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Bonnie Lais: One thing I learned, oh, maybe a couple of years ago, at some point along the way I decided that enough is enough. I'm not going to beat myself up anymore. I am not professionally trained as a care partner. I don't know what I'm doing. And so I say things to myself that I would never say to another person. Like, "Oh boy, that was sure stupid! What did you ever think would come of that? That takes the cake. That's amazing. That was really, really dumb." I'd never say that to another person, and yet for years I was saying it to myself. And so I made the decision to be kind to myself and being kind to myself actually made it very, very easy for me then to be kind to other people, especially my husband.

Christy Turner: Right. We always say you want to fill yourself up with the Good Stuff--with respect, kindness, love, empathy, and compassion. Turn that loose on yourself; that allows you to share it with your person. And for some people, they do struggle with, "That's kind of a waste of time. Why would I need to turn it loose on myself? You know, I understand the principle." Because if you're blowing it off like that, if that's your mindset, like, "Well, why would I need to do that for myself?" That means you have a nasty little voice in your head that is telling you you're not worthy. And that nasty little voice is a liar. If you wouldn't talk to your best friend that way, you don't deserve it either.

Bonnie Lais: Absolutely. I'm so glad that I came up with that, made that decision.

Christy Turner: Yeah. Well you see what a massive difference it made. Luckily, it doesn't sound like you were in a position where you were struggling all the time, although you definitely had those moments.

Bonnie Lais: Well, I was struggling in trying to run the household, and be Don full-time caregiver, sole caregiver. Don was, that was a blessing beyond measure, that Don didn't have any other conditions. And so we were actually able to do this medication-free, up until the very end when he was dying. Yeah, it was, it was a total blessing. It was really great. And I know because he didn't have behavioral issues, we didn't have to medicate him for that. Well, I believe--now, I may be very naive in this--but I think he didn't have the behavioral issues because I treated him with dignity and respect.

Christy Turner: I would say a couple of things to that, Bonnie. So number one, no, I don't think you're being naive at all. We get, and this is a, it's funny how much of dementia, it really comes back to life lessons that are applicable across the board. But we get back what we put out. So when we approach another person, no matter who it is, bringing the Good Stuff, when we're respectful, when we're kind, we're going to get a good reaction back, versus when we are looking at a person, but seeing a task that needs to be accomplished. Or getting irritated that they didn't understand what we said and acting like they should be able to. So I think that that's exactly right.

Christy Turner: The other thing too is that it's really important for everybody listening to know that the medications that are used for behaviors in dementia are not FDA-approved for dementia use. There's a black box warning against using them for people over age 65. There's also a black box warning against using those medications for people living with dementia. So there are definitely better ways to manage that, in a way that allows them to stay bonded and communicate in a way that makes sense to their person and not have to use unnecessary medication. So that was a really good point that you brought up, Bonnie. Our approach is really key.

Bonnie Lais: Yeah, it is. It is very key. It's everything. I learned many years ago, a little acronym, positive. It was p-a-c-e: positive attitude changes everything. Yeah.

Christy Turner: Oh, I like that!

Bonnie Lais: Isn't that good?

Christy Turner: Yeah. And, and try to stay positive and, when you can't, just say, "Honey, I'm so sorry. I don't know what I'm doing. I'm learning as I'm going on. Going as I'm doing this. This is on the job training and no one has taught me how to do this and I'm doing the best I can. Please forgive me. Do you understand? Will you forgive me, please?" And Don always forgave me.

Christy Turner: Because what you just said was so heartfelt. I love that. I wonder how many times it's occurred to care partners to say something like that. I think a lot of times we feel like we should know what we're doing in every instance and you know, when we really think about it, for most people they're going through this experience for the first time ever. And even the really experienced care partners among us, maybe they've gone through it with a couple of parents and now maybe a spouse, so it's still very limited experience. And that is kind of silly, that we would think that we should know exactly what we're doing.

Bonnie Lais: Right. And that's going to, that goes back to being kind to myself. I'm doing the best I can.

Christy Turner: Right.

