

The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa
[Episode 105: Sanctuary in the Midst of Alzheimer's](#)

Elizabeth: All of our emotions, they don't need to necessarily be labeled good or bad or bad. They just are. And so to identify them, identify, you know, kind of for ourselves, I just think is a great starting point.

But you're right, we a lot of times in the church, there is this judgment. And yet if we could just embrace these, I think, God-given emotions and acknowledge them, then maybe we can figure out what to do with them.

Christy: *You're listening to The Alzheimer's Podcast with Christy Turner of Dementia Sherpa, where we're all about bringing the Good Stuff --that's respect, kindness, love, empathy, and compassion--for people living with dementia, their families, and the professionals who support them.*

I'm Christy Turner, AKA The Dementia Sherpa. I've enjoyed the privilege of working with over 1,500 people living with dementia and their families so far, including multiple experiences in my own family. In the course of my career, I've transformed from total train wreck on my first day as a professional to local go-to expert, speaker, trainer, and consultant. And if I can go from scared spitless to confident care partner, I promise you can, too.

Christy: *Today, our guest is Dr Elizabeth Shulman. She's author of the book [Sanctuary in the Midst of Alzheimer's](#). Elizabeth has a Doctorate of Ministry and Counseling and she has, I think, a very compelling personal experience that led her to doing this kind of work. So, we really look forward to hearing that story. And for right now, welcome, Dr Shulman.*

Elizabeth: Well, yay! Thank you for having me, Christy. And please, call me Elizabeth. I'm happy to join you.

Christy: *Great. So, tell us about Sanctuary in the Midst of Alzheimer's. What is that book?*

Elizabeth: It's essentially a Bible study for spousal caregivers of dementia patients and also includes a curriculum for pastors and church leaders or just congregation members who want to know more about the experience of caregiving for a spouse. Kind of giving them the opportunity to walk in their shoes, and then be able to provide better support to those caregivers.

Christy: *Okay. And so how does that work within a church and is it--let me be clear right here, out of the gate, is it for churches only? This is inappropriate for synagogues or other places of worship?*

Elizabeth: Well, I mean I think anyone can use it. With regards to--I mean, my husband is Jewish and he likes the book just fine. But because it's essentially not an evangelical tool, per se. It's really just reading scripture that gives inspiration and is thought-provoking. But it's also heavily grounded in personal stories and narratives for caregivers.

I developed it out of my research interviewing the impact of dementia on marriage, the experience of marriage for spouses. And so it's not only used in churches, it can be used--there are two studies within the book.

And assisted living facilities may use it as a way to bring community members into their doors to see their facilities and to have some education on spousal caregiving. It can be used, you know, the lessons are self contained.

Sometimes people like Alzheimer's support groups just use the first part of the book, which is just for spouses. And then other times, a church group may say, *Hey, let's see what it's like to, you know, what can we do to better support these spouses?* And then they'll use the second half of the book, which is for, you know, general community members who just want to learn how to provide support.

Christy: *Support to the spouse, or support to the person living with Alzheimer's?*

Elizabeth: Support primarily to the spouse. But that can look like, you know, coming over and sitting with their loved one for an hour, you know, so it's kind of providing support to both. Giving the caregiver a break and interacting with the person with dementia.

Christy: *Okay. And then circling back to where you were probably about three minutes ago, you mentioned the word scripture and so I just wanted to be clear, you're talking about the New Testament, correct?*

Elizabeth: New and Old.

Christy: *New and Old. Okay. But you are talking about the Bible; not any other religious text.*

Elizabeth: Right.

Christy: *Okay. All right. So what--this is the part where we get to this story, and I always love stories, love people's stories and getting the privilege of hearing them. So would you share with us how you came to a place where you were doing this work?*

Elizabeth: Yes. Well, I had kind of two life experiences that converged. I was serving as a chaplain and at the same time was, had been married for 12 years to this very kind, brilliant organic chemistry professor at a major university. And he started acting a little quirky. And now granted, he was a chemist, so he had a kind of a geeky quality to him to begin with.

