

Daughterhood the Podcast Episode 19: Susanne White and Being a Caregiver Warrior

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SPEAKERS

Rosanne, Susanne

RESOURCES MENTIONED

Brene Brown <https://brenebrown.com/>

Mel Robbins <https://melrobbins.com/about/>

Pema Chodron - <https://pemachodronfoundation.org/>

SUPPORT GROUPS

Daughterhood <https://www.daughterhood.org/>

Leeza's Care Connection <https://leezascareconnection.org/>

Alzheimer's Association <https://www.alz.org/>

Hilarity for Charity <https://wearehfc.org/>

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Rosanne 00:43

Hello, and welcome to Daughterhood The Podcast. I am your host Rosanne Corcoran, Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in daughter hood. Susanne White is the caregiver warrior. She believes caregivers are fearless, courageous and passionate about protecting those they care for Susanne's goal is to offer strategies based on the experience strength and hope she found while surviving her own caregiving journey. Susanne and I

talked about the many obstacles that are so common in caregiving such as shame, judgment, the importance of finding time for ourselves, and the three ways we can become more self confident caregivers. I hope you enjoy our conversation. I think part of the challenge in caregiving is you have to be so aware of what you're doing all the time, all the time, you have to be aware, you have to be aware of what your face looks like what your body posture looks like, your tone sounds like everything, you have to be alert the entire time. And that's part of the struggle. Yeah, because you're an exhaustion and the exhaustion because you you are fully on all the time. 24 seven, and I don't think people realize just what goes into it. Because why would they?

Susanne 02:31

Yeah, and I and I think that's the thing that I when all this is done, I hope I can finally figure out why it's so hard for us to understand what we're feeling and how there's stress we have, you know, like, you know, we ate a smacked in the head almost. So my whole thing around that is really self aware. Like every minute like, why am I sitting like that? Like, you know what I mean? They were like realize you sit like with your shoe?

Rosanne 02:58

I do. My shoulders are up to my ears more times than they're not

Susanne 03:02

unbelievable, right?

Rosanne 03:03

Yes. You don't even really yeah. And you're not breathing. You're not breathing, you're shallow breathing?

Susanne 03:09

No, you're not breathing at all. So I mean, and I agree with you completely. It's a 24 seven. And now I think on top of it because I'm I grew up on high alert. So I have that. So that compounds it. So I couldn't take on the high alert the night about watching every minute like to see if you know I was being too abrupt or whatever. Then I had the high alert just in general with the high alert about like my life. That's what I had to work on. I had to show my life out and show how I was dealing with my life so that I could be alert for my mom.

Rosanne 03:40

Right. Right. Right.

Susanne 03:41

Yeah, I never, you know, thought about until you just said that, you know?

Rosanne 03:44

Yeah, because it's it's constant. It's constant. And especially when you live with them. It's constant. And we're, Oh, my goodness. I mean, we're almost a year into this pandemic. Now. You know, for caregivers at home, we that means we have no help. We have no break. We have none of that for

caregivers that would visit their parents or spouses in facilities. They have no contact. What advice do you have for those of us that are caring going forward? In this? Not there's there's not it's not like, oh, in three weeks, it's going to be fine. There isn't an end date to this pandemic?

Susanne 04:20

Yeah, it's really hard to see the light the end of it. Although I think it's coming I I'm gonna I'm an optimist, and I do believe it's come. That's really kind of a loaded question. I think, because here's the first thing to do. And you just nailed it, is we're communicating about the awareness of it and talking about and sharing it because you know, don't you realize that when you like you, like you, like get stuff out of my head, beating your head alone is like being in a really bad neighborhood. Although, you know, it's like, it's a really bad roommate era. So I think the most important thing we can do is tell our stories and share and be open you know, asking for help or just just think so I think that's Really important, I think then my three selves self awareness, self love, and self care, all three of which sound like really simple and like, whoa, whoa, yes. You know, I can literally to this day have to go oh my God, what am I shoulders to crow actively say what what the heck is my body say? And then you know so you have to be self aware you gotta be self aware like what what you're feeling and then self love which is you know, but you know really appreciate yourself I can't imagine like I'm not actively caregiving right now I see it, I don't know how you guys are doing it. But this whole self love thing is just self appreciation, do not beat yourself up about anything. You know, that's second nature for a lot of us second guessing ourselves to you listening to what you're saying yourself up there, don't do it. And then, you know, the self care because you got to pay attention. And you got you got to take all these things and put it in this big soup and say, you know, I gotta care about me and what I'm thinking what I'm feeling and what I'm doing for myself. And it sounds like really like hippie stuff. But it really does make a difference. I think,

Rosanne 06:06

well, it does sound like that. And it sounds so simple. Like, okay, I'm going to do these three things, I'm going to feel better, okay. But it's true, because you can't care about yourself, if you don't love yourself. And if you're not aware of what you're doing anyway, right? Because then it does sound like Whoo, whatever happy day, see in the 60s. But it's important. And I think in the midst of all of this caring, you still have to care for yourself. And it's hard. And it's doubly hard. It's it's 1000 times harder, but you have to find the people that you can that can support that as well. Right? Yeah, that's the other part. That's important. You have to find those like minded because nobody if you don't have that support, you think that you just want you're just gonna sit, you're just gonna sit here? Oh, well, if you don't have the support of Yes, you are important. Yes. You need to take some time for yourself. Yes, you're doing a great job. it all falls you haven't

