Daughterhood the Podcast
Episode #81
Finding Your Zen in Caregiving
with Roy Remer

- 57:42

Rosanne Corcoran 00:00
Hello and welcome to Daughterhood, the Podcast. I'm your host. Rosanne Corcoran, Daughterhood circle leader and former primary caregiver to my mom, who lived with vascular dementia for 12 years. Through that journey, I experienced every phase of caregiving firsthand, the heartbreak, the joy and the aftermath. That journey showed me how vital support and connection truly are, and that's why this podcast exists. No matter where you are in your caregiving journey. I'm so glad you found us, because caregiving is far too much to do alone. So welcome to Daughterhood, the Podcast part of the Daughterhood community, where we empower caregivers to navigate both the practical and emotional sides of caregiving together. Here, your efforts aren't just good enough, they're heroic, and here you're never alone. Join me in daughterhood Before we dive in. I just want to share a quick note. This podcast is part of the Whole Care Network. The conversations you'll hear are here to inform and inspire, but they're not a substitute for professional advice. The views you'll hear are those of the host and guests, and may not always reflect those of the Whole Care Network. If you have medical questions, please talk with your doctor and for legal advice, check in with your attorney. I'm so glad you're here. Stress, anxiety and overwhelm are often just accepted as being part of caregiving. But my guest today wants to change that. Roy Remer is the author of Zen Caregiving, How to Care for Yourself While Caring for Others, an educator and end of life caregiver since 1997 He is the executive director of Zen Caregiving Project in San Francisco and lead creator of the mindful caregiving education curriculum. In this episode, we dive into how mindfulness can transform caregiving from being present and building emotional resilience, to practicing self compassion, processing grief, avoiding burnout and so much more. I hope you enjoy our conversation. How can caregivers who barely have enough time for themselves practice mindfulness?

Roy Remer 02:17

I love this question. You know, when I think about the teachings that are included in the book. I think of them as moment to moment self care. So self care is this big word, right? And sometimes people throw it around like it's nothing. And when you're a burdened or busy caregiver, it can almost feel insulting for someone to say, Oh, just focus on better self care, you know, or make more time for self care. But when we're talking about mindfulness, it's really about using the activities that we already engage in in our daily life as opportunities to cultivate mindful awareness. So just to give an example, if a caregiver needs to get to the laundry right, can they use that experience of folding the towels, folding the sheets, folding the clothing, and, you know, really sense into the texture of the fabrics that they're folding, and just give their full attention to that process. What does it feel like in the body to, you know, stretch the arms with that towel and bring it together and fold it and feel it, and then what's the weight of the folded towel? So this is not so different, really, from what we're doing in meditation. You know, this is really about present moment awareness. So if we're assisting someone with feeding, you know, just noticing when the mind becomes distracted by rumination or anticipation of the future and just coming back to what's right here right now. And as we do this, we are really creating new neural pathways in the brain. We're really training ourselves to be able to come back to what's true in this present moment. And this has a lot of benefits that are really quite tangible. I think for caregivers in their role.

Rosanne Corcoran 04:26
I fully agree. And you know, when it comes to rumination, it's almost like it feels productive in some way, because it feels like you're trying to solve something.

Roy Remer 04:37
Yeah,

Rosanne Corcoran 04:38
But how do you how can you help somebody see that it's really it's worrying and it's not actually helping, it's just kind of keeping you in that loop?

Roy Remer 04:47
Yeah, well, your use of the word loop, I think, is really important. So it makes a lot of sense to think about what has already happened in our lives. And sometimes we ruminate. On, you know, mistakes that we've made, perhaps, or something that someone said to us, and the way we responded, or the way we could have responded, and that's healthy. I think that's how we learned from the past experiences we've had. But I think it's really about reclaiming some agency, being able to make a choice in where we direct our thoughts. So when we are able to step back and observe our own thinking mind, we see that we've actually been caught in a loop. I mean this. This happens to everyone. It happens to me. If I have a difficult conversation with my wife, you know, I might find myself the day after the week after still thinking about that

