Lisa Tschudi: Welcome to Love Doesn't Pay the Bills, where we make visible the often unseen experience of family caregiving.

Lisa Tschudi: I'm Lisa Tschudi.

Lisa Tschudi: I am a family caregiver.

Lisa Tschudi: Karen Warner Schuler is the author of The Sudden Caregiver, which came from her own caregiving experience.

Lisa Tschudi: Welcome, Karen.

Karen Warner Schuler: Thank you, Lisa.

Karen Warner Schuler: I'm so honored to be part of.

Lisa Tschudi: This podcast, and thank you for joining me.

Lisa Tschudi: So can you give my listeners the brief chronological outline of your caregiving experience?

Karen Warner Schuler: Yes.

Karen Warner Schuler: My late husband was diagnosed in 2014 with stage four cancer.

Karen Warner Schuler: Overnight, we did not see it coming.

Karen Warner Schuler: And overnight I became a sudden caregiver.

Karen Warner Schuler: We spent the next 18 months battling, looking for clinical trials, any kind of treatment, driving back and forth to treatment appointments in the middle of snowstorms and rush hour traffic.

Karen Warner Schuler: And he finally just they basically said, all of our options have been exhausted and there really is no more hope here.

Karen Warner Schuler: And so then we began the process of dying, that last phase, which in my book, I call resolution.

Karen Warner Schuler: And then when he passed away, I decided to take the experiences that he and I had talked about, like, how do we turn this into a resilient platform or set of recommendations or a roadmap for other caregivers?

Karen Warner Schuler: Because when I became a caregiver overnight, I couldn't find any best practices that spoke to me for the issues that I was dealing with at the time.

Karen Warner Schuler: And so I did that's.

Karen Warner Schuler: I wrote the book.

Karen Warner Schuler: The sudden caregiver.

Lisa Tschudi: That's beautiful that you turned your attention towards helping others.

Lisa Tschudi: And I really love the title.

Lisa Tschudi: Yeah, I really love the title a Sudden Caregiver as well, because I think for a lot of us, caregiving is not something we intentionally choose or think about happening.

Lisa Tschudi: And part of my purpose here is definitely to share these stories and to understand that in actuality, most of us, to some extent or another, will need care and or will be a caregiver, and likely both.

Lisa Tschudi: So it really is a public, communal thing that we haven't been addressing properly at all, and we've been kind of locking behind closed doors.

Lisa Tschudi: And my aim is to change that.

Karen Warner Schuler: Yeah, I love that.

Karen Warner Schuler: And that's my aim, too.

Karen Warner Schuler: There's a great Roslyn Carter quote.

Karen Warner Schuler: I think I started one of my chapters.

Karen Warner Schuler: There are only four kinds of caregivers in the world to your point those who have been caregivers, those who are caregivers, those who will be caregivers, and those who will need caregivers.

Karen Warner Schuler: And talking about sudden caregivers, when, of course, I had these sudden experience, one day were one way, and the next day it's all changed, literally.

Lisa Tschudi: Very sudden in your case.

Karen Warner Schuler: Yeah, but as I was writing my book and interviewing caregivers, because I started becoming a magnet for people who were entering caregiver situations, sudden caregiver situations.

Karen Warner Schuler: And then was observing my elderly mother, my now late mother, but at the time, my younger sister was her caregiver.

Karen Warner Schuler: And I was seeing that the sudden peace while my mother was aging and therefore needed an increasing amount of care.

Karen Warner Schuler: There were those.

Karen Warner Schuler: She gets the call at work, she's got to leave work.

Karen Warner Schuler: She has to go get my mom, take her to the Er.

Karen Warner Schuler: And then that whole cycle of Er to rehab, to assisted living begins.

Karen Warner Schuler: And it happens again and again.

Lisa Tschudi: The systems are set up in a way that really requires informal family member kind of support as well and really heavily relies on us.

Karen Warner Schuler: Yes.

Karen Warner Schuler: And I've just been reading a report from the Boston Consulting Group on the topic of what do we do?

Karen Warner Schuler: This is a tsunami that is coming to our beach any day.

Karen Warner Schuler: They say by 2030, it will be what they call the care economy.

Karen Warner Schuler: It will be such a big economic hit to our GDP that we need to get ahead of it, which the World Health Organization has been warning us about this since 2002.

Karen Warner Schuler: But yeah, there are many caregivers mentioned to their report or care child care or things like that.

Karen Warner Schuler: The care economy consists of a lot of things, but 40% of that care economy is unpaid, informal caregivers who don't have a choice and whether they want to or not, they need to do it.

Karen Warner Schuler: I didn't have a choice, although I wouldn't have chosen something different.

Karen Warner Schuler: It sounds like from your circumstance, you would not choose another life.

Karen Warner Schuler: And yet the economic strain, physical strain, the emotional strain are all real.

Lisa Tschudi: Given the choices that I had and the fact that my daughter had these needs and somebody had to meet them, I feel like the choices I made were the right ones for my family and myself and my daughter.

Lisa Tschudi: And I really wish there was a different set of choices.

Lisa Tschudi: I think that the sets of choices that we face really depend on those social structures, depend on where we choose to put money in.

Lisa Tschudi: Resources depend on a lot of factors that are not in individual control.

Karen Warner Schuler: Very true.

Karen Warner Schuler: The idea that love doesn't conquer all, right?

Karen Warner Schuler: There are real economic burdens that come along with caregiving or choices that I did not think of as a burden.

Karen Warner Schuler: But when my husband and I were both two income we were two income family, our kids were already launched, but we had a mortgage that both our incomes were based on.

Karen Warner Schuler: And I was losing him.

Karen Warner Schuler: And he could no longer consult.

Karen Warner Schuler: He could no longer travel.

Karen Warner Schuler: He could no longer do the things that we just based our whole life on these assumptions that no longer existed.

Karen Warner Schuler: I will say that there are, I think, more resources than we see and know are available.

Karen Warner Schuler: And I'll get on a soapbox about what I think we have to do between now and 2030.

Karen Warner Schuler: But I felt like I had never been a caregiver before, so I was unaware of what my community offered and where I could go for some funding or something to tide me over until I could figure it out.

Karen Warner Schuler: I was lucky that I worked, but then I had to cut back my hours, as many caregivers do.

Karen Warner Schuler: Most caregivers in the situation we're in are women.

Karen Warner Schuler: So one solution has to be, can we expand the base of caregivers to include, I don't know, men, more men?

Karen Warner Schuler: That it's not just the default solution is I made less money, I'm the one staying home or cutting back my hours.

Karen Warner Schuler: But those situations are real.

Karen Warner Schuler: One thing that I found, it's a very central part of my book, is that when I became a caregiver and I was looking for that road map, I was just finding article after article that just said, look out.

Karen Warner Schuler: You could die before the person in your care because caregiving is so stressful.

Karen Warner Schuler: You're at more risk for stroke, you're at more risk for your own health issues because you're going to neglect your health to care for this other person.