Bonnie Lais: And then communicating that to Don. I think that our communication was pretty good. When he could no longer use words, I would just try to figure out what he was trying to say. Judge by his face, by his body language, by his tone of voice. Just try to, just try. I think that's the biggest thing.

Christy Turner: Put the effort into it, right?

Bonnie Lais: Yeah. Yeah. And um, my husband was incredibly blessed that he never was in a facility. Never, ever.

Christy Turner: I was going to ask you about that. Did that ever occur to you? Did you ever think that there would be a time?

Bonnie Lais: I hoped that there would not be a time, but I knew that if he ever became violent, or he became too heavy for me to lift and I was not at the point where Medicare would cover, you know, like he would go into hospice or something like that, that we--we're not made of money. We have some savings, but you know, we're two people. You look at me, you know, now Don's gone. But what if the same thing happens with me and I use up all our money? You know, I might live another 20 years, and do I have 20 years of savings? I don't know.

Bonnie Lais: Don was at home. He had at home hospice. He had a hospital bed that I, did not put him in another room. He was in the family room. It was just me and him. Whenever he didn't know where I was, he could look up and I could see him looking around the room and I'd say, "Honey, I'm right here. I'm right here sitting at the kitchen table." And he would then look over, hear my voice, and he'd look over at me and go, "Oh." I said, "You were looking for me, weren't you?" And he'd say, yeah, he was. So I'd just kinda guess what he might be thinking. We're going to make a lot of mistakes, gonna make a lot of mistakes.

Christy Turner: Yeah, and it's okay. It's okay to make mistakes. There are very, very few mistakes in life we can't recover from. The important thing is the trying. The other thing I wanted to ask you about, Bonnie, that's come up as we're talking, is you mentioned hospice several times and I know that a lot of families really struggle with the idea of putting their person on hospice service. Either they think that means they're throwing in the towel and just saying that the person doesn't matter anymore, or they think, "Well, I don't, I don't really think it's time," or, "How would I even know that it's time?" So can you share, do you mind sharing, about how you came to that decision?

Bonnie Lais: Yeah, the first time--So Don went into hospice about three and a half months before he died. The doctor had mentioned that word and I just kind of, you know, looked at it like the h word, like, ooh, this means six months to live. And my doctor said, oh, no, not at all. It doesn't mean that anymore. It means that there's a person has a terminal illness to which they are not responding to the treatment that has been given to them. Say that over again. They're not responding to treatment on the illness that they have. That's still not coming out right. But I think you know, and your listeners know, what I mean. What the goal of hospice is, is to make him comfortable and to approach this as naturally and as comfortably as possible. Through hospice, we had a chaplain that we could talk to if we wanted to, and he came once a week. I had a grief counselor that I could talk to ahead of time. It didn't have to be after, a bereavement counselor after my husband died. I could do it before he died. And that was great. And maybe every hospice group is a little bit different, but this is what I got. Plus, we also had some volunteers in this group, that would come--and this is what they did--they just volunteered to give a person maybe couple hours off, so they could go to the grocery store by themselves or they if maybe they want to go take a walk in the park, whatever. Just to have some, a little respite. And it

made it, and this was all paid for, by Medicare. And it made it possible to have some normalcy in my life, and Don get the help that he needed. Now, I think I probably went past your original question. I'm sorry.

Christy Turner: That's okay. I think you're a good hospice ambassador. I'm so glad that you mentioned some of the misconceptions you had about it and then what your actual experience was and that it was so positive, which is fantastic. So Bonnie, one thing that I want to make sure that we get in during our time together--if you're okay with it--this is not the first time that we have communicated. We actually, you made contact with me in July of last year over a particular issue.

Bonnie Lais: Yes.

Christy Turner: And I was wondering, would you like to share what the issue was and how you came up with a solution?

Bonnie Lais: Oh yeah, absolutely. No problem.

Christy Turner: Because I think this would be super helpful.

Bonnie Lais: I think it might be because I'm sure I'm not the only person who ran into this problem. I'm so glad you brought it up. Um, yeah. Uh, my husband had very, very thick fingernails, that grew very quickly. It was a shame. It was wasted on a man, when a woman needed to have such beautiful nails.