And he started behaving in ways that were odd. He would fixate on knots in the dog leash, or carrying items in his pocket that he couldn't be without. He started being very judgmental toward just groups of people that he had never expressed that before. You know, like old people: *Oh, they don't know what they're [doing]*, you know, just odd statements.

And I continued to acclimate and acclimate and acclimate. And it--I realize I was, as I was serving at a 600-bed nursing home and I found myself drawn to the spouses who are coming in to visit their husband or wife in the nursing home and

hearing their stories. And I just started relating to them and I thought, *You know, something is just not right.*

And finally my husband's behavior just became--I found him once sitting in a car with the windows rolled up, wearing his winter coat in 90 degree weather, just sitting there sweating. And finally he told me that the voices were telling him to do this. So, with the help of his family, we were able to get him hospitalized and he was diagnosed with paranoid schizophrenia. So...

Christy: So that is unusual just for his age, correct?

Elizabeth: Yes. 'Cause he was in his young, he was in his early 30s and so it was, it was characterized as late onset schizophrenia. So, once he was diagnosed and I went to go find support, I would go to [NAMI meetings](#), which are wonderful except that--

Christy: Can you clarify what [NAMI](#) is for people who may not know?

Elizabeth: Oh, oh my gosh. I only know it as NAMI. National Alliance for Mental something.

Christy: Illness?

Elizabeth: I'd have to look it up. I've just always--it's so ingrained as NAMI in my head. I'm sorry.

Christy: So it's a support group for people who have a mental illness or people who are supporting a person who has a mental illness?

Elizabeth: Right. Right. And the thing was, most of those people were parents of those people. So I really wasn't able to relate to that. National Alliance on Mental Illness. There, I had to look it up.

And so I felt very lost in that. And it took two years of trying different medications. And all during this time, I was continuing to work with caregivers of dementia patients through my job at the nursing home.

So that's when I decided to, to go back and do my doctorate and interview spouses. And then from that, design a ministry. This was in the south, so it was the Bible Belt and a lot of people went to church, especially that cohort of older adults. And so I just wanted to write something that would help them.

And in the meanwhile, my husband would go on his medication. He would then decide he was doing fine and go off of his medication. And we had four daughters, have four daughters. And it just, the cycle was back and forth and back and forth. And it got to the point where my kids were starting to be afraid.

Q He would carry a baseball bat around with him, not, I don't think, intending to hurt anyone, but because he felt unsafe. And of course that was very jarring for the children. And after another eight years--we were married just about 20 years--I did leave and moved closer to be with my parents, whose--my father had, also, health issues. So, I was also moving to be closer to them.

But so, and then we, we eventually did divorce. And he now is not at all medicated. And um, it's just very, very sad for him. So he refuses help. We've, his family and I, tried several times to seek hospitalization, but unless he, you know, was a threat to himself or others, we can't do that against his will.

And, as one time a police officer actually said to me--he was on the streets, not safe, I didn't think. But, you know, the police officer said, "You know, people have a right to be crazy as long as they're not hurting themselves or others."

And I thought, *Well, okay, but if he were medicated and you know, being treated effectively, I know he wouldn't want to be this way.* But unfortunately, the laws are sometimes not helpful with seeking help for people with mental illness.

Christy: *Right. So, you're taking this experience of being the spouse of someone with a brain illness and then marrying that with the work that you were doing with people living with dementia in a nursing home and you're ministering to them as their chaplain and decided you were going to do your dissertation on interviewing spouses of people living with dementia and what that experience was like for*

them? Or were you studying a particular piece of this? What, what did that look like?

Elizabeth: I was actually very interested in the impact that dementia had on their experience of marriage. That was, selfishly--it was something that I really struggled with, with my husband, because I didn't want to--I didn't believe in divorce. It was something--and I had a lot of guilt over that.