Karen Warner Schuler: There's a lot of documentation right there's.

Karen Warner Schuler: So where's to happen?

Lisa Tschudi: Why is it this way?

Karen Warner Schuler: And then I thought, well, that's not my whole experience.

Karen Warner Schuler: And I began to actually talk to caregivers, and they were saying the same thing.

Karen Warner Schuler: So one central premise of my book is that caregiving is a paradox, right?

Karen Warner Schuler: It is both a burden and a strain and can deplete us and challenge our health.

Karen Warner Schuler: And it is also a source of happiness and closer like the way you were describing your daughter to me earlier.

Karen Warner Schuler: You increase the intimacy of your relationships and your family.

Karen Warner Schuler: You increase you draw to yourself the positive things that you have to pay attention to.

Karen Warner Schuler: In my case, I was losing them.

Karen Warner Schuler: I had a finite number of hours on the planet to have those happy moments.

Karen Warner Schuler: So to me and these other caregivers who I was speaking with, it wasn't all bad.

Karen Warner Schuler: It wasn't all like, such a burden.

Karen Warner Schuler: I can't live my life.

Karen Warner Schuler: COVID made it exponentially more difficult for caregivers.

Karen Warner Schuler: I'm sure you experience that.

Lisa Tschudi: I've heard from other caregivers, more so than my personal family, we were somewhat set up for it.

Lisa Tschudi: We already had this household by this time.

Lisa Tschudi: My older daughter has grown.

Lisa Tschudi: She is a caregiver as well.

Lisa Tschudi: For her older ones, we've got three family members, my husband, my older daughter and myself.

Lisa Tschudi: For one person that requires care in the household as well as that, we had started a business from home that was entirely remote and available at home as well.

Karen Warner Schuler: Perfect.

Lisa Tschudi: Yeah.

Lisa Tschudi: And from a lot of other families, though, I mean, I've definitely heard plenty of extreme challenges.

Lisa Tschudi: And in Oregon, one of the things that came out of that I have another interview with Shasta Kearns Moore that will be playing.

Lisa Tschudi: She's one of the main advocates for parents to remain paid caregivers.

Lisa Tschudi: There's been a temporary exclusion yeah.

Lisa Tschudi: That allows parents, even if the children's under 18 children are under 18, to be paid in the roles of a direct service provider or a personal support worker for their child.

Lisa Tschudi: And that's been enormous.

Lisa Tschudi: It's made tremendous difference.

Lisa Tschudi: Families are talking about a lot of health improvements in their children, fewer hospital visits.

Karen Warner Schuler: What an example to set for the other states and the federal government, quite honestly.

Karen Warner Schuler: But yeah.

Lisa Tschudi: And COVID really made brought this issue to a point where people are willing to consider paying the parents.

Lisa Tschudi: I think because so many people experienced a challenge of young kids or people who were cared for in more formal situations no longer having access to that and became a lot more interested in and open to considering these kind of ideas as well as the fact that when it comes to children with particular care needs extra.

Lisa Tschudi: Support needs due to a disability.

Lisa Tschudi: There were so many families that suddenly could not find a hired caregiver.

Lisa Tschudi: And in some cases, the child's at an extremely higher level of risk from COVID For example, if they are out in public and with a rotating change of caregivers, yeah, it's safer for them to be in their family.

Karen Warner Schuler: No, I think Oregon is really ahead in that when you look at the kinds of support that caregivers need.

Karen Warner Schuler: So I said earlier, there are resources, but it is nowhere near what it needs to be for helping us really address the problem.

Karen Warner Schuler: The tsunami.

Karen Warner Schuler: If you saw your San Juno beach and you're told a tsunami is coming, what would you do?

Karen Warner Schuler: You would run for cover.

Karen Warner Schuler: We have no cover as caregivers, but I think it will come from a variety of places.

Karen Warner Schuler: I think we traditionally look for informal people like us to step in.

Karen Warner Schuler: But the reality is with the birth rate lower and cost of childcare, one reason why people aren't having as many kids, the replacement of caregivers is like we're baby boomers.

Karen Warner Schuler: I'm a baby boomer.

Karen Warner Schuler: You might not be as a baby boomer.

Karen Warner Schuler: I have one child, there are two of us.

Karen Warner Schuler: So you start looking at my daughter will be in the situation that my family was in, where she's taking care of kids and she's taking care of an aging parent, in this case, me.

Karen Warner Schuler: And lucky for her, I understand caregiving.

Karen Warner Schuler: So we turn to informal caregivers, then we turn to formal public programs like government assistance or wisely government changing our tax structure or subsidizing caregivers.

Karen Warner Schuler: And as you point out, or again in other states, Oklahoma, I think New York are starting to look at legislation around that.

Karen Warner Schuler: But then it's also looking at the private sector and what can CEOs of all of these companies, I mean, Google the number, the deficit to the United States in one year.

Karen Warner Schuler: Come 2030 of the impact of the care economy, we're going to lose $290,000,000,000 a year in terms of wages that don't get replaced, people dropping out of the workforce, cutting back their hours, not having the funding to really support the infrastructure that is being created.

Lisa Tschudi: It's really staggering.

Lisa Tschudi: And I really think most of us can't even comprehend a number that big, truly.

Karen Warner Schuler: Right.

Karen Warner Schuler: And the company, Alphabet, the parents holding company of Google, that's about their annual revenue.

Karen Warner Schuler: So we have such an imbalance of where we prioritize.

Karen Warner Schuler: But my daughter was born in the had one when I was a working mom and when I had to take medical leave at that time to have a baby, I was told, well, you can have six weeks because if you had a broken leg, that's the amount of time you would get.

Karen Warner Schuler: And I would say, well, having a baby is nothing like having a broken leg.

Karen Warner Schuler: And I brought yes, and they said yes.

Karen Warner Schuler: But the men like, we have to give equal disability leave.

Karen Warner Schuler: So if we give the women six weeks for maternity leave, we would give the men six weeks for breaking a leg, something like that.

Karen Warner Schuler: And that was in 1084.

Karen Warner Schuler: And I am still having this conversation on the other end of spectrum and I do think corporations are starting to realize I mean, we saw some companies, PepsiCo for example, where they put $2 million into onsite childcare and it made such a difference for people.

Karen Warner Schuler: But that's one solution of many that might work for a parent.

Karen Warner Schuler: Every family is different, so the subsidizing would be the way to go.

Karen Warner Schuler: So you have private sector, you have public sector.

Karen Warner Schuler: And then I also think there's an individual responsibility in kind of two ways.

Karen Warner Schuler: One is to do the kinds of things you're doing, shifting the narrative around caregiving so that it's not women's work and therefore degraded and also shifting it from a cultural perspective of pay attention to the tsunami.

Karen Warner Schuler: It's coming and it's like everything we can solve for it now or we can wait until it's a disaster and we can't do it, but now is the opportunity.