Susanne 07:01

having having a team and this support. I mean, my my, you know, I have a younger sister, who you know, will just go person to tears because I love her so much. And she was just and I wrote a blog once about how she was so much braver than me, because she let me handle everything I could have done that she was just go okay. Oh, yeah. Okay, that's cool. Yeah, all that. I mean, she was so supportive by just being a solid listener. And by just never questioning me, ever, even if I was even, it was the worst thing in the world. She was like, Okay, that sounds good. So having that team and having people

who support you is extraordinary important, even if it's one person, interview your dog, and people who don't get rid of them. That's another, I mean, get by. Next Bye, Felicia, get rid of them. Because God bless them. They have issues and whatever issues with enough because they're not showing up or because they can't handle it or whatever. Don't let you know what people think of you is none of your business. So I think that having a team and that support and checking, you know, podcasts like yours, and like listening to other people support the fact that you're not crazy that, yeah, you're under an extraordinary amount of stress. And you better chill out girl or boy, because you're going to hit the wall, and it's going to be bad, you know, and you're doing a great job, which is why you need to take care of yourself. I think all those conversations are really important.

Rosanne 08:25

Agreed.

Susanne 08:26

I love that.

Rosanne 08:26

It's so it's so much easier now to connect with people, which seems so counterintuitive, right? We can't be in the same room together. But I can talk to you like this. And yeah, and it's so important. And it's so easy to find a group to find a support group to find anything like that to find resources online where you can connect and and again, people may think it's silly, well, what's that going to do for me? It's going to validate you, it's going to make you feel like you're not alone, because you're not alone.

Susanne 08:53

I love that. It validates you and no matter what the circumstances caregivers need validation. Yes, I found that with everyone I've ever talked to and I don't know why that is care. That's why claws warriors, you know, caregiver warriors are like angels walking on earth. And they were warriors. And we were facing caregivers face atrocities, really, I mean, and challenges. So I mean, who would think a war or you would need to be validated, but we do because I just think you're hardwired? I think caregivers are hardwired to think of everyone else. And then they beat themselves up about it.

Rosanne 09:28

Well, yeah. And I know in the dementia world, you're fighting a battle that you're not going to win. So you're trying it's you know, you're trying to put that fire out, the fire just keeps going. And you know that you know it from the beginning, but it's a matter of trying to make it the best road that you can.

Susanne 09:43

Yeah. And how do you how do you? And it's interesting to cut back on you a little bit because I mean, I had a very complicated relationship with my mom and as she got dementia, I mean, it was the best thing that ever happened to us me caring for her. I mean, it was healing for both of us, I believe. I mean, I know what I walked away. With in my relationship with how is better, so I knew she had peace. But I mean, it was so complicated to sort of be self aware and to sort of walk through that fire of dementia, all the different levels of it of accepting what you know, when she would be like doing what she would be like clear for a minute, like she'd have a week, then she would look at me like on her

deathbed. She said some really extraordinary things to me, like, you know, they say sometimes they summon themselves, right before they leave. I mean, we had this amazing conversation. And I mean, like, what is so like, you're kind of always going back and forth with the with this dance with that disease? And I mean, what how do you have? How do you cope with that? Like, what, what helps you accept who she is on a constant basis as opposed? That's what I had trouble with? On the bad side, on the good side? Like, I kept holding on to who she used to be?

Rosanne 10:50

Right? That would be and that would make it harder? That makes it harder? Absolutely.

Susanne 10:54

It makes it harder, right? So I would hold on to like the old mom that I was afraid of, you know, and she would yell at me, why are you doing my chip off? Why are you writing in my checkbook? And then I would hold on to the good mom that I had that I was both sleeping away from me. So that was a battle. I mean, that was like a that was a head game for me all the time.

Rosanne 11:10

Oh, yeah.

Susanne 11:11

And I think, you know, the end, getting to that acceptance was really hard. I knew I had I think I would know, I had to do it here. But I had a really hard time doing it. Right. And I think that's a battle that we all have to sort of go through and accept and, and just sit with.

Rosanne 11:26

Well, yeah. And one of the issues with that is the more you struggle with it, you're losing time.

Susanne 11:32

Yes.

Rosanne 11:33

So as hard as it is. And as upsetting as it is, you need to sit with that. And come to terms with that. Because the more that you continue to try to be, oh, she's just blah, blah, blah, oh, it's just a little this or just a little that. You're, you're you're missing it, you're missing it. Because when those windows close, they close, and then there's no going back.

Susanne 11:54

And there's no going back. And I think that's really I think this is a big secret big lock you just unlocked because that's what helped me get over it. You know, I remember my favorite stories is that I was you know, my parents were both sleep, and they were napping in bed together. And I took care of both of them. And my dad had open heart surgery, and he has heart stuff. And he had open heart surgery at 87 because he wanted to help you take care of her. Wow. And then she mentioned Yeah, it was amazing. So I was in the bathroom cleaning the bathroom, which is our caregivers. No, you know, yeah, you know, the parents, oh my god. Anyway, so I finished, but I came and I, you know, and I looked at them,

they're both out on the bed, you know, my dad had his foot out of the bed. And I thought to myself, Oh my god, you know, they're safe, and they're calm, and I just changed the sheets. And, you know, they were warm. And there was heat, you know, and I thought to myself, Oh, my God, take a picture of this right now in your with your head in your mind, because you're not going to have this for much longer. And, and that that the acceptance slid in place, right? But it was just like, you know, grow you better. It's, this is what it is. And this is a really good moment and hold on to it. And just, you know, you're not going to have you're losing time, if you waste time on anything other than appreciation and gratitude for right now. And I think that did help me, you know, that that's sitting with it. And then thinking, you know, how long am I going to have that, you know, no matter how they're acting or what they're doing, right?