And ironically, now that I am not married to him, I have so much more compassion toward him because I'm not in this situation where, through no fault of his own, he is not able to love me as a husband typically does. And I think I was interested in knowing how other people kind of navigated that whole territory.

And I found in my interviews something that was very reflected in the research, is that there are so many types of marriages and types of caregiving. And you know, from those who I--I interviewed one gentleman who was just so in love with his wife that it was not in any way a burden to him to care for her. And it was so inspiring.

And then you had, you know, people who were committed to the idea of marriage and fulfilling the vows. And so that above, almost, their care for the person. It was the care to the obligation, to the commitment. And so I found people, you know, *Till death do us part, I am going to see this through. It doesn't matter if I'm happy or not. This is what will make me happy, is following through on my commitment to care*, to people who didn't have a good marriage to begin with.

They married for the wrong reasons, back in the 1950s. And they were resentful then, and now their spouse has dementia and they're even more resentful.

And then there are those who develop other relationships, such as you know, oh what's his name, Dan. [Dan Gasby. He was recently on the Today show talking about his care for his wife](#) [model and author [B. Smith](#)], who--she doesn't even know who he is anymore. And he has a relationship with another woman, and she also helps provide care for his wife. Very nontraditional, but not that uncommon.

Christy: *Yeah. That was recently a storyline on Chicago Med, I think last week, or the week before. A similar thing. And then I actually had somebody write to me that was extremely upset because they had participated in a support group where somebody shared that that was their situation. And the person that wrote to me*

just thought it was a moral apocalypse, essentially. Anyway, go ahead and continue.

Elizabeth: Yeah, no, that is--and I'm, you know, it's not for me to say what's right or wrong, but I think people--I'm finding that so many caregivers are trying to not only live up to their own expectations, but other people's expectations and it's making them miserable.

Christy: *Right. It's interesting because you're talking about all of the different ways people came into marriage. Because they were madly in love with someone and that's lasted, or because they have a commitment to the institution, or because it was just a bad idea, but for whatever reason they have remained committed to the bad idea.*

Elizabeth: Right, right. Yeah. See, caregiving just doesn't happen in a vacuum. It brings so much history and sometimes baggage, and personal philosophies and, and all of this. And so with my book, I try to explore all of these things, hoping that the outcome is that people, caregivers, learn to just, hopefully, be very honest with themselves about what they truly feel about their caregiving experience.

Because I think once we're really honest with, you know--once we can identify our true beliefs and not judge ourselves for them being right or wrong, they're just where we are, then I think solutions and opportunities can present themselves. But I think sometimes we block those opportunities by being stuck in a certain, you know, *I should do this, I should do that*. As my chaplain supervisor would say, "You know, people should all over themselves and then they can't--they're not open to what could be available to them if they have an open mind." And then, you know, also for those who participate in it, who are not a caregiver but want to learn more, hopefully they will be less, less judgemental and open-minded, also.

Christy: *Okay. So that--this sounds really intriguing to me, because you're talking about a book that contains scripture, that is targeted or marketed to churches. And then you're also talking about being nonjudgmental.*

Elizabeth Right.

Christy: And I think for many of us, those two things do not go together.

Elizabeth: Unfortunately, I think you're right. Depending on the church, of course. But you know, I think one of the things--I may attend synagogues these days, but you know, Jesus is my homeboy and I think when he said, "You shall know the truth and the truth shall set you free [John 8:32]," to me, that's just a foundation. Stay with what is true.

And when it comes to feelings of love, for example, it's hard to force that. It can develop. But when you fall in love with someone, it's just this power of its own, you know. The feelings of love and all of our emotions, they don't need to necessarily be labeled good or bad or bad. They just are. And so to identify them, identify, you know, kind of for ourselves, I just think is a great starting point.

But you're right, we a lot of times in the church, there is this judgment. And yet if we could just embrace these, I think, God-given emotions and acknowledge them, then maybe we can figure out what to do with them. But when we don't acknowledge them, or we pretend they're not there, or we wish them away, even though they're there, you know, I think resentment is a big emotion that I often hear caregivers talk about: "I resent that we were going to travel in our retirement and now we can't." And that's not necessarily a bad emotion. It doesn't feel good. But when we acknowledge that we have it, then we can maybe figure out what to do with it.