conversation, and that's okay, but when those ruminating thoughts become persistent and I can't let go of them, then it becomes a problem. So we can get caught in rumination without awareness. I mean, that's why we get caught. And so when we apply mindful awareness to our thoughts, we can decide, okay, now is not the time, and come back to what's right here. And when we come back to the body, we come back to the present moment. In the book, I talk about using the body as a refuge, and what I mean is the when we drop into awareness of sensations, we disrupt the thinking mind. We disrupt these unuseful or even harmful thoughts, and that's when we can reset. So we come back to feeling our feet on the floor, or we come back to following the breath for three or four breaths in and out. And that's how we reset. We make a choice, yeah, I'm going to stay right here. I'm going to let that thought go and we do this on and on constantly. We are so distractible as human beings because we have these really brilliant, powerful brains. And sometimes I say the brain is the organ that secretes thoughts. You really can't stop it. I think it's a misunderstanding of meditation or mindfulness, to think that we empty the mind of thoughts. I don't think that's possible.

Rosanne Corcoran 07:26
I fully agree. And I think that's the part that makes meditation so like, over there, it's like, I don't have time for that. I can't get there. I can't settle myself down enough to be

Roy Remer 07:40
I hear that a lot,

Rosanne Corcoran 07:41
Right? And I mean, what do you do with that? How do you try to broach that? Because it's a lot as a caregiver to try to look at that and be like, oh, I'll just meditate. No, like, how do you break through that?

Roy Remer 07:52
Well, part of the, one of the barriers for caregivers is this recognition that they have difficulty settling the mind, so they avoid or resist meditation, because they know this about themselves. But then I also want to just mention, for a busy caregiver, when we talk about meditation, they may feel like it's just one more thing to add to their busy schedule, right? And that can feel impossible. So if a caregiver was able to go out and buy a meditation cushion and a bell and find a quiet place in their home to meditate each day, that would be wonderful, and they would probably notice real progress in terms of being able to maintain mindful awareness, but that's not necessary to accomplish or to achieve a mind state that we're talking about here. I think when someone just has a very active mind and feels like they can't meditate, I think they need to give themselves permission to sit for five minutes and try to follow their breath, or try to just attune to the sounds around them in the their immediate environment, or to, you know, feel the weight of the body and the chair they're sitting upon, and just allow these persistent thoughts to

arise, and when they notice that they've been swept away in thoughts, to just come back and to give themselves permission to be in that cycle. And in the book, there's one illustration, and it's this cycle that we go through, and we're aware of the present moment. We're fully present, and then distraction happens. We notice distraction. We let go and come back. It's this cycle. And so just to understand that for five minutes, that's the process, that's the cycle, I'm going to be engaged. Engaged in, and that's okay. And then little by little, people I trust, and this, you know, I've heard this from people who try it. Little by little, the mind does begin to settle. And then those spaces, those periods where I'm aware of my breath, I'm aware of the present moment experience, they begin to lengthen and it gets gets easier. Doesn't mean the distracting thoughts go away, but we get more space in between those thoughts. And this can be really quite useful.

Rosanne Corcoran 10:36
Yeah, really useful, especially because, I mean, I will speak for myself here, I know that it was almost, there was only almost two parts of me, right? I was caregiving, but i i dissociated from it, because there was so much that happens, and sometimes it's, it's upsetting to the point where you're like, I can't, I can't process this right now,

Roy Remer 11:00
Yeah,

Rosanne Corcoran 11:00
And I don't know if, if that's pushing it away or pushing it down or whatever, but it what you just described. Sounds like that could be helpful in processing everything that we're going through as caregivers. Is that accurate?

Roy Remer 11:16
Oh, absolutely. You know, it's funny, I use this word process a lot, and as you were just sharing, it brought me to kind of a realization that I think processing is very much associated with thinking about something right, and when a caregiver is feeling overwhelmed and when they begin to distance themselves from what's going on around them, I can't process this right now. My encouragement would be to drop into feeling like, what are the emotions that are arising around this experience? I think often we try to suppress emotions because we don't have time to deal with them. As I go into in the book, every emotion manifests in a particular part of the body. It's expressed in a particular part of the body, and if we can rest our attention on that part of the body, then it interrupts the thoughts that trigger the emotion, and we get we disrupt this cycle of thought, emotion, thought, emotion, and this is the way we can honor the emotions that are arising without getting stuck in the emotions. And for a lot of us, emotions feel like they just last for so long, but that's because we're in that cycle,

Rosanne Corcoran 12:43
Right.