Rosanne 13:23

And it's, it's hard because you do want to remember those things. And listen, I write everything down. And I've done this for years. So that I know, I used to leave myself notes like, this is what happened. You're not crazy. And so that I knew you because you know your mind plays tricks on you. Susanne plays tricks on you. And you're like, Oh, well, what if I, you know, you shoulda coulda woulda and you can shoulda woulda coulda yourself into the ground. And this way I have it right there. This is what happened. So I completely agree with that. And then the offshoot of that is that pressure of why you better enjoy this. Gotta enjoy this. And it's like, wait a minute, wait a minute, wait a minute. Hold on everybody. Yeah,

Susanne 14:03

yeah, it's like, you know, on this, we're on this constant dance with ourselves, you know, it's like, and it's trying to find that balance, you know, I, I, you know, I'm really at the forces and I, you know, walking down a road with the horse, like, sometimes the horse goes this way in the back, now he's gonna have to pull it back. You know, it's sort of like this battle of balance is you're going to go over there and you're going to go over there. But you know, just when you can best you can just kind of get back in the middle of the road, because that's, that's where the the easiest steps will be. And I think that and that journaling things amazing. I think that you know, I wrote down, it was done on my Blackberry, you know, just because the show how long I was, yeah, you know what I mean? writing it down because you do your mind does play tricks and your heart plays, tricks and anything you can do to validate and feel Give yourself a hug. And just give yourself a break. And it's just so silly, simple, but just to ease up on yourself, because all you really do show up.

Rosanne 15:11

Yeah. And it's and I think part of it adds to why caregivers don't want to say anything. Because of that. Well, you know, they took care of you when you were little or while you're gonna miss this when they're gone. And it's like, Yeah, I am. But that doesn't negate the fact that I'm drowning. Now, it doesn't negate the fact that I can't even see straight. And when you say things like that, around people that don't understand it, it only comes back to you, which then makes you go see, I'm just an awful person. And I you know, I think all these awful things, and I shouldn't when you Yeah, you should, because it's true. None of this is easy.

Susanne 15:49

None of it is easy. And we don't we don't give any credit. I think that's really, and it's a really important point. I mean, that's why it's like there's this weird connect between asking for help and thinking you're a bad caregiver. Absolutely. And that's where the work is. That's where the work was, for me. A lot of it is that just the self awareness that I am not giving myself a break. And just because I need help, doesn't mean I'm wrong, or I'm not perfect that perfectionism or ideas,

Rosanne 16:21

or I don't love my loved one enough.

Susanne 16:23

Yes. failing them. No, you're gonna fail them if you get sick, and you can't take care of them. Which stress kills, as we all know. So you know, but yeah, that's that I'm failing them. I'm not good enough. You know, a lot of this stuff. Look, a lot of this stuff we bring those bags are coming on the trip with us from the beginning from In other words, a lot of that stuff. That's why this the whole thing with my mom especially was so healing for me. Because that I mean, I got I'm clean and sober. 35 years, and I've done a whole bunch of recovery work and all that stuff. You know what? Yeah, good for you. Thanks. Thank you very much. But bottom line of it is, is that I start taking care of my mom. I upped my game, you know what I mean?

Rosanne 17:10

Because because then you're 10

Susanne 17:11

Yeah, yeah, cuz, yeah, it's six for me. But yeah, then you're six.

Rosanne 17:14

Yeah. Yeah.

Susanne 17:15

So you bring a lot of this stuff. And that's where the self awareness comes in. And that's where the work can come in. Because you got to say to yourself, wait a minute, you know, why do I feel like I'm failing? Why am I second guessing? What am I saying to myself? What are these patterns of putting myself down and, and not feeling like I'm worthy, or whatever it is, you know, and it takes a lot of work, or

Rosanne 17:38

How do you do it? How do you become more self aware? Especially when you're caregiving? And you know, you're lucky if you're aware you have shoes on?

Susanne 17:47

Yeah, yeah, really? Exactly.

Rosanne 17:48

Is it Monday? I don't know.

Susanne 17:49

Yeah, exactly. Who knows the day? That's another loaded question. But I think we have to remember that just showing up as enough period that we have where we're in service, that it may look like people around us enroll caregiving, and we have friends or whatever. But you know what, there's a lot of people that can't show up. They can't deal with it. And that alone, is that alone is the first step. And how do you become aware? I had a really, it hit me that my mom wasn't going to change. She can't change. She's dementia. Right. Me shouldn't change 50 years ago. Not gonna change. I mean, she did to change with dementia. The good things adventure for me was my mom used to get angry and like, hold a grudge for a week. So it to mention, it was over 10 minutes. You heard my prayers, but I didn't mean it. That one. Yeah. So I think that, you know, we have to realize that, you know, that she got she wasn't going to change I had to write. So if I was going to continue to care for my parents, and feel so crappy and depressed. And I mean, literally, depressed and frightened I mean, you know, let's talk about the fear two o'clock in the morning. Okay, in the depression, were you. Here's the thing. It's amazing. Do you ever see a caregiver like waving a flag? Never stop even hearing her caregiver like halfway? Oh, you know what, I don't want to do this anymore. I'm out of here. No, none of us. We're in it till the end. So the fact that we get out of our depression, the fact that we go through it, even though we're anxious or shaking in the middle of the night, two o'clock in the morning, or when we wake up, do we mean it's like, the resilience and the power that we have inside of us to show up for this is, you know, you got to really plug into that. And you got to realize that they're not going to change. If, if we want to change this and feel better. We have to look, it's an inside job. And sometimes, you know, caregivers get paid. And I can tell the difference between just total burnout and exhaustion. And this thing where, you know, like none of my families Helping me, it seems like you're never. And always and no one. I'm like, you know, very gently, like, it's an inside job. And there are people there and there are resources, and you are doing a good job. And you can look at yourself in the mirror and say, I love you. I mean, I think the lifeline is, you know, you have to try to realize that you have to make these changes, to help yourself and be proactive about it. Absolutely. Right. And I mean, it doesn't take away the fear or the depression or the grief. I mean, there's all this pre grief and there's ambiguous grief. You know,

Rosanne 20:41

It's every kind of grief you could fit. Yes.