Karen Warner Schuler: So the individual we can start shifting that narrative.

Karen Warner Schuler: We can start planning for it just like any other major expense in our lives.

Karen Warner Schuler: There are people, I'm well aware that don't have family members who can drop things and step in.

Karen Warner Schuler: And there are really sad stories about how people are impacted by that.

Karen Warner Schuler: Or the person that, you know, in the case of an elderly couple, the person who's nominated to be the carer is also themselves in some form of medical issue or dementia or something where they can't and there are no kids to step in.

Karen Warner Schuler: So I have heard so many caregiving stories where I feel like, oh, my goodness, my husband was so lucky that he had me only in that I was good for it.

Karen Warner Schuler: Like I was the resource.

Karen Warner Schuler: Just as your family is lucky they have you.

Karen Warner Schuler: And so many families don't have a you or a me.

Karen Warner Schuler: And it's a really sad and intractable.

Lisa Tschudi: Issue you're hitting for me.

Lisa Tschudi: What is really the crux of these matters, I think all the time when it comes to myself being ill or injured, my family is not going to have extra capacity to also take care of me.

Lisa Tschudi: How is that going to work?

Lisa Tschudi: And also when you start hanging out for 21 years in disability related groups, in moms groups, for the mothers whose children have disability, things like that.

Lisa Tschudi: In groups associated with a specific condition every single day, for example, in the Facebook groups, whether it's in person or however, a lot of my socializing has been on Facebook because I've been so extensively caregiving and it's really difficult to make those in person things happen very often.

Lisa Tschudi: But when you hang out in these spaces that are specific to people with disabilities, it's every single day there's somebody with a new diagnosis that comes, they're explaining this really untenable situation yeah.

Lisa Tschudi: And huge needs and saying, and I'm in danger of losing my job, and then how am I going to pay for my home and what am I going to do?

Karen Warner Schuler: Right?

Lisa Tschudi: And nobody really has an answer.

Karen Warner Schuler: Yeah, no one has an answer.

Lisa Tschudi: We can do so much better than that as a society and collective.

Karen Warner Schuler: Yes.

Karen Warner Schuler: And one reason that I wrote the book I Did The Way I Did, which is about resilience and that paradox, right?

Karen Warner Schuler: That it is actually a source of meaning and achievement for caregivers is I have a degree in positive psychology, and there's a concept in positive psychology called Growth Mindset by a professor from Stanford, Carol Dweck.

Karen Warner Schuler: And growth mindset is everything you just said.

Karen Warner Schuler: And then let's add the word yet to the end of it.

Karen Warner Schuler: Like there is nothing available yet because that's the work you and I are doing to get to shift that narrative and that's back to the individual.

Karen Warner Schuler: That's the thing.

Karen Warner Schuler: I don't know.

Karen Warner Schuler: I admire so much that you woke up with everything else on your plate one day and said, I'm going to do podcasts on the informal unpaid caregiver and try to change the caregiver story.

Karen Warner Schuler: Same thing with me.

Karen Warner Schuler: There are just things where we see it and we're able and we do it, but it's relentless.

Karen Warner Schuler: We cannot lay down the manslaught once we picked it up because people need us on the other piece of the.

Lisa Tschudi: All the future generations to come after us, need it to be so much better than this.

Karen Warner Schuler: Oh, yeah.

Karen Warner Schuler: And culturally, there is an expectation, even though the demographics, there's a mismatch between the supply and the demand as we age and as this tsunami comes and we culturally aren't shifting our expectations.

Karen Warner Schuler: So the cultural expectation is my daughter, who's now 38 and really healthy when she's in her 80s, like my mom, are there going to be people available to take care of her?

Karen Warner Schuler: Which leads to my other my second piece of things we can do as an individual, and that is to not need caregiving in the first place, to stave it off as long as possible by I follow Sanjay Gupta.

Karen Warner Schuler: He's written a book called The Sharp, and it's a very wise set of get ahead of dementia and bad health.

Karen Warner Schuler: And by developing, he's got a little, you know, kind of a formula of habits.

Karen Warner Schuler: And man, there are times when it's raining and I have a mile to walk to the gym and I don't feel like it and it's cold, and then I go, this is why I have the knock on wood.

Karen Warner Schuler: I have the health I do so far.

Karen Warner Schuler: And it's because I go to the gym or do something right, I do something to care for that aspect of my health.

Karen Warner Schuler: So it sort of saved that off as long as we possibly can.

Karen Warner Schuler: To your point, how good are we going to be to people?

Lisa Tschudi: That sounds a bit into the territory that I've been really allergic to for a long time, of telling women who are in untenable caregiving situations to self care.

Lisa Tschudi: I know, and I can hear it.

Lisa Tschudi: And I can hear that.

Lisa Tschudi: Yes.

Lisa Tschudi: There are a lot of ways in which we can take care of ourselves the best possible in our own situations and with whatever our resources happen to be.

Karen Warner Schuler: Yeah.

Lisa Tschudi: And it can make a difference.

Lisa Tschudi: Also, you never know whose health is going to go when and which way you gave the of your own husband.

Lisa Tschudi: That was, by all appearances and all experience doing great, and it wasn't.

Karen Warner Schuler: Yes.

Karen Warner Schuler: And Lisa, I want to make a distinction.

Karen Warner Schuler: Thank you for saying that, because I am also allergic to an experience that where people would say, now you take care of yourself.

Karen Warner Schuler: And I would be, how is that supposed to happen?

Lisa Tschudi: Like, okay, I'm going to come watch my daughter for the hour so I can go take them on walk or whatever.

Lisa Tschudi: Yeah, exactly.

Karen Warner Schuler: So I want to separate.

Karen Warner Schuler: What I was talking about was more the person, the random, you know, 45 year old who's not sick and not a caregiver and making life and even younger, like making life choices.

Karen Warner Schuler: Where so I was talking about the non caregiver individual, because the longer that non caregiver individual doesn't need a caregiver, the better it is for everyone, including caregivers and the economy.

Karen Warner Schuler: But I agree with you.

Karen Warner Schuler: My book.

Karen Warner Schuler: I tread gently.

Karen Warner Schuler: But I do think the self care piece I just talk about it the way, like when I went off to school for the first time, my mother sat me down and gave me five things that are the rules.

Karen Warner Schuler: Of being a human.

Karen Warner Schuler: And they are.

Karen Warner Schuler: Eat your vegetables, go outside and play, get sleep, hang out with the right people and have a hobby.

Karen Warner Schuler: You have to have a hobby or a sport.

Lisa Tschudi: Sounds fantastic.

Lisa Tschudi: That's a smart mama.

Lisa Tschudi: Yeah, yeah.

Karen Warner Schuler: And so that's in my book, those are the five things, and it can be.

Karen Warner Schuler: I do think getting out in blue and green, like seeing nature is a good thing.