Roy Remer 12:43
So if we can disrupt the cycle, then it allows us to move on to whatever's next, and we don't have to resist the processing or the feeling about a particular circumstance. And I think this can be really helpful for people. It gives them a sense of agency. Because if we're constantly trying to suppress our emotional experience or think our way through a particular problem we're encountering, we can begin to feel kind of helpless. And when it comes to emotions if we're trying to push them away or suppress them, it only works for so long, and I think it can actually be harmful to us physically if we're trying to suppress that physical manifestation of the emotion.

Rosanne Corcoran 13:34
Totally agree, and it's it was interesting to me, because when I read what you had written in the book about emotion itself only lasts a moment or two in the body. And I'm like, wait, what? How it's it seems like it's a lot longer. And then when you add in the rumination,

Roy Remer 13:52
Yeah

Rosanne Corcoran 13:53
And the pushing it away, I think all of that makes it longer than it has to be?

Roy Remer 13:58
Yeah And, you know, I think it's worthwhile to mention the role of self compassion in this experience of difficult emotions,

Rosanne Corcoran 14:08
right.

Roy Remer 14:08
And, you know, I don't want to give emotions a bad rap. It's what makes life just so poignant and beautiful, right?

Rosanne Corcoran 14:16
Yeah,

Roy Remer 14:16

But sometimes big emotions can really disrupt what we're trying to do, and, you know, weigh us down. So I think when we're having a big emotional experience, it can be really useful to even placing a hand on the chest, over the heart, right, and just taking a moment to acknowledge your experience, like in this moment, I'm having a tough time. This is really difficult, or I'm struggling here, whatever the language is that works for you. And then secondly, to acknowledge to yourself that to be human means we're going to experience difficulty. We're going to experience suffering. This is just. Just the nature of human reality. It's just the way it is. And while my circumstances are unique to my life, I recognize that I'm part of this shared common humanity. There are other caregivers out there who face similar struggles. And so in that sense, I'm not alone in this, you know, I'm part of this greater container, this greater community of caregivers. And then upon recognizing that, thirdly, it's just really about in this moment, can I hold my experience with kindness toward myself. Can I be kind toward myself? And this little moment, this little experience of self soothing or self coaching, can really help build our emotional resilience in the role of caregiver. And it may seem like such a simple thing, but it can be challenging to, first of all, remember to do this, but it can be really impactful. And again, it offers us a reframe and a reset, I think, to bear the burden that we're presented with

Rosanne Corcoran 16:20
Well and it's kind,

Roy Remer 16:22
It's kind, yeah, and it's hard for a lot of people to be kind to themselves,

Rosanne Corcoran 16:26
Yeah, yeah.

Roy Remer 16:27
And as a meditation teacher out here in California has said, you know, if our compassion doesn't include ourselves, it's incomplete. And I think for a lot of people who are inclined toward caregiving, it's easier for them to generate compassion for someone else than it is for themselves. But caregiving, as your listeners well know, it's a reciprocal relationship, and I think if I can generate more self compassion for myself, it's healthier for me, and it's really better for the person I'm caring for. And conversely, if I have difficulty generating self compassion for myself, I'm probably really not going to be able to generate that much compassion for someone else, or I'm going to find that it more easily, you know, decreases or wanes when things get difficult.

Rosanne Corcoran 17:25

An interesting thing that you brought up in the book also was setting an alarm twice a day just to pause and be present. And it almost sounds too simple. Do you know it because it's small and and you're saying, just sit and be present, but it's a big deal.