Susanne 20:45

But let's make sure we get to that doctor's appointment on time. And, you know, you know, and we do it virtually, and everybody's okay. And, you know, oh, my God, you know, I ran out of, yep.

Rosanne 20:55

Well, and and also, I think the important thing is, if you don't have that in your life, right now, if you don't have that structure, and you can get hung up on well, but I have this, you know, my friend or my sister or my cousin or my whoever, whatever, whoever's in your life. Now, if they're not giving you what you need, then you need to go elsewhere. A stop trying to get blood from a stone, yes, just go elsewhere. There are there are organizations, there are resources, there are groups that you can join, where you can meet your people. And that's okay. It doesn't, it doesn't make you a bad person. It doesn't. It's helping yourself. And you have to help yourself.

Susanne 21:31

Yeah. Yeah. And I and I love that, that you put that out there. And that you encourage that, because I think a lot of us hesitate. And we get very wrapped up in setting boundaries. Yeah. And I think, and I and I, honestly, from my heart believe everyone is trying to do the best they can. I really mean that.

Rosanne 21:53

No, I agree with you.

Susanne 21:54

You know but, you know, what, if you're right, like, you know, don't go to the hardware store for oranges, as we said, You know, I mean, like, you know, if they keep letting you down, or you keep there are, there's something else out there. And if you believe in any kind of power greater than yourself, the universe will help you, you know, I mean, dump, dump the Debbie Downers, and I can help you. Charlie's.

Rosanne 22:20

Right, right. And it's okay. It's okay. And, you know, I know people. I mean, I was like this, I'm not going to a support group. What the heck yeah, I don't know doing that. Even if you just go and don't speak doesn't matter, listening and hearing the same things that you're thinking and the same things that you're feeling? Is validation enough? And if it if it allows you to show up the next time, and then maybe you'll say something, and then have somebody go, yeah, it's a gift. It's all a gift. But But it's okay to look outward.

Susanne 22:52

Absolutely. Listen, I you know, look, I can't even begin to tell you what a control freak I am. Once once I was, and I got it that I better reach out. And I reached out, somebody helped me that was like, Oh, this works. I don't want anybody to think that I did struggle with that. I know, I never want help. I still don't want help fail. It's like, I have to work on it. It's like, you know, it's really hard for me, because I feel like I'm less than whatever. But you know, you're absolutely right. Just go and look, you can lurk on a zoom meeting or, or look, you know, or listen to a podcast, just like there is yes. And you can be poolside. You don't have to jump in. Right, eventually. You will but you know what I mean? It's like, I agree with you completely. It does not make us bad people, bad caregivers. If we look for help. I know there's a stigma to that. But help. Is there. Help? Is there.

Rosanne 23:46

Yes. Yes. It's everywhere. And it's online. It's in person. I mean, now, you know, my daughter had group we added a meeting and we're on zoom. Okay. Most of most of the daughter had groups are on zoom. It's out there. Yeah. But you have to allow yourself to open that door. Right. And it's hard because there's, there's shame involved. There's, there's what what are people gonna think of me? Whatever. Yeah, and that just goes away. It just goes away.

Susanne 24:13

Let's talk about shame for a minute.

Rosanne 24:14

Sure.

Susanne 24:15

Because I think that's, I think that's brilliant. Let's talk about shame. Let's talk about caregivers who feel shame STOP IT! Stop! And, you know, and I'll put my hand up. I mean, shame is one of my big things that I work on. How crazy is it that we feel shame? When we reach out like, what is that? So that's where the self awareness and that's see and it's so good to be talking about these things? Because some if one person hears us talk about shame, today, one, and they go, Oh my God, those two, I mean, they have podcasts and and websites and they're saying that they felt shame. I think the camaraderie of that yes, if one person hears it, because we all feel it, and I don't know what I still, I'm still learning about what that's about. But man, do I feel it? And the bottom line of it is, is I'm mad at shame because it stops me from feeling whole. Or getting help.

Rosanne 25:17

Wow, yes. Wow, you're right.

Susanne 25:20

It's my enemy. It's my frenemy. Right?

Rosanne 25:26

You're right.

Susanne 25:26

And I don't want to judge myself about it, because it's just the human condition that most of us for some reason in our lives, that it's just an outside thing that becomes internalized. So we, we've got to face it, we've got to shine the light on it and say, Hey, you know, this is making me feel shame that I have to reach out like, and I just want everybody to know, I feel it.

Rosanne 25:53

Yeah, I think everybody feels it. And it's it's judgment, and it's preconceived notions. If I do this, then they will look at me like, and it doesn't matter who they is. And it doesn't matter what you're thinking, it's in your it's an inside job, it's in your mind that you're going to be judged or looked at, in a bad way, in a bad light.

Susanne 26:15

Yeah, that's, that's why I just love the saying, what someone's thinking of me is none of mine is none of my business.

Rosanne 26:22

Yes.