Bonnie Lais: And the problem was, was that they grew so fast and he hated having them cut. Even when he was a healthy man, he was not good at keeping his nails clipped short and when he had dementia, he would get dirty stuff under there. And being long, they would certainly be at risk for tearing and that could pull into the quick and that could really hurt and even bleed. So I, I was beside myself. I didn't know how to do it, 'cause he was afraid when I would clip his nails. He would jerk his hand back. He pulled his hand back because he was afraid that I was going to cut him. Well, he was actually setting up a scenario where I actually could have cut him, because he was pulling. And I didn't know what to do. And finally, with one of the nurse assistants, the certified nurse, CNA, certified nurse assistant, she said, "We are not allowed to clip the fingernails." It's a health thing, something to do with diabetes or something. I don't know. But they're not allowed to actually do the clipping. She says, "However, we can file." And I went, "Yeah but his nails grow so fast. How are we ever going to file it?" What she did is, she watched. She sat there while--and distracted my husband--while I clipped the nails on one hand. I didn't want to push it. And then the next week, I clipped the nails on the other hand, and then they were short. And then each time she came, she filed all 10 of them and kept them short. But it took us a long time to get to that, and he died just a few weeks after we finally hit on the solution. So if that helps anybody who's listening, excellent. I wish I had figured that out ahead of time.

Christy Turner: So it took some trial and error, but that actually worked. And I think that it speaks to how creativity can really be helpful when you're looking at maybe various care issues, which can then be complicated, as in Don's case, with his past history of how he did things and the situation changing so that that needed to be modified. So, um, I loved that you were always open to let's try this, let's try that. And that you had such a great, good humor about it. Like, "Well, I don't know the answer yet, but I know I'm going to, so I just need to keep asking good questions and I'll figure it out!" That was how you came through. Even the first time that we met, um, online was, "I don't know the solution yet, but I'm sure I'll figure it out!" And I think that is an amazing quality in a care partner. So I'm sure that has helped make you successful over these past 10 years.

Bonnie Lais: Yeah, yeah. I, I, oh, maybe. I'm sure you're right. One thing I wanted to mention, because I'm, I'm thinking about these things. I, I got to be quite creative in my solutions to things. And one of the problems I had was with Don wandering. And I went and got him an ID bracelet. It was the very first thing I did. I bought it ID bracelet online, but I needed to prevent it from happening in the first place. Well, I asked my people in my support, caregiver support group, you know, and they said, well, you know, you can, you can get some kind of a security system on your, on your home and it's going to cost hundreds of dollars and you can do that and it will always tell you when the doors open or you can, you can buy this thing here, or that thing there. And I went, "Phooey to this, I don't have any money." So I got a very, very long shoelace and I just tied the front door, most elaborate, jumble of, I've got some jingle bells from Christmas and I put that in front of the door knob and I, and I tied up the shoe string in such a way that he could not open the front door. That's all we needed to do. It was to make it so he couldn't open the front door. I could, I could take that off, but he couldn't. So the, the solutions to many problems are just very, very simple. We just need to be creative.

Christy Turner: I feel like you're a dementia MacGyver. Necessity is the mother of invention, right?

Bonnie Lais: That's exactly right. So true. And I feel really good about myself when I look at it. I used to feel like I was like nothing. You know, I was like a little worm, nothing. And to think now, wow, I've done this and look how creative I'm being, and wow, haven't I shown the other people who thought I was nothing that I really am something. And I, I feel good about that. I feel good about that.

Christy Turner: As well you should.

Bonnie Lais: Yeah.

Christy Turner: Well, thank you so much, Bonnie, for sharing your story and your experience with Don and what has worked for you. And I just want to reiterate again that if you were just kind of doing a casual listen and you were doing something else, this is an episode that I think you'll want to come back to and listen again, especially if you're feeling low. Because Bonnie has just one positive, hopeful

message after another about how you can find solutions, about how important your mindset and your outlook is, and these messages--if you, if you need some reinforcement, please go back and listen to this episode again so that you really hear what she's saying. Thank you so much, Bonnie.

Bonnie Lais:

Thank you for having me. It was a pleasure. I really enjoyed this.