Roy Remer 17:43
Yeah, it's a big deal. And I think this practice of setting an alarm, it's really when our caregiving is asking so much of us that that way of pausing just doesn't come naturally, but I think the more someone does that, the more they just take those pauses on their own. And you know, there have been some really interesting studies that show if we can pause and just follow intentionally three breaths. It stimulates the parasympathetic nervous system in the body, which helps us calm down. It calms the body, it calms the mind, and so the more. And I think most people can find time anyways, to follow three breaths. And if we can do this throughout our day, you know it's like with kids, it's time for time out, right? It's just to let things settle, to down regulate, and it becomes really easy for a caregiver to get agitated or up regulated. And the reason this is so essential, it's so important, is, you know, as we're able to calm ourself or down regulate, it allows us to, well, I think just very naturally, helps the person we're caring for to calm down or self regulate as well. And when someone's living with long term, chronic or terminal illness, you know, it can be quite chaotic, emotionally speaking. And you know, especially when someone's living with a dementia related illness, they can be highly agitated a lot of the time. And even when someone is experiencing advanced dementia, they, based on my experience, they seem to respond really well to someone else's energy. So if I enter into the space and I'm agitated or upset, it's going to trigger them in a particular way that's going to increase their agitation. Conversely, if I can stay calm and ground. Grounded and present, then it can have have a calming effect on them. You know, we're blessed with these mirror neurons in the brain, right?

Rosanne Corcoran 20:08
Yep,

Roy Remer 20:09
So we're constantly responding to each other's energy. We're these relational beings. So as another teacher once said to me, all it takes is one person in the room who's present and grounded. It can really change everything. Can change the energy, you know? And so that's one of the benefits of mindfulness practice and our caregiving. So typically, I think of three primary benefits, calm, focused attention and increased awareness. And so we talked a little bit about calm and focused attention is really useful for the caregiver and for the care recipient and for the caregiver. I think focused attention is really the antidote to mental physical exhaustion. It helps us conserve our energy. But another benefit of focused attention is that I've learned in my years of being with people at the end of life or people living with chronic illness, and I think it's true for everyone, whether we're living with an illness or not. Ultimately, I

think what we long for, what we crave is a sense of deep human connection. And if we're distracted by our cell phone or by thoughts of what's going to happen after this encounter or what happened yesterday, the person we're with is not going to be able to experience or feel that sense of connection. And while deep human connection may not be curative, I do feel it's healing in the sense that it allows us to feel a sense of wholeness in our experience. It allows us to experience a sense of connection to something bigger than ourselves and our experience of illness. And I think this is really important, and we can't really offer that if we're highly distracted. And then, thirdly, is this quality of deepened awareness, awareness of oneself, but awareness of our environment. And this is really useful in caregiving, because, you know, we talked about being aware of our own thoughts and emotions, so there's that. But if a caregiver who's heavily burdened working really hard, they may start to get ill, and because they're stuck up in their head, they're not as attuned to what's happening in the body. So heightened sense of awareness allows us to address things before they become problematic. There's a lot more to be said on that point. But the other thing about awareness is, if we're caring for someone who perhaps is nonverbal, our attunement, our awareness allows us to read their nonverbal cues, either through their body language or through, you know, facial contortions, you know. So this can be really useful. Or maybe we notice things in the environment that, if they're left unaddressed, may have an adverse impact on the person's sense of well being. So we notice a little bit more readily. You know, for instance, is that heating register blowing directly on them, or is there a fluorescent light that's starting that weird little buzz that fluorescent lights do eventually, you know, things like that. You just sense things more more deeply,

Rosanne Corcoran 24:00
Right And if you're not present, you you miss it.

Roy Remer 24:04
You miss it.

Rosanne Corcoran 24:05
And even the the interaction with with your person, with the person you're caring for. How did your work with Zen hospice Center help you realize that you needed to support caregivers earlier in the process?

Roy Remer 24:18
Yeah, love that question. So the organization that I run, legally speaking, it's Zen hospice project, and it was founded in the late 80s, and when I made contact with the organization in 1997 and trained to become a volunteer caregiver. The focus was very much on end of life. We had two sites of service. We had a beautiful, six bed residential care facility known as the guest house, and I served there for about seven years, and then I moved over to our second

