can be in the now.

I think as the COVID-19 quarantine is going on, people are starting to appreciate what I've been saying about there is something about having the ability to walk into a room where your person physically exists. You won't always have that. And to be able to do that is huge. And I never want people to miss any of that.

So, I'm wondering, in that span where you were going through that, Donna, was there a particular thing that was kind of like a slingshot out of that thinking, or was it a gradual process? How did you get to a place where you realized, *These are my four walls of freedom?*

Donna: Well, I think time is one element. I think that a lot of it as well is that being alone with someone whose needs are very high, and it was like this with my mom at the, towards the end of her life too, it was a little bit different because she was not happy with where she was. And Nicholas is very happy with who he is and where he is. He always has been. There's never been a rage in him that wants life to be different.

And there was that in my mom. But I would say that, you know, that slingshot moment? I think I realized that I would attach my identity to him instead of the hopes, in a way. Because when he was younger, you know, I was the a star student of therapy. I was going to be the best, honestly, you know, the speech therapy, the physio therapy, the occupational therapy. Every, everything that he was supposed to do, in his exercises and everything we did like times 1 million.

And you know, one day I realized—and he was only about three years old—and I realized that I had not been looking at his face. I had only been looking at his arms and legs to see if they were doing the right thing. And I thought that was a slingshot moment. That was, *Oh my gosh, he is not my project! He's my baby and I am just gonna forget about this stuff and I'm going to spend the next however long just looking at his face and I'm going to sit down and I'm going to hold him, and that is all.*

And I needed to do that several times, like big moments like that where I would say, *Give this up. This is not what you're supposed to be doing. You're supposed to be loving him, you know? That's what you're supposed to be doing.*

And, so then I would say, *Stop listening to other people. Let's just listen to each other.* And that's where isolation, and solitude comes in handy.

Christy: It cuts out a lot of the extraneous noise.

Donna: And the comparison, like, *How good of a caregiver are you?* And you know, so much of the language of caring is about the battleground. You know, “you got this;” “the enemy;” “you can beat it.” And I'm supposed to be like a warrior all the time. *No! No! No!*

Christy: Right.

Donna: Let's go to the garden and feel the sun on our faces and look at the same view holding hands. And that is perfectly perfect.

Christy: Yes, it is. And I'm so glad you mentioned that too, because there is so much *fight* and *war* and *warrior* and, you know, *we need to be victorious* and *we're in this battle*. And I know for some people that language really works.

Donna: Yeah.

Christy: And for me, I guess part of what I always hear—I mean, yes, a victorious warrior is fantastic.

Donna: Right.

Christy: We'll definitely throw a parade for that all day long.

Donna: Yes.

Christy: But that imagery to me—and I don't mean to take away anything from professional soldiers—but when we're talking about war, I always feel like there's an underpinning of rage.

Donna: Yeah. And sometimes I think, you know, it's rage against the disease, nature, aging—

Christy: Yeah. Oh, yeah.

Donna: The things that we cannot control.

Christy: That's it. That's the problem, right there.

Donna: Yes.

Christy: It's something that we can't control and that's what I'm picking up on, is that undertone of rage. It is just such an ugly, vicious circle to get into because I think so often it leads to carers feeling like, *I'm not good enough. I'm not doing enough. Because if I was, if I loved him more, if I did more, if I was a better advocate, we would be seeing different results.*

Donna: Yes.

Christy: And that leads to such frustration and wanting to smack a head against a wall. That's where I just want to put my arms around care partners and say, "You know, this isn't about you, in the sense of, it's not that you're lacking."

Donna: Yeah, that's right. I mean, I absolutely want to throw my arms around people, for the same reasons. You know, when they say things like that, I just feel like, you know, you and your person can be together and give each other the confidence and the solace of reconciling the hard truth about where you're at, you know?

but a lot of it is about being together without an agenda other than to get through the day with what you need to do as a human being. In other words, eat, sleep, breathe. Wake up the next day. Nothing more ambitious than that. And you know, being able to find meaning and beauty and intimacy with just that.

Atul Gawande really talked about this in his wonderful book *Being Mortal*, and just making peace with ourselves and the inevitability of our own and other people's death, people that we love. And the fact that we are all mortal, we need to make peace with that.

Christy: Absolutely. I think that people are getting more of an opportunity now to see the value in having maybe a significantly pared down agenda of like what you were saying:

Today, I'm going to get up and take a deep breath because I can, thank you very much. And, Wow! Look, the sun is shining today. Magnificent!

And just things are much more basic. And I agree: it is a process. I remember a time, not that many years ago when my business was, I was seeing clients face-to-face in the five counties nearest my geographic location. So, I was spending an average of 12 to 14 hours outside my home every single day.

Donna: Wow.

Christy: Going client to client. I loved the work. I love spending time with people living with dementia. And I think it's because of all of the things that you have said, right? It's, you get so much out of being able to step into that moment. And it's a very, very Zen experience, at least for me, of spending time with people who are very in the right now. That is the only thing that matters.

That said, that's kind of a grind that is unsustainable. I've been very lucky that over the past several years I've been able to transition from that into where now, up until about six weeks ago, I had five clients that I was seeing face to face and the rest was doing online classes or my private clients were doing video chats via Zoom.

So, I was able to sit in my happy little office and have those conversations without needing to zip all over creation. If I had had to make that shift overnight from all the time being out of the house 14 hours a day, to *boom!* sitting in one place for hours, that would be really tough, to do that overnight. And I think, again, this is where it's so important for care partners to hear that no matter where you are in the process of being there beside your person, no matter where your person is in the disease process, it's all a process.

Donna: Yeah, it is. And there's an inevitability about the outcome.