Susanne 26:23

Because you know, what the they is in here that once again, inside of your inside your head, you know, there's a day in there, there's a judge and jury in there, you know, you got it, you got it, you got to get rid of the judge. And it's, I'm with you completely. And I just think shame needs to be talked about more and more and more, you know, Brene Brown does all that kind of work. But it's got to be talked about, and everybody feels it and it stops us and and we just can't do that. Because it really doesn't matter what anyone else thinks, you know, what took care of my mom when it was not pandemic so I, you know, we would go out a lot, you know, we would go my dad would love to go out to dinner. So we would go out, you know, local thing. And you know, you know, my mom, my mom got very verbal, she's always verbal, but it she really I don't like this restaurant. Um, you know, it was just, I worried a little bit in the beginning about oh, my God, Mom, you know, and I thought, you know what, screw that. It doesn't matter what anybody else thinks not about my mom, not about me not about anything. It matters what I think it matters how the good part if how I feel about me, and how I love my family, and the rest of it is nothing.

Rosanne 27:30

You're absolutely right. But that's what factors in it's the stigma. It's the stigma of the change in the person. It's the stigma in how they're going to be perceived. Again, it's all out there. It's all of that thinking instead of Listen, this is how it is. And we can't, we can't expect things to change if we continue to do that same thing. So everybody likes to put put things in little boxes. Do you know yeah, so that well, then I know what that is. Okay. Well, if you if you try to tell them that it's something different. It goes against that.

Susanne 28:06

Yeah.

Rosanne 28:06

And they don't want to hear it. They don't hear it anyway. No, yeah. So as long as and especially when it comes to dementia, all of the dementia is Alzheimer's and everything. If as long as it stays in that, oh, you forgot something. You must have dementia, you must have Alzheimer's, as long as it stays in that category. Oh, it's just a memory disease and not the total and complete annihilation of your loved one.

Susanne 28:28

Yeah, yeah.

Rosanne 28:30

Things aren't going to change.

Susanne 28:31

Yeah.

Rosanne 28:32

Do you know what I mean?

Susanne 28:33

I do. I do know what you mean.

Rosanne 28:35

Because it's like, well, yeah. So you forget things. Oh, well,

Susanne 28:37

yeah.

Rosanne 28:38

No, that's not it.

Susanne 28:39

Yeah. Yeah. Yeah. Yeah. And it's and I think it is, it's different for everyone. You know, and I love seeing on social media as you are a lot. And you know, I love people with dementia and Alzheimer's, who post and who have Instagram accounts. Yes, you know, because it humanizes it, I think, I think we all do this. And like, just in general, I think we generalize so much stuff. And I think everybody's in a special individual. And I think the disease does a dance with everybody differently. But I love I love seeing the fight and people talking about it and sharing about it and reminding me that I have no idea what that person's going through. I mean, you know, I came up with something to help me care for my mom. And the main thing was, you know, I think she was always anxious or her life anyway, which is why she was so who she was. So I'm sure she's even more anxious. So my whole thing my mom was okay, just assume she's frightened about something or unsure, and just be soft and gentle as possible. But I think it's really important for people to understand that there's individuals in there.

Rosanne 29:43

Absolutely. And you have to you have to meet them where they are.

Susanne 29:46

You have to meet them.

Rosanne 29:47

You can't just expect them to continue to be whoever they were 10 years ago,

Susanne 29:52

Right? And

Rosanne 29:53

You just can't you're not who you were 10 years ago.

Susanne 29:55

Of course not ohh oh my God. So then there's always a combination of keeping suit like suit Have rituals going. Because that makes them more comfortable, you know, like you sort of do the same things over and over again. And then but you have to be open to, you know, changing everything. You know what I mean?

Rosanne 30:13

Yes,

Susanne 30:13

That's another balance. That's another type of rope. You have to walk, you know, it's like, Listen, it was something else you were saying inspired me in that, you know, look, this is what this is. It's so great to talk about it, but we're entitled to peace, and serenity.

Rosanne 30:27

Yeah, yeah.

Susanne 30:31

We're entitled to it. We're entitled to being serene and peaceful, and even joyful at times around this. It's really hard to get there. But it starts with not feeling that I'm entitled, I'm entitled to have peace during this journey. I'm a child that entitled to it. I'm entitled to demand that of my life, and not so much the ones I care with and the people around me, right. I'm entitled to it. And if that's like, you know, if that's like, I'm shopping, you know, like ice cream, and, you know, two o'clock in the morning, get in the tub babe as long as it's Breyers. So, you know, it's like, I think, I think that I think that's the mission, you and I are on more than anything, right? You know, what I mean? is to try to get caregivers to understand not only is it okay, but you're entitled to draw to just please, if it's for a minute, even it's your five minutes you go and sit someplace and listen to the choir the birds or whatever, it whatever floats your boat, you're entitled to that. And I think that's the real message. We got to get out for them. You know,

Rosanne 31:39

I agree,

Susanne 31:40

whatever you have to do. You're entitled,

Rosanne 31:42

I always say you matter too. Yes, the person that you're caring for matters, but so do you,

Susanne 31:46

You matter too.

Rosanne 31:48

And it doesn't have to be a grand. I'm going to book a cruise for a week. It doesn't have to be a grand thing. It can be Breyers ice cream at two in the morning, it can be standing out in your driveway. And looking at the stars or screaming at the moon. Yes. Listen, I've done that before.