Karen Warner Schuler: So it takes planning, but you need to build that in and then reaching for the apple instead of or the granola bar instead of the cheeseburger.

Karen Warner Schuler: And I spent the time among in hospital cafeterias with cheeseburgers.

Karen Warner Schuler: So these are just things to be again, it's a mindfulness play.

Karen Warner Schuler: More than but also meditation.

Karen Warner Schuler: And I'm not a big meditator, just about everyone I know would be horrified to hear that, because I should be.

Karen Warner Schuler: But I do think spending and there's some research.

Karen Warner Schuler: When I was researching my book, there's the idea that as a caregiver, you're depleting, you're sending, you're sending, you're sending your energy.

Karen Warner Schuler: And that if you can take some small portion of your day, 15 minutes and do something only you want, only you want for yourself a CrossFit puzzle, spelling, B word or whatever it is, call a friend, walk outside and take a deep breath, whatever that is.

Karen Warner Schuler: For me, it was like at 03:00, get a cup of coffee and just cold, look out the window.

Karen Warner Schuler: If it's nice, go and walk the dog in the backyard.

Karen Warner Schuler: But that idea that if you can spend that, it actually in an out of proportion way returns and restores some of that depleted energy.

Karen Warner Schuler: So those are just kinds of things that I think fall into self care for caregivers.

Lisa Tschudi: Yeah.

Lisa Tschudi: And I can definitely hear that and appreciate that and would encourage everyone to listen up.

Lisa Tschudi: For me personally, it took me until really pretty recently to get consistent about the things that I can do to take care of myself.

Lisa Tschudi: Like starting my day in a calm manner that is about me and in particular, first thing in the morning for me makes a really big difference and not jumping into everybody else's demands right away.

Karen Warner Schuler: So true.

Karen Warner Schuler: I totally get that.

Karen Warner Schuler: Yeah, very important.

Lisa Tschudi: I think that even at my busiest, like I could see and find times where it's a matter of taking five minutes, two minutes, whatever, to like make the cup of tea I want open or close the window so it has the breeze or it's warmer or whatever I need.

Lisa Tschudi: And it just reinforces that message for yourself when you do those little things that your comfort matters, that you get to do things the way you want them.

Karen Warner Schuler: Yeah, no, and it's challenging.

Karen Warner Schuler: But the thing two questions that I was always asked as a caregiver that I found maddening, one was so how are you taking care of yourself?

Karen Warner Schuler: As I said, I'm not.

Karen Warner Schuler: But I plan to.

Karen Warner Schuler: And I'll get like everything else is gold and I'll get there.

Lisa Tschudi: Right.

Karen Warner Schuler: But the other question, I don't know if you find this, but people will say, well, how can I help?

Karen Warner Schuler: And to me, I hear that and I've heard other caregivers say this, like that just gets me one more job.

Karen Warner Schuler: Now I have I'm taking care of this person and now I have to help you help me.

Karen Warner Schuler: And so one day I was out shoveling snow in that first winter when my husband was diagnosed, it was the worst winter Boston it had since 1872.

Karen Warner Schuler: We literally had seven lizards one day after the other.

Karen Warner Schuler: And I would just, like, walk down to the driveway and get the paper and walk back up.

Karen Warner Schuler: And it just seemed like every day the snow was just getting higher and higher.

Karen Warner Schuler: It was almost up to the roof.

Karen Warner Schuler: And so when you as you know, you live in a snowy climate, you've got to get ahead of the snow.

Karen Warner Schuler: Like, you're out shoveling all the time.

Karen Warner Schuler: And then people would call and go, what can I do for you?

Karen Warner Schuler: And I'd be like, in my mind, shoveling the snow, like, give me come shovel my walk.

Karen Warner Schuler: I had that thought, never uttered it out loud, because it was just me blowing off steam with myself.

Karen Warner Schuler: And I came in from shoveling a walk one day, and my phone rang, and it was the assistant of one of my clients, because I'm an executive coach in my day job.

Karen Warner Schuler: And she said, Alan would like to give you snow removal because he knows that you're in this caregiving situation and you're getting pounded with lizards.

Karen Warner Schuler: And he lived in a place that wasn't snowing, and I just thought it was a capacity.

Lisa Tschudi: Yeah, that's the thing that's so beautiful when people realize they have the capacity that you're struggling with right now.

Karen Warner Schuler: Yeah.

Karen Warner Schuler: And so what he did was, because he lived somewhere else, he had his assistant find this person in my neighborhood who had a snowblower.

Karen Warner Schuler: And every single time it snowed, that person would come and shovel the walk around my house so I could walk the dog, I could get my husband to the car, I could get the mail, I could get the paper.

Karen Warner Schuler: And it was not a small thing.

Karen Warner Schuler: So to me, I think about the lessons that we learned from caregiving, and one of them is that there is grace in the world.

Karen Warner Schuler: And that was just the most graceful gift, because and not that there's anything wrong with this, but we didn't need any more chicken soup left on our porch.

Karen Warner Schuler: We needed things that were hoping to live our lives.

Karen Warner Schuler: Yeah, that was just such a beautiful gift.

Karen Warner Schuler: And for someone to just wake up the out of clear blue sky and go, this is what I'm doing, it was just really special.

Karen Warner Schuler: And those were the kinds.

Karen Warner Schuler: At one time, my husband, as he was sicker and not going to recover, and we were aware of that.

Karen Warner Schuler: He was harder to change, like, to dress and undress.

Karen Warner Schuler: No more the jeans and whatever.

Karen Warner Schuler: And so I was talking to a friend of mine on the phone who had been a caregiver and has lost his partner.

Karen Warner Schuler: And I said, yeah, I don't know what to do, because getting ready, getting dressed every day is getting harder and harder.

Karen Warner Schuler: And he was empathetic.

Karen Warner Schuler: And then the next day I woke up and I went to get the paper.

Karen Warner Schuler: I opened the front door and he had stacked bags of sweatpants that he had gone to the local department store and just bought sweatpants in my husband's size and left them there on the porch.

Karen Warner Schuler: So that it makes so much sense, right?

Karen Warner Schuler: Just hold sweatpants on and off.

Karen Warner Schuler: You don't have to do all the fancy stuff.

Karen Warner Schuler: So those were the kinds of things that if someone stops for a few minutes and just thinks about it and I don't care what it is, chicken soup is fine.

Karen Warner Schuler: Like, I had someone call me and say, just tell me where your refrigerator is in your house, I'm going to fill it with food.

Karen Warner Schuler: And she did.

Karen Warner Schuler: She just put stuff in the freezer and that was what I made every night for dinner.

Karen Warner Schuler: But that was also that wasn't the day in and day out part of it.

Karen Warner Schuler: We're in an urgent situation.

Karen Warner Schuler: Part of it, yeah.

Lisa Tschudi: Those are beautiful stories and I love the way that you have people around that have had that wisdom and understood you and your need right in the moment.

Lisa Tschudi: And I think it's beautiful.