Christy: And so does this book take it to that next step of, okay, now you are aware of what you're feeling. What's the next step?

Elizabeth: Yes. Yeah. In fact, one of the lessons, I have a list of emotions and I encourage the participant to review the list and identify what are they feeling? And it can be a positive and a negative emotion, quote unquote positive, negative. At the same time, you know, we can, we can be really angry about something and yet still so in love with. You know, it's just the whole kit and caboodle.

So, my goal in the book was to really kind of help draw people out, create a safe space where they can share with other spouses what they're experiencing. But I use personal narratives from other people anonymously so that--and I specifically

chose stories that I have seen so many times that I knew it would resonate with participants.

And the focus, the goal, is to draw people kind of into a safe space. Oh, and I use narratives that I have seen just countless times. So I know that it's something that is, is, you know, reactions or personal stories that are common to caregivers that way. For someone who may not feel comfortable sharing, they still get to hear a story and hopefully it resonates with them and over time, it may be they'll feel more comfortable talking about things. Or at least find some reassurance knowing that they're not the only person going through some of these struggles.

Christy: *Right. So does this offer any sense of resolution at all? In terms of, Okay, now you've identified your feelings, which direction are you going to go? Is it a commitment to the institution? Is it a commitment to the person? Or is it a divorce?*

Elizabeth: You know, it can be.

Christy: *Or are there other options?*

Elizabeth: There are other options. The final lesson in the--well, I will say that the resolution is that, at least in a church setting, so there are these two four-week studies and in the fifth week both groups come together, the spouses and then the general congregation members or whomever who was, you know, just wanting to learn more about it, come together and offer ways to develop a ministry that will be most helpful for the spouses.

I don't find that many spouses, you know, say, "Oh, I just want a divorce." But a lot of spouses really struggle with admitting their loved one to a nursing home. That's a big struggle. There's a lot of guilt related to that. And so knowing that that is a struggle, the general church congregation can offer support, you know, and they can--it's designed in such a way that the ideas that come out for the ministry are unique to that congregation and the gifts that they can provide. So, the resolution is developing a plan of ministry to better support the spouses. That's kind of the goal of the whole program.

Christy: *And have you participated in one of these programs? Like, did you pilot this before you wrote the book? Or did you test out a congregation after you had your manuscript together?*

Elizabeth: Yeah, when I was down in Tennessee, as I was working on my dissertation, I would test the lessons. And from the feedback I got from those, I would kind of tweak some of the questions, or add a scripture here or there, just based on the feedback that I got from, from the lessons that I did. And then those lessons are what compiled the whole program.

Christy: *Okay. So definitely it has been tested by people who have lived this.*

Elizabeth: Yeah.

Christy: *Okay. Through the research you did and in the process of putting this book together, in road testing the lessons in it, did you land it at some essential ingredients for what is most helpful for spouses of people with brain illnesses?*

Elizabeth: Oh, yes. So probably the most significant, the two most significant struggles that caregivers have is, one is isolation. So they don't--they're embarrassed to take their husband or wife to church or to the store or because of their behavior, and they're embarrassed. You know, there's still such a stigma. So, helping caregivers not feel so isolated was a main goal in developing this program.

And so, which is why the whole congregation or you know, general participant curriculum is there, to help them feel more comfortable around a person who has dementia. Because they really, people really--I do a program a lot for assisted living facilities where they're often, a lot of couples live and the couples participate. They play cards each week and, and then, say, the husband starts not remembering how to play the game, or he starts saying outlandish things, or he wears his shirt the wrong way, or you know, or he refuses to take a shower.

People who have been friends with this couple may fall away because they don't know what to say. They don't know how to interact with this person. And so it's just easier to not interact at all. I find that often. And that's so true with, with other

illnesses, cancer and things, you know, people don't know what to say. They want to be helpful, but they don't know how. And so they kind of just fall away.