Susanne 32:05

Yeah, yeah, absolutely, absolutely. At that, you know, the hand fist to the sky is okay, too. That's peace. You know, your peace comes in a lot of serenity comes in a lot of different ways. You know, I used to screen out a friend who took care of you, she would get in the car, you know, driving long distance and scream, scream at the top of her lungs for like, you know, mile in which I started doing the New Jersey Turnpike, which is you know, and I mean, that, yeah, I yeah, I think that, that were, and I like that you matter to I'm going to use that in a tweet, I'm going to say, you know, that's going to be a weapon of my day. I'm going to, I'm going to credit you and say you matter too

Rosanne 32:46

You do

Susanne 32:46

You matter too your allowed, you know,

Rosanne 32:49

It's just so hard. Because when you're in the midst of this, and you're you're underneath it, because that's, you know, you're crumbling under the weight of carrying it is what you're doing. It's hard to think well, what what's going to help me? I don't I don't know what's gonna help me. I don't know. But if you can just do those little it's, it's almost like little bits of oxygen until you get to the where you need to go

Susanne 33:12

Step at a time day at a time. And you know, look up, you know, and there are times even now my life but you know, there were times where I would have to do 15 things until I got till the 16 thing.

Rosanne 33:22

Right, worked made me feel better

Susanne 33:24

Made me feel bad made me feel this. You know, I'm a I'm a I'm a big fan of Mel Robbins. I don't know if you know her?

Rosanne 33:30

I do.

Susanne 33:31

She recently came up with something. That was wonderful. Because she says she wakes up in the morning and feels like she's done something wrong.

Rosanne 33:40

Oh, well, yeah.

Susanne 33:41

Okay.

Rosanne 33:41

Yeah, it's a bad day when you're starting out like that.

Susanne 33:45

So she has this sweet little thing. She goes and she basically says to him, you know, I'm sorry for the Mel Robbins fans out there. I'm paraphrasing. But she says, you know, she says a couple things to herself. And the first thing is, you're safe. You're okay. You're a good person. And that's now Yeah, it's that's like the, that's how you wake up. So I mean, I think it's like all those little tricks, things that you know, quote, like my tool bag, it's like, sometimes I have to like throw, like all these things out of my tool bag, until I get to a place where I say, Oh, you know what, I'm safe. And I'm a good person. And it is it says baby little steps and whatever floats your boat. I don't care what it is. And it may not be the first thing you grab for because like you said, you're under the weight of this elephant that standing on your chest. You know, you might have to try a couple things before you feel better. You may not feel better at all that day.

Rosanne 34:36

Right? Right. And that's okay. It's not a failure.

Susanne 34:39

Yeah,

Rosanne 34:39

it's just a day.

Susanne 34:40

Right.

Rosanne 34:40

It's just that day.

Susanne 34:41

Right. Yeah.

Rosanne 34:42

And, and, you know, it's great. You say first thing in the morning and there are times I'm waking up to the sensor mat is going off like that's how I wake up so, for me, for other caregivers that might be running around with, you know, both parents or children or spouse, whatever. It could be at any point in the day that you could say that. If you could go back to that, right? You've got to go to the bathroom at some point. So even if you're in the bathroom, yes, and you're saying that,

Susanne 35:09

Yes.

Rosanne 35:10

Just to check in with yourself,

Susanne 35:12

Just to check in with yourself, and it's amazing. And you can restart your day all day long. And if you do that little check in I love that you got to go the bathroom. I mean, and we don't as often as we should know, you know

Rosanne 35:27

We're not drinking enough. We're not exercising. We're not Yeah.

Susanne 35:29

We're not doing any of that so why should we go to bathroom? So yeah, but just to take that five minutes to close the door.

Rosanne 35:36

Yep. And just just say it to yourself,

Susanne 35:38

And then just have that little affirmation. You know, I literally feel my body, like, relax the first time I did. I was like, What was that?

Rosanne 35:45

Right?

Susanne 35:46

You know, because

Rosanne 35:47

And to exhale.

Susanne 35:48

Yeah. You know, it could it's just that little thing. And that Yeah, now I'm saying it all day long. You know, I had an amazing friend of my parents had helped me. His name is buddy. I mean, his nickname is Buddy, because he was such a buddy. Anyway, he was amazing. He was just a very special guy, you know, and had a great sense of humor. But he would say to me things like, Susanne look. He said, Go outside. He said, and I said, you know, I'm afraid to leave. And he goes, look, he said, you could go from the living room to the kitchen, to get them a glass of water. And the minute you left the room, something could happen. You can't control it all. It you know, if God, you know, is very religious, he said of God wants to take them in that minute, between you gone from the living room to the bathroom, because you need to get something for yourself or go outside for five minutes. Doesn't matter. It's going to happen. You can't stop life or time or destiny or you know what I mean? So do it. And I was having to think, okay, I can leave them for five minutes. Because, you know, what I mean,

Rosanne 36:50

Yes, I do know what you mean.

Susanne 36:52

Because here's the other thing, nothing you worry about happens. No, none of it other crap happens. But none of this stuff you worry about happens none of it.

Rosanne 36:59

And even if it did, okay,

Susanne 37:02

You'll fix it or you'll deal with it.

Rosanne 37:04

You'll figure out exactly, exactly. But it's it's that responsibility. Susanne, it's that responsibility, you're responsible. And that doesn't just end that you can just turn that off. And that's part of what keeps everybody in that state. It's it's that constant state of on and trying to look at things that you might consider woowoo like, Mel Robbins, or listen, you listen to Brene Brown, and you're like, Oh, my God, I can do anything. Right. Yeah, I can conquer the world. Yeah, there are there are those people that have that. And they have the research to back it up. Yeah. It's not like they're just Yes. Out of the ear.