Lisa Tschudi: I can think of a handful of times for myself, but it's a skill when people can do that.

Karen Warner Schuler: Yeah, I think it is.

Karen Warner Schuler: I think it's a little like my daughter and I, and my daughter's 38, so I've raised her.

Karen Warner Schuler: She's definitely my kid.

Karen Warner Schuler: And we are really good gift givers.

Karen Warner Schuler: Like, we do Christmas, birthdays, we try to zero in on what will make this person's life better or more meaningful or something that we experience.

Karen Warner Schuler: And she does it for me and I do it for her, but we do it for everyone in our family.

Karen Warner Schuler: And no one can out gift us because we're just that way.

Karen Warner Schuler: We spend all year long, every waking moment trying to divine what that will be for the special people in our lives.

Karen Warner Schuler: And I think that's like, my husband will say, well, I'm not like you guys.

Karen Warner Schuler: I wasn't raised that way.

Karen Warner Schuler: And we're like, it's fine.

Karen Warner Schuler: Like, I know what color to paint a room.

Karen Warner Schuler: Not everyone does.

Karen Warner Schuler: Right.

Karen Warner Schuler: I know how to do this.

Karen Warner Schuler: But you're good at what you're good at, and he's really good at what he's good at.

Karen Warner Schuler: But it's the idea that not everyone has to be that.

Karen Warner Schuler: But it is nice if you go the extra, even if it's just, can I stop by and give you a break so you can run to the store?

Karen Warner Schuler: Right.

Lisa Tschudi: That was always I love the encouragement.

Lisa Tschudi: The idea of a really strong encouragement and this is what I would say to my audience, is to think about where is it that you have capacity that feels very doable to you, that would make a difference in somebody else's.

Karen Warner Schuler: Life that's so well, sadly, I think that yes.

Lisa Tschudi: And not to especially the holidays are coming up and.

Lisa Tschudi: People so often think of gift giving and this kind of thing is such a burden in itself.

Lisa Tschudi: Another thing to do on the checklist, oh, I have to get all the teachers this and I have to get all the indefinitely the kids and I have to make it magical for them and all this stuff and pick the meals.

Lisa Tschudi: And now my friend is sick and yet needs me to bring the soup.

Lisa Tschudi: I have to bring the soup, right?

Lisa Tschudi: And then I have to go back to the next day and pick up my dishes and like we put all of this extra burden, especially on women, sometimes everybody, but especially women.

Lisa Tschudi: And it doesn't feel real good to me.

Lisa Tschudi: It feels so much better when people you can just feel the difference when somebody really is coming to give a gift from a position where they really have abundance in that area or skill in that area or something.

Karen Warner Schuler: Yeah, I think that's a good thing.

Karen Warner Schuler: It's so good to encourage your listeners to do that because it doesn't have to cost anything, it doesn't have to take a lot of time.

Karen Warner Schuler: If you're tapping in to the gift that you have for another person, that's really what matters.

Karen Warner Schuler: And it would be easier to give something you're good at giving.

Lisa Tschudi: Thank you for that.

Lisa Tschudi: Yeah, I like that a lot.

Karen Warner Schuler: Well, and I do think the holidays are quite when I was in a caregiver support group, when my husband was ill, we would sit and it was an ever changing panel of people who would show up.

Karen Warner Schuler: We never knew who was going to be there because people were always getting diagnosed or getting better or not getting better.

Karen Warner Schuler: And one day our leader of the group, which she was a social worker, and she said, okay, holidays.

Karen Warner Schuler: And we all just went, no, we don't want to talk about the holidays, we don't want to think about the holidays, we're not having holidays.

Karen Warner Schuler: But it was really helpful for to hear all these different people with different family situations and different caregiving situations.

Karen Warner Schuler: It almost gave permission to go, I'm going to do it easy this year.

Karen Warner Schuler: One person said he had a big family, his wife was ill, and he said, my family is going to descend.

Karen Warner Schuler: There's no keeping them away.

Karen Warner Schuler: I rented a haul and that's where we're going to celebrate our Christmas dinner.

Karen Warner Schuler: Because we can't entertain, we can't keep cleaning, we can't all the things that we want to do.

Lisa Tschudi: Yeah, that is functional.

Karen Warner Schuler: Exactly.

Karen Warner Schuler: And it gave me permission as a caregiver to really go what is essential here, and then let's do that.

Karen Warner Schuler: And what we ended up doing was a really nice family, create a really nice family memory for the, you know, when you're in the situation I was in, are we going to have another holiday?

Karen Warner Schuler: So you don't want to not do it, but at the same time, it has to be something that works for the caregiver and the care receiver.

Lisa Tschudi: It's time for a break.

Lisa Tschudi: Please stay right here and we will be right back.

Lisa Tschudi: And we're continuing our conversation with Karen Warner Schuler.

Lisa Tschudi: I'm Lisa Chudy, and this is Love doesn't pay the bills.

Karen Warner Schuler: One more thing I put in my book, which is in the second chapter, which is like, I felt like I couldn't just give a roadmap to caregivers without first saying, before you go on this journey to take the road map, here are some ways to build resilience.

Karen Warner Schuler: And so I call them.

Karen Warner Schuler: I have six things that I call resilience builders.

Karen Warner Schuler: One is just have a map, have an idea of what you're in for and what that's going to look like.

Karen Warner Schuler: But one is create a caregiving squad.

Karen Warner Schuler: And I put that together because I'm an executive coach.

Karen Warner Schuler: And when I'm coaching someone who say, looking to change their career or change jobs, one of the pieces of advice is put your cheerleading squad together.

Karen Warner Schuler: Like, who's really good at what you're not good at?

Karen Warner Schuler: Like, can someone write a resume?

Karen Warner Schuler: Can someone edit it?

Karen Warner Schuler: Can someone practice interview skills with you?

Karen Warner Schuler: So we do that.

Karen Warner Schuler: So I started thinking, well, if we use that squad for caregiving, what would that look like?

Karen Warner Schuler: And for me, my needs would be different than yours, but who's on the squad and who's not on the squad?

Karen Warner Schuler: And I had a couple of rules, but one was, what are the tasks that you cannot do or don't want to do or simply not good at, and who in your world is good at those?

Karen Warner Schuler: So one for me was keeping up with all the financial stuff when my husband was no longer doing it.

Karen Warner Schuler: He had always done it, and it was extreme.

Karen Warner Schuler: It was, I'm getting this insurance bill, and it's for $64,000.

Karen Warner Schuler: I know I don't have to pay it, but I don't know what to do about it and who to call.

Karen Warner Schuler: And there was a lot of that.

Karen Warner Schuler: And so I have a friend, Richard, who just loves that.

Karen Warner Schuler: He's great, he's analytical, he has that brain.

Karen Warner Schuler: And so he just took that over, and he would just say, you need to pay attention to this, not that.

Karen Warner Schuler: And just kind of being a small.