So I do a program on helping friends become more comfortable if one of their friends is diagnosed with dementia. How to, how to engage with them. Things to say; things to maybe avoid saying. Because when they feel comfortable interacting with someone with dementia, then the spouse feels such relief because they get it. You know, they're still accepted, they're still looking to include them in activities and spouses can be so appreciative of that. And that helps mitigate the whole sense of isolation that spouses often feel.

Christy: Absolutely. That's really important. So, any final thoughts today, Elizabeth? Anything that we didn't cover that really needs to be said?

Elizabeth: No, I think, you know, earlier, we touched on, you know, just being open for a variety of responses to caregiving and you know, the, the adage caregiving can kill the caregiver. I've actually seen that twice where someone was a spouse, was caring for the loved one, and ignored their own health concerns and ended up dying before their loved one with dementia.

Christy: Yeah. Statistically, that happens 40% of the time.

Elizabeth: Wow. Wow.

Christy: It's gone the wrong direction. It used to be 30%.

Elizabeth: And I think, I guess to use another example of Jesus, before he would approach the masses, he would go off, and go off by himself to pray. And to me, that was a lesson in selfishness. It's got a negative connotation, but I think that when we can be selfish and really care for ourselves, we're just automatically able to provide better support to other,s because we've kind of nourished ourselves first and then we have the strength and the stamina to share that love and to provide that care. But when we ignore ourselves at the expense of, you know, in hopes of, you

know, struggle, I think society values the sense of struggle and hardship and making it through--

Christy: The compelling story that comes through that, right?

Elizabeth: Right.

Christy: Yeah. Right. And I would say that there is zero that is selfish about self care.

Elizabeth: Right.

Christy: So, for those believers out there that hold up Jesus as their example, if Jesus did it, I think by definition it's not selfish. Correct?

Elizabeth: Right, yeah.

Christy: So, if Jesus made a point of taking care of himself prior to going out and being of service, if it's good enough for Jesus, it's good enough for you. So, if people who are interested in [this], like, "Okay, this sounds good, this sounds like something that I would like to use in my community or in my faith organization." How do they get that started?

Elizabeth: Well, more information is available--the book has a website, it's SanctuaryInTheMidst.com.

Christy: Okay. We'll get that in the show notes.

Elizabeth: Yeah. And I also have ElizabethShulman.com. I have some articles there that I've written. And then the book's available on Amazon.

Christy: *Okay, great. So if somebody wanted to start this in their organization, they would just get the book and take it from there?*

Elizabeth: They could. And I'm always, you know, love talking to people who are, who are using this. The book is designed so that anyone can lead it. All the directions are embedded within, within. All it needs is someone who's willing to read the questions out loud.

Christy: Oh, okay. Okay. Great. It sounds like you're open to answering questions. People can reach out to you?

Elizabeth: Oh, gosh, yes.

Christy: *Okay. And so I would imagine that would be at ElizabethShulman.com, they can find your contact info?*

Elizabeth: Yes. Yeah.

Christy: *And we'll get that in the show notes also. And so if you're driving or at the gym right now, no worries. We got you covered in the show notes. Okay, well thank you very much. Again, this has been Dr Elizabeth Shulman who has a book, Sanctuary in the Midst of Alzheimer's, and that is a multi-week program designed for helping both spouses of people living with dementia as well as other people in their community, to give them more education and concrete ways that they can help support those spouses so the spouses can continue doing the important work of care partnering. Thank you, Elizabeth.*

Elizabeth: Thank you very much. I enjoyed this.

Christy: *And that's our show. Thank you so very much for being with us today. Links to resources or programs mentioned in this episode are in the show notes at DementiaSherpa.com/Episode105.*

You've been listening to The Alzheimer's Podcast with Christy Turner, wishing you a blessed and easy week ahead. Be sure to check out the show notes and subscribe by going to DementiaSherpa.com/podcast.