Susanne 37:42

Yes. Yes. Have Yes. Research? Yes. Both of them. Both of them are, are are are brilliant. educated. Yeah, they're the science tells us that self care works, period, that it changes your physiology. Yes. Period. And and caregivers don't understand that or think it's woowoo or whatever, telling you being a piece, taking time for yourself, all these things that we're talking about working on shame, all of this stuff, changes how we function and feel physically, emotionally and spiritually. That's a great point that you're making this stuff that we're talking about. And this is not just a bunch of baloney, this is this is this stuff changes your life.

Rosanne 38:28

It does. And, and we need something, we need something to hang on to, and we need something to focus on for us. Because the facts that come into play when you are a caregiver, and what that means to your life and your body. And your own mind. You know, they are facts that you can't you can't look away from. We're doing damage to our ourselves by carrying we just are. So we have to try to find a way to minimize that. Or to at least make it manageable.

39:02

Yeah, absolutely. I think I mean, my adrenals are still not right.

Rosanne 39:06

I'm sure they're not, I'm sure they're not.

Susanne 39:09

I mean, you know what I mean? I mean,

Rosanne 39:10

How long has it been? How long's it been?

Susanne 39:11

10 years?

Rosanne 39:12

Yeah, I'm sure. I'm sure they're not

Susanne 39:14

I'm telling you my body, there was permanent damage to my adrenals telling you. And that's okay. I mean, I you know, it's it's something

Rosanne 39:24

It's part of, it's part of it,

Susanne 39:26

It's serious, it's serious, it's serious. If you don't take care of yourself, you're going to hit you know, you got to open the new toilet, opening the door to getting help, or finding the tools. You know, if you're, you'll slam into that door, so you should open it. Because I don't know. I mean, you know, when you face that really bad bout of burnout, where you're throwing up and you're shaking and you can't eat, you can't sleep and for days on end, and you're just depleted and you got somebody staring at you.

Rosanne 39:56

You still have to do your job and and now with the pandemic You know what? You can't You can't have people in, right? So what the heck, what do you do? And who knows, maybe this will start people on that path of, Okay, well, I've got to figure something out. I mean, the whole world, the whole world is experiencing a bit of what caregivers deal with every day.

Susanne 40:17

Yeah, exactly.

Rosanne 40:18

Being home, you know, being home, your being your home, hey, you're home again. Your home. Right?

Susanne 40:25

Yeah. Yeah, it's amazing. Because, you know, normies, you know, the great percentage of the normies. Can't take it. No, you know, that's why it's why the disease keeps you know, that's why it's taken us so much longer. Like, I don't, I can't, I've done it. I've done it for months now. Yeah. How about that? How about years?

Rosanne 40:42

I know. Hopefully, if something good can come out of this. Maybe that's it?

Susanne 40:47

Yeah, I think there's empathy. I think that I think I think hopefully, we'll get back to empathy. I mean, I think empathy is a really important tool in men in many, many different ways. And I think that I think people are, I think, if nothing else, this is how people appreciate health, and being afraid of not being healthy and being around people who aren't healthy. I mean, I think our human, you know, our human nature to think we're immortal. And, you know, nothing can happen to you know, whatever. I think this is scared the crap out of a lot of all of us internationally. And I think people, I think people are looking at life a little differently.

Rosanne 41:21

Well, now, let me ask you,

Susanne 41:23

Yes maam.

Rosanne 41:24

Three powerful ways to become a more self confident caregiver, you have three ways.

Susanne 41:30

Yes. Remind me what those three ways are?

Rosanne 41:32

I certainly will. trusting myself. Negative thoughts are usually lies, questioning my negative thinking, saying is believing and visualizing a great outcome? How do we get to that point of being a more self confident carry on for the caregiver?

Susanne 41:50

Well. Here's the first. The first thing is the foundation to build a house for me is that I don't have to do it all at once. Do you know what I mean? Yes, I don't have to do all of it. And I don't have to do it perfectly. So. So the first thing you have to do is I have to go all in all at once and be perfect all the time. So I have to deal with my perfectionism. So that's one thing where I have to say, you know, what, if anything can help me be more confident or, or anything, I have all of these tips that I have to come up with, for the tools that I have, I have to like, dip my toe into the water, and know that I can do a cannonball down the road, you know, and okay. So, for me, the self awareness, like my mom couldn't change, I had to change, you know, thank God, good. God, that lightbulb went off. So then it was like, right, and then I started thinking about, then I sort of, like, started researching it and like thinking, Well, what do I do? And like, What am I thinking, you know, like, I think the self awareness, watching myself talk was a really important one for me, because my confidence would just go down the drain, because I would be telling myself, I wasn't doing it fast enough, good enough, you know. So, awareness, I think, you know, awareness is really important. And I think self awareness is, is the most important, then I think there's acceptance, like you sort of have, you'll come up with stuff, like, you'll accept that, how put myself down, or I don't feel good about this, or I get scared, you know, so I think sort of accepting the

situation and sort of, that's who I am and how I gotta help myself and hug myself, you know, and then I think there's action so I think the whole process for me starts very small. Yeah, it's to say baby steps. You know, it's like small steps, you know, and I think any change we make has to come really slowly and and then feel good about that.

Rosanne 43:40

Right, celebrate it,

Susanne 43:41

Celebrate small victories all along the way.

Rosanne 43:44

Well, and that goes back to the well. I haven't eaten carbs today. I don't know why I didn't lose 10 pounds. Like it takes a while.