Lisa Tschudi: Business owner, I am amazed with the number of small business owners that don't have an accountant.

Karen Warner Schuler: I was just talking to someone about my yeah, I know.

Karen Warner Schuler: I have a virtual assistant who's like a magician, and she just started this business, and now she's hiring people to be also virtual assistants.

Karen Warner Schuler: And I said to her, do you have a bookkeeper?

Karen Warner Schuler: Just because the best thing I ever did for my business was hire a bookkeeper.

Karen Warner Schuler: And she hopefully she'll watch this pot.

Karen Warner Schuler: She was also one of my favorite caregivers in my book, but she just makes my like I get paid when I'm supposed to get paid.

Karen Warner Schuler: My invoices go out on time.

Karen Warner Schuler: She knows, like, she'll know in intricate detail, like, oh, you went to Starbucks four times and you bought this.

Karen Warner Schuler: What was that about?

Lisa Tschudi: She knows all of you.

Karen Warner Schuler: But it really is great if you have that ability that is part of the caregiving squad, right?

Karen Warner Schuler: It's like, what are we at a bad winter?

Karen Warner Schuler: Our ceiling started leaking because of all the ice on them.

Karen Warner Schuler: I'm not good around the house.

Karen Warner Schuler: My husband was ill, but we had a guy named Nick who had to drive past our height as a builder.

Karen Warner Schuler: He had to drive past her house all the time.

Karen Warner Schuler: So I called him up and I said, could you just be part of my squad?

Karen Warner Schuler: And if something goes wrong with my house, could you come over?

Karen Warner Schuler: And I lined them all up, and then when the time came, I could call upon them and say, you know, you need a shrink.

Karen Warner Schuler: You need someone who you can say things to in the privacy of a quiet room where you're stressed and no one else has to know.

Karen Warner Schuler: But you can express my best friend who just would show up and help me clean the house and hand me a cup of coffee and just say, 03:00.

Karen Warner Schuler: Go sit over there and I've got this.

Karen Warner Schuler: But the point of that is that two things that I had rules about.

Karen Warner Schuler: One is nobody is on my squad if I'm not comfortable with them.

Karen Warner Schuler: So I didn't, for example, have people that had great close relationships with my husband, the care receiver, and didn't get along with me.

Karen Warner Schuler: I'm sorry, they're not on my squad.

Karen Warner Schuler: They can be on his squad.

Karen Warner Schuler: And the other thing is to really be a little there's a selfishness I think I had with caregiving where I felt like selfsufficiency syndrome.

Karen Warner Schuler: I'm the only one who can really do this.

Karen Warner Schuler: And that's not true.

Karen Warner Schuler: There were things that other people could do as long as I trusted them.

Karen Warner Schuler: So that's my care leading squad advice for resilience building outsource if you can if you trust people.

Lisa Tschudi: I love that too.

Lisa Tschudi: And I think back to one of the advocacy trainings I had and one of the refrains that we heard quite a few times in the course of that it was nine months long training was frequently trust humanity.

Lisa Tschudi: And being that sometimes, it is true that a lot of times we get really hesitant to call on the people who have that capacity or have that skill or have the ability that we're needing and make it so much harder for ourselves than even it has to.

Karen Warner Schuler: Be just the way I'm wired.

Karen Warner Schuler: I don't like to ask anybody for help, and I found that people were willing if I asked, no one said, oh, no, I really can't do that.

Karen Warner Schuler: I don't want to do that.

Karen Warner Schuler: Because I wouldn't ask someone who would say that.

Karen Warner Schuler: I would ask people who would I always said they have to be able to see my dirty laundry, like, because literally, that is what they're going to see when they come into my house.

Karen Warner Schuler: It's not going to be pretty.

Karen Warner Schuler: So those kinds of things, I think, again, it's a little like taking a break.

Karen Warner Schuler: No one has time to take a break.

Karen Warner Schuler: But if you allow it, if you give yourself that permission, find a way you can get some of that back.

Karen Warner Schuler: And it builds resilience.

Karen Warner Schuler: And when you build resilience, just don't even do it for yourself.

Karen Warner Schuler: It's good.

Karen Warner Schuler: We have research that says it's better for the person in your care if you take those little breaks and you selfcare.

Karen Warner Schuler: Some people said you should go on vacation.

Karen Warner Schuler: I'm like, I'm not going on vacation without my husband.

Karen Warner Schuler: No, I can't.

Karen Warner Schuler: I don't want to.

Karen Warner Schuler: But I did manage when my mom, at one of her episodes where she ended up in the hospital, I did bring in someone to stay with my husband, and I went overnight.

Karen Warner Schuler: And it was not a vacation because I was visiting my mother in the hospital, but it was a break.

Karen Warner Schuler: It was a different type of scenery.

Lisa Tschudi: Yeah.

Lisa Tschudi: I think it's okay if it doesn't feel great and appropriate to go take a vacation, for example, then don't, especially.

Lisa Tschudi: I haven't been in the same situation, but I can imagine in your case, knowing that there is a terminal diagnosis you might want every single second that you can get to be physically present or nearby.

Karen Warner Schuler: Yeah.

Karen Warner Schuler: And again, you recast what I just said.

Karen Warner Schuler: I love that it is okay to take a vacation if you're a caregiver, especially when it goes on for a long time.

Karen Warner Schuler: I mean, my bookkeeper cared for her father.

Karen Warner Schuler: There was a situation where her mother was caring for her father who had Alzheimer's.

Karen Warner Schuler: Her mother passed away unexpectedly.

Karen Warner Schuler: And my bookkeeper, whose name is Patty and is in my book, stepped in and cared for her father for ten years, and he's recently passed.

Karen Warner Schuler: And there's all of that to process and deal with.

Karen Warner Schuler: But it is like, for ten years, she's never going to take a vacation.

Karen Warner Schuler: Of course she is.

Lisa Tschudi: It's great to take the vacation, especially as time goes on in that kind of extent.

Lisa Tschudi: It's also great not to want a vacation, especially if we're talking a year or two or a relatively shorter term.

Lisa Tschudi: You may care more about your loved one right there.

Karen Warner Schuler: We made up vacations.

Karen Warner Schuler: We did them the way we could do.

Karen Warner Schuler: That was it for packing the car to drive into a zone of war, because you don't know you're on the road, what's going to happen?

Karen Warner Schuler: But we drove because that was going to be doable.

Karen Warner Schuler: And I think the other thing I wish I had had the opportunity to do more of as a caregiver, especially in a terminal situation, is to have gotten my husband earlier to say, what if he doesn't make it?

Karen Warner Schuler: So from the time he was diagnosed, we put all of our effort and energy into growth mindset like we're going to do unturned every stone and we're going to and I have that energy and I'm wired that way.

Karen Warner Schuler: And he was we're big problem solvers.

Karen Warner Schuler: But at some point it was clear that it was going to resolve and the way it resolved.

Karen Warner Schuler: And we only had a couple of conversations that edged around that.