Christy: There is! And as humans, so many of us really don't like to think about that.

Donna: Yeah. Yeah, it's true. I'm just thinking right now, as you're speaking, about a conversation that I had yesterday. I have a very dear friend who is younger than me, who has early onset Alzheimer's.

I got an email from her husband saying, *Can you call? Because I don't know what's the matter with my wife. She's not usually depressed, but she's very, very sad today.*

And I picked up the phone immediately and I called my friend and I said, "Hi, how are you?"

And she said, "I'm not well, I'm not doing well." And she burst into tears. And that's very unlike her.

And I said, "Oh, sweetie, what's the matter?"

And she said, "I don't know, I'm just depressed."

And I said, “If it weren't for this stupid Covid-19, you know, I would be at your house with my arms around you.” And I said to her, “Because guess what? I would want my birthday hug. It's my birthday.”

And I said that because it was my birthday yesterday, but I said it because I know my girlfriend and I know that she would say what she said, which was, “It is? Happy birthday, girlfriend!” And she became in a caring mode for me. And I often think about this idea of reconciliation, solitude, isolation, and the big challenge of finding meaning and purpose in it, like, for ourselves as caregivers, but also for the people we love.

And I know that she is just a naturally giving person. And when she began to say to me, “Oh, I want to say something, I want to do something for you now.” And it was like a switch for her, because she was able to have some kind of a role of contribution in our conversation, even though we were apart.

I would say that effort or that learning curve—for me, to help identify what meaning and purpose might be for everybody in this secluded setting, that it is the big challenge that I think, if you can achieve it once in a while, it can really help you stop wishing you're somewhere else all the time.

Christy: Right? Yeah, that's true. In memory care, we say that people need a purpose. They need a reason to get out of bed in the morning. They have to have a sense of purpose throughout the day, because who wants to feel unwanted, unneeded, unnecessary? That's an unnatural state for humans.

And you know, in 12 step programs, that's a key component, is being of service. Because when we take a step outside of ourselves and shift that focus away from looking at ourselves in the mirror and looking at others around us [to], *How can I be of service? How can I be helpful? How can I contribute to someone else?* It causes a massive shift in thinking and in feeling and, hopefully, in action, also.

I'm starting to see more and more of this on social media, which makes me so happy, where people are really noticing the helpers and [asking], *What can we do to support the helpers?* And we don't have to be in the midst of a pandemic to think that way, or to act differently.

When we just start taking a look around and [thinking about], *How can I make sure that my person has the opportunity to feel useful, needed, necessary?*

Donna: I think it's the biggest challenge in caregiving.

Christy: Yeah, I can see that. Because I think a lot of times as carers, we maybe don't understand the subtlety, or really recognize and receive the subtlety, of what our person is giving us.

Donna: It's always reciprocal. It's always reciprocal. And my mom never felt better than when she said, “Come here.”

“Come here, little one,” she said to me. You know, with my white hair, she'd say, “Come here, little one. Sit down. You sit down.”

Christy: I love that. Moms never stop being moms.

Donna: No, they don't. And you know, she would always want to take out her checkbook. And, I learned after a while—because I think at first we think that we need to relieve, I at first I used to think like I need to relieve her of those responsibilities.

Then I figured out, no, let her write the check. Let her give me the check. Let me thank her for it. [Then] go home and rip it up.

Christy: Right. Exactly, exactly. So many care partners are giving people and always forget that giving is not a solitary act.

Donna: No, it isn't.

Christy: If you're going to be a giver, you have to have someone who is willing to receive what you are giving. I think it is such a lesson in life, particularly for people who really identify as givers, to really embrace the other part of the equation, in the receiving and being able to do it graciously, and understanding how important it is, just like you're saying.

I love that you shared that story. That's exactly right. Take the checks. Say thank you. Rip it up later.

Donna: Yeah, I know. My mother,= was someone who also found it difficult to receive. So, the other half of that equation, too, was kind of brokering the relationship so that I would give her help without it appearing that she needed help, if you see what I mean.

Christy: Yep.

Donna: Yeah. So that's a learned thing, too. And you could see her react to sometimes when helpers would come in and treat her like a child or something. She just couldn't stand that! But in assisted living, the wonderful helpers figured out that my mom liked to dry the dishes.

I mean, she's paying whatever it was, thousands of dollars a month; she did not have to fold laundry or do the dishes, but she was one who wanted to do those things.

Christy: A sense of purpose, a contribution; being necessary and needed. Absolutely.

Donna: Yeah.

Christy: We can all use that. Donna, thank you so much for your time. Talking to you is like a balm for my soul and I know that just getting to talk to you is a gift to the listeners of *The Alzheimer's Podcast*, too.

So, thank you for sharing your thoughts on solitude today. And can you say the name of the book again? I'm sorry, I can't remember it off the top of my head.

Donna: Yes. The first book that I was referring to is called [The Four Walls of My Freedom: Lessons I've Learned from a Life of Caregiving](#). And my more recent book that we talked a little bit about, in another podcast that you and I recently recorded, is called [The Unexpected](#)

[*Journey of Caring: The Transformation from Loved One to Caregiver*](#), and that is co-written with Dr. Zachary White.

Christy: And obviously, we're going to link everything up to the show notes. I think that I can safely say, without this episode even having aired yet, that I feel like the listeners are going to fall in love with you as much as I have. So, thank you so much and we look forward to having you back again the next time you'll let us.

Donna: Thank you so much, Christy. I'm very touched. Thank you.

Christy: And that's our show. Thank you so very much for listening. Head on over to the show notes at DementiaSherpa.com. You've been listening to *The Alzheimer's Podcast* with Christy Turner, wishing a blessed and easy week ahead.