Susanne 43:51

Oh my god, that's so perfect. That's a perfect analogy. Yeah, I see. And why do we do that? Because life doesn't work like that. You know, we don't we don't do it to the people we love We don't expect them to be so why don't we do it to ourselves so yeah, I think that that going to be more self confident or or self care all these things and big awareness The first thing and then baby baby steps together.

Rosanne 44:14

And that your your questioning your negative thinking I think is huge. Because it's almost like at the stop yourself and say, Would you say this to your friend? Would you say this to your best was because if you wouldn't say it to them, then you're not gonna say it to yourself.

Susanne 44:29

It's that it's a battle. Let me tell you something, and we don't even hear it sometimes. I mean, my tape is playing in the background constantly. So it's you know, you got to turn the tape over slowing it down or trying to change it, you know, and giving yourself other things to think because you know, it's constant. And again, you got to be really patient because you can be great for two minutes and then you know, then you're often running down on monkey minds. I love it. The Buddhists call it monkey mind. It is like

Rosanne 44:54

It is and like it's like a Pema Chondran who says the the attachment let go of the hook. I'm paraphrasing, of course. But yes. And when you think of it that way, it's easy. Because you think, Well, I'm not going to let it hook me. Yeah, I'm going to, I'm just going to drop it and drop it.

Susanne 45:11

Yeah. Right. Yeah. It's wonderful. Absolutely. And see, and I think we haven't really spoken about this, because it's probably not a podcast, but just the spirituality of it. In other words, whatever you believe in what, you know, whatever higher power you believe in, or, or just just, you know, there is something out there guys, period. I don't, it can be anything you want it to be. Anybody can believe anything they want. And I think it's a very individual thing. But I mean, there is a power greater than us. And I think,

for me, personally, that matters. In other words, I believe I believe in a universe out there, there's something out there that's bigger than me, and and then I can kind of believe is going to help me whether it's angels, were my dad talking to me or whatever, whatever you want it to be, whatever, whatever it is, if you really open your mind to it, you know, there's something out there like coincidence, or why did that whatever. So I think that's a big aspect for all of us. So whether you meditate or you jog or you are creative, or whatever it is, if you tap into something that's creative, or a little bigger than yourself, very gently, you know, you don't have to be you know, just ask, you know, a friend of mine once said that, the way he prays gets very difficult when he gets so crazy and nervous. So his prayer is help and he said You know what, I'm sorry, but I feel better if I do that.

Rosanne 46:37

Well, and that's, and that's the thing, whatever works for you. Now, if meditation is your thing, great. If you try to meditate, and you're like, Oh, no, I can't do this. Fine, then try something else. You know, if it's music, if making if listening to music makes you happy, listen to music, like, whatever you want to color color, you want to do cross stitch happy day, whatever, whatever it is, that makes you feel like you're you're getting just something just something because it can be that little

Susanne 47:03

Yeah, yeah. And, and that's your inner self. And that that's there to help you know, it's it's it's so However, you can sort it. Get into that and and it'll help with the self talk. Because your inner self doesn't want to hear that baloney.

Rosanne 47:16

No, it's gonna fight you. It's gonna fight you don't I don't need I don't need to talk about it. I don't need to read about it. I don't want to think about it. Right. Right. And it keeps you in the same spot. Yeah. And then when you visualize how do you visualize it, do you? You know, and again, we're going to isn't, you know, I'm on a beach, the waves are cascading, like, what are you visualizing?

Susanne 47:38

Well, you know, I, it's hard for me, because I'm, you know, I have a hard time finding a happy place. You know, I'm tired. I'm a Type A anxious person

Rosanne 47:47

Doing doing doing yup I gotcha.

47:48

I know. And I have anxiety, you know, you know, so I have a hard time finding a happy place to go to so I work at finding Happy Places. You know, I was on a horse once in, in the snow. galloping, you know, it's Wow, that was amazing. You know, for me, personally, that was amazing. Singing, you know, needs to sing. You know what I mean? So it helps me to sing, you know, which I haven't done for a really long time. But even thinking about singing helps me. So I mean, I, you know, it's whatever floats your boat, but I think that it works. And I don't know why it works. But if I can get to that in my head, as opposed to going through the 47 things I just screwed up, and what can I change? And why can't I get better? And I'm old now you would think by now? I would, you know, I mean, you know,

Rosanne 48:32

Right? I'm never gonna do this. I'm never the Nevers come out.

Susanne 48:35

Yeah, then that was never always. Yeah, it's just you know, so I mean, I think any affirmation, you know, I'm safe. You know, I'm a good person, anything that works. And I think we just have to keep at it, you know, you got to be consistent. And just be patient with yourself and your mind and, and yourself and your mind, be patient. We got to be kind to ourselves, you know, we deserve to have serenity and peace, and we have to be kind to ourselves around it. You're not going to find it easily, but we deserve it. So because while we're looking, I think kindness is a real, real important thing to remember is we do it we do it for those we love, we pride, you know, 99.9% of us have a very easy time being kind to those we care about. So why can't we be kind to ourselves?

Rosanne 49:21

Thank you to Susanne White for being my guest. You can find more tips and strategies on Susanne's website caregiverwarrior.com I hope you enjoyed our podcast today, head over to Daughterhood.org and click on the podcast section for show notes including the full transcript and links to any resources and information from today's episode. You can also find us on the Whole Care Network as well as anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood The Podcast Feel free to leave me a message and let me know what issues you may be facing and would like to hear more about or even if you just want to say hi, I'd love to hear from you. Also A very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song Mamas Eyes, from her album Lessons In Love that you can find on the iTunes Store. I hope you found what you were looking for today, information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you join me next time in Daughterhood.