Karen Warner Schuler: But I don't know if you've seen the book atul Gwandi's book Being Mortal.

Lisa Tschudi: I have been encouraged to read it by more than one person, including my daughter.

Karen Warner Schuler: It should be read by everyone over the age of 40, I think, but because it's about preparing for the eventuality that you might need a caregiver or die, it's about being mortal.

Karen Warner Schuler: One of the things I love about that book, I think it's like in chapter five, he talks about and I actually reproduced it in my book, he talks about having the hard conversations with the person in your care.

Karen Warner Schuler: So that if that person is incapacitated and cannot tell you what they need, you'll have the confidence to know and draw upon that knowledge.

Karen Warner Schuler: And he tells the story of one of the nurses who is involved in end of life care, whose own father was hospitalized, and she's just doing the oh, dad, I'll be back tomorrow.

Karen Warner Schuler: And she said she drove away and realized if he's going into surgery, what if he doesn't wake up?

Karen Warner Schuler: What if he's in a coma and they're asking me to make a decision?

Karen Warner Schuler: So she turned the car around and she went back and she said, you don't want to have this conversation.

Karen Warner Schuler: I don't want to have this conversation, but I need to know the following what decision do you want me to make?

Karen Warner Schuler: And in this case, if he were incapacitated, there was an opportunity for him to not come out of the surgery hole and how would you want me to call it?

Karen Warner Schuler: And he said, as long as I can eat chocolate, watch football and eat chocolate ice cream, I'll be fine.

Karen Warner Schuler: And so, sure enough, he went through the surgery.

Lisa Tschudi: I love it.

Karen Warner Schuler: Yeah, it's in Guani's book.

Karen Warner Schuler: And I repeated it in mind because I love that story.

Karen Warner Schuler: But the idea is, in fact, when he went in surgery and he was still out, there was a situation where the surgeons were saying, we need to go back in, we need to do whatever.

Karen Warner Schuler: And she said, can you watch football?

Karen Warner Schuler: And he chopped that ice cream when he comes out of this.

Karen Warner Schuler: And the surgeon said, yes, okay, do it.

Karen Warner Schuler: But it's a list of five questions, and I think they're really important to understand from your care receivers perspective.

Lisa Tschudi: Just your family member in general, because we never really do know.

Karen Warner Schuler: Yes.

Karen Warner Schuler: You also brought up the idea of a plan B, because I didn't have that in my book until I coveted.

Karen Warner Schuler: And I started talking to caregivers who are saying, like, if I go to the grocery store and bring back COVID and and comprom this was before the vaccine, and now the person in my care will now be compromised and die of COVID That's my fault.

Karen Warner Schuler: Like, if I make their life more complicated than it already is just from the care that they require, I'll never be able to live with myself.

Karen Warner Schuler: And so yes, you need to think all that through.

Karen Warner Schuler: But also, is there a plan B?

Karen Warner Schuler: Is there somebody you trust who could be that back up and it's not a conversation anyone wants to have.

Karen Warner Schuler: And I would say, no, there's no one.

Karen Warner Schuler: And my sister taking care of my mother would have said, no, there's no one.

Karen Warner Schuler: But my mom, in fact, had four kids or five kids.

Karen Warner Schuler: So one of us could have been a plan B if that had been required.

Lisa Tschudi: Absolutely.

Lisa Tschudi: And there are resources around, for example, end of life planning, particularly when there's a family member that has a significant disability.

Lisa Tschudi: My family has recently gone through some of that longterm planning and we're still in process with it.

Lisa Tschudi: But it does bring a lot of sense of relief.

Lisa Tschudi: And the public formal systems, for example, that my daughter does rely on a lot, really push against you doing any kind of future planning.

Lisa Tschudi: They're really where you have to reach the point of crisis first and then we might step in.

Lisa Tschudi: Even when my daughter is turning 18 and just switching services from children to adult services, a different set of issues, different roles.

Lisa Tschudi: And I knew that birthdays coming up.

Lisa Tschudi: Of course her birthday is known.

Lisa Tschudi: And a few months before, I went to some of the agencies that we would be involved with and tried to start the processes and I had even been encouraged to do so in a class and by some of the other professionals in our lives.

Lisa Tschudi: And I kept getting the answer of oh no, you can't do that, until the birthdays actually happened.

Lisa Tschudi: I think that's one thing that I would really love to see changes in.

Lisa Tschudi: For example, with SSI being able to name a secondary representative payee who would immediately be in place if the incapacitated.

Karen Warner Schuler: Yeah, that's really good.

Karen Warner Schuler: That's the public private support that we need to shift.

Karen Warner Schuler: I also think I put this in my book.

Karen Warner Schuler: One of the things that happens when you become a sudden caregiver, but in caregiving in general is how are you going to fund your life, your lifestyle, while you're caring?

Karen Warner Schuler: And that's one immediate thing.

Karen Warner Schuler: And I read some statistics that said 59% of Americans don't have wills, don't have plans.

Karen Warner Schuler: I think we have a youth culture that says we're going to live forever.

Karen Warner Schuler: And you and I, because we're in tenuous situations, or I have been, I still am, I look at myself and say, what if this happens to me?

Karen Warner Schuler: What if something happens to me?

Karen Warner Schuler: And now my daughter is stuck with me.

Karen Warner Schuler: I am remarried my husband.

Karen Warner Schuler: But what if something happens to him?

Karen Warner Schuler: I mean, the reality of it's, the being mortal approach, which is, what happens if something happens to you?

Karen Warner Schuler: And where's your paperwork?

Karen Warner Schuler: Who benefits?

Karen Warner Schuler: Who's your healthcare proxy?

Karen Warner Schuler: When my husband was incapacitated, he had leased his car, and all I wanted to do was pay the car payment.

Karen Warner Schuler: So we decided he was never going to drive again.

Karen Warner Schuler: So I called him up and I said, I want to pay his car payment and just need the details.

Karen Warner Schuler: I actually want to give you money.

Karen Warner Schuler: And they said, no, your name is not on the lease.

Karen Warner Schuler: And I said, oh, well, what do you need?

Karen Warner Schuler: And they said, well, he needs to submit that paperwork, and he's not going to be able to do it.

Karen Warner Schuler: That day has gone, and this is the situation we're in.

Karen Warner Schuler: And it was just sad, and it was hard for me because I didn't understand at that moment, he's never going to drive.

Karen Warner Schuler: Karen, what are you thinking?

Karen Warner Schuler: Within three weeks, he won't really be able to get out of bed by himself.

Karen Warner Schuler: But that wasn't how I was thinking about it.

Karen Warner Schuler: I was like, I've got to preserve our lifestyle.

Lisa Tschudi: It makes perfect sense.

Lisa Tschudi: If at that moment you aren't ready to give up the car, it's probably really good.

Lisa Tschudi: I always had the idea that he would recover.

Lisa Tschudi: Yeah, that makes perfect sense.

Karen Warner Schuler: Yeah.

Karen Warner Schuler: I always felt like I was chasing like, my doctors were, like, a week ahead of the event, and I'm still planning for yesterday.

Karen Warner Schuler: And then all of a sudden, usually, like you say, I would get up early in the morning to start my day.

Karen Warner Schuler: On Sunday morning, I would review a conversation with a doctor and go, there's no one saying it to my faith.

Karen Warner Schuler: They want me to know.

Karen Warner Schuler: And other carriers are, I'm sure, more astute than I was.

Lisa Tschudi: You're doing good if you were only a week.

Karen Warner Schuler: We had a friend visit, and he was my husband's best friend for years, his kids, and he was helping transfer, like, helping my husband stand and walk and use the bathroom.

Karen Warner Schuler: And he said to me, he took me out of earshot, and he said, what's your plan here?

Karen Warner Schuler: What are you going to do?

Karen Warner Schuler: And I said, what do you mean?

Karen Warner Schuler: And he said, well, you can't go up and down.

Karen Warner Schuler: This is dangerous.

Karen Warner Schuler: You can't go up and downstairs.

Karen Warner Schuler: You're too small to transfer this big man.

Karen Warner Schuler: And I was like, well, I'm doing okay.

Karen Warner Schuler: And of course, then I thought, maybe I should have healthcare people come to the house, which is a good thing to do, and look at what we have, what's our set up.

Karen Warner Schuler: And then that immediately was no more steps in the bed.

Karen Warner Schuler: And there are machines you can get, but you might not need them.

Karen Warner Schuler: You get that sort of.

Karen Warner Schuler: No one's saying it, but this will get worse.

Karen Warner Schuler: It was like an earthquake constantly.

Karen Warner Schuler: And my roadmap, by the way, spells the acronym care crisis as normal as possible resolution and evolution because I was going from crisis to normal as possible, me stable and then crisis into normal as possible and then evolution like moving into that sort of we're on a precipice something bad is happening, but it is happening really slowly.

Karen Warner Schuler: So I'm not seeing it as fast as other people are seeing it who have seen how this movie ends before and I had never done that.

Karen Warner Schuler: So that's the care and then evolution is really I'm out of a job as a caregiver.

Karen Warner Schuler: So now how do I learn the lessons of care giving and pick up and evolve my life forward?

Karen Warner Schuler: And I once said that and I gave a talk on this at a conference and someone said well, how long does evolution last?

Karen Warner Schuler: And I said I wish I knew because I hope we're always evolving but it's hard to know for everyone it's different.

Lisa Tschudi: And this has been really, really wonderful.

Lisa Tschudi: I appreciate it.

Karen Warner Schuler: Thank you.

Lisa Tschudi: What you've learned from your personal story and your really encouraging approach to that resiliency and growth.

Karen Warner Schuler: Thank you.

Karen Warner Schuler: Sometimes I feel like when I hear myself talk about resilience and whatever, I did live it and I also feel like caregivers will hear this and go, oh my gosh, this is too hard, like I can't do this.

Karen Warner Schuler: I did want to say that way.

Lisa Tschudi: For the people that are feeling that way.

Lisa Tschudi: There was a time for me, for sure, where some of this conversation, I would have heard it and I would have been rolling my eyes and I would have been like, OK, on top of all the stuff I'm juggling, now I'm supposed to find a positive way to frame it and I'm supposed to be growing and what?

Lisa Tschudi: And more pressure and more like feeling like there's more responsibility put on.

Lisa Tschudi: And that is not the point at all.

Karen Warner Schuler: Yeah, it's a little like yeah, it's like saving where you have to put in 80% of the effort in the beginning and you get 20% back and then it lifts and it takes 20% of the effort to have the benefit.

Karen Warner Schuler: But yeah, I mean, I talk about I think the hardest part of the things I'm talking about are holding yourself from going under the wheels of all the negative chatter that there is about caregiving stories.

Karen Warner Schuler: Because, as I said, there's a lot.

Karen Warner Schuler: And the paradox is that we actually inherit with our caregiving roles the opportunity to have closer relationships, experience pride or joy, or those positive moments.

Karen Warner Schuler: Even if they're pleading, it happens once a week or once a month.

Karen Warner Schuler: But to really feel gratitude because you can rewire your gratitude brain to see it rather than just like oh, it was a terrible day.

Karen Warner Schuler: What?

Karen Warner Schuler: But I just talked to a client, I said tell me something good.

Karen Warner Schuler: And he said nothing bad happened.

Karen Warner Schuler: That's good.

Lisa Tschudi: And I said, sometimes that's the good.

Karen Warner Schuler: You got, that's it OK.

Karen Warner Schuler: That was today.

Karen Warner Schuler: But I think that's the and also can look back.

Karen Warner Schuler: I come back on my caregiving journey and I encourage others to see the achievement of it, to see the amazement of you being able to do this.

Karen Warner Schuler: We're just like you said earlier, we're just human, we're just people.

Karen Warner Schuler: We don't have any special, nothing else.

Karen Warner Schuler: Caregivers have no more or no less than many, have less than other people.

Karen Warner Schuler: We just have to figure out our own path.

Karen Warner Schuler: And I think that's the individual aspect of it, the hope, the growth mindset of the public and private sector helping us will be that they'll help us find the path.

Karen Warner Schuler: We won't be rolling our own and doing it all by ourselves.

Karen Warner Schuler: Wouldn't it be nice in Oregon?

Lisa Tschudi: It was a really good partnership between the public formal services and the families.

Karen Warner Schuler: Yeah.

Lisa Tschudi: A really true relationship.

Karen Warner Schuler: To meet the need, not apply the rules to your situation, but to say, what's the situation and how can we support it?

Lisa Tschudi: Exactly.

Lisa Tschudi: Yeah.

Lisa Tschudi: And to truly be there for the needs.

Lisa Tschudi: Yeah.

Karen Warner Schuler: One other thing is I think you know this, but I have a website that has a resources page for Caregivers.

Lisa Tschudi: I was hoping you could share.

Lisa Tschudi: Where can my listeners find you?

Karen Warner Schuler: The suddencaregiver.com my email address contact info is there, but if you go the sudden caregiver.com slash resources, I keep a page fresh of, you know, at first it was just the organizations that were disease related, but now people reach out to me and if it seems reasonable, I post things that are of interest to caregivers.

Lisa Tschudi: I would encourage everyone to check it out and definitely take a look at your book.

Karen Warner Schuler: Thank you.

Karen Warner Schuler: And there are free downloadable resources on that site too, so that are part of the book that you can just get if you're on that site, so avail yourself.

Lisa Tschudi: Thank you for all of that.

Karen Warner Schuler: Thank you.

Lisa Tschudi: This is love doesn't pay the bills.

Lisa Tschudi: I'm Lisa Chewy.

Lisa Tschudi: You can find me on your favorite podcast app.