site of service, which. Was the long term care facility for the city county of San Francisco, and we were based on a hospice floor. And in those days, there really wasn't that much talk about palliative care. It was really hospice care. But since then, it has evolved into longer term palliative care. But in 2015 I worked with a colleague to develop what we call our mindful caregiving education, and this is a curriculum that's designed for family caregivers that is very much rooted in our volunteer training, which is rooted in these 2500 year old wisdom traditions. And I should add, you know, practices that I believe, you know, exist in every religious spiritual tradition. It's just so happens, we started off at the San Francisco Zen Center. Hence, you know, we're Zen caregiving project. But and the book is really not so much about teaching about Zen, it's taking these practices and putting them in a universal language that honors every spiritual tradition. But when we created mindful caregiving education, it became clear to us that as we were talking to caregivers. We were talking to caregivers at every stage of the journey with illness, and the word hospice became kind of problematic. If it wasn't frightening to people, it was irrelevant, because their loved one could be years away from end of life. So we decided to rebrand who we were for and name ourselves Zen caregiving project. So I've witnessed so many volunteers and later caregivers who have come through our programs, and I've been able to see how relevant the teachings are for, you know, the longer term experience of caregiving. And in fact, I would even say these are really life skills, and ideally, someone would begin to integrate these approaches into their life long before they find themselves in the role of caregiver. And most of us, if not all of us, will sooner or later find ourselves in that role. And for many caregivers who are at the beginning of the journey, and maybe you even experienced this yourself, Rosanne, things are going smoothly, you know, so they don't really worry about or think about acquiring skills that strengthen their emotional resilience. But then when they hit that point where it becomes more burdensome, or it begins to take its toll on them, emotionally, sadly, I have to say, that's not the best time to start learning these skills. It's nice to have these tools in your tool belt before you reach that point. And by the time someone is companioning on this journey towards death, they're already starting to show signs of distress, or, you know, burnout, and it becomes much more difficult to learn these skills. So I think that answers your question. Please redirect me.

Rosanne Corcoran 28:30
No no, well, I know that, and you had a personal experience in caregiving, correct?

Roy Remer 28:37
I did. I have the book is actually quite self revealing in using my own stories to convey these practices and approaches and the benefits of them. But I do want to admit, you know, I have yet to find myself in that kind of caregiving experience where it's just all consuming and immersive. Nonetheless, I do have such faith in these practices. But you know, all these years of sitting with people who have been living with illness, it's been a blessing in my life in so many ways. And so the practices in the book are made real, or, you know, born out of that

experience. And then the opportunity that I had to be one of the primary caregivers for a teacher and dear friend of mine as she approached the end of her life was really revealing. It was one of those experiences where it was kind of 24/7 and I really had to lean into the practice, as we sometimes say. And there's a chapter on what I call Healing Touch, which is dedicated to this person. Because. I learned so much from Irene, is her name, about the importance of touch for people who are living with illness. And then my mother died in 2016 and admittedly, for so much of the end of her life, I was what is sometimes described as a long distance caregiver, but you know, and this may be true for some of your listeners, there's the caregiver who's right there with a person who's requiring care and support, but then there's this next layer of people who are like caring for the caregiver, and I think that was really my primary role, because my father was her primary caregiver, and I talk about my father quite a bit in the book, and his experience with my mom, and one thing I'd like to say about his experience was he was an example of how it can be for caregivers, where they deny their own physical experience because they feel like they don't have time, they can't possibly make time to go see a doctor, and they're concerned that if there's something wrong here, they're going to have to step away, and they don't have an alternative. And my dad went for months caring for my mom, and we found out right after she died that he had this systemic infection in his body. And you know, we got through those really difficult days following her death, you know, the funeral, etc, and he went right into the hospital and spent a lot of time there trying to recover from this and also tending to some other things that he had put off, and this is the way it is. And I think that story is useful, because it reminds us that if a caregiver doesn't tend to their own physical well being, and they go down, it's certainly not good for them and it's not good for the person they're caring for. So I don't want to make light of this, but it sort of points us towards, you know, recognizing the importance of certain boundaries, and then, you know, calling in the help we need to make it possible to, you know, see a doctor when we need to see a doctor, etc. And that can be complicated for some caregivers, there's so much social isolation that's being experienced by caregivers, some of it is brought on themselves only in the sense that it's easy for a caregiver to think that they don't want to burden friends with their reality, or maybe they believe that friends aren't going to be able to relate, but I always encourage caregivers to reach out to those family members, to those friends, and ask for what they need. And if you know of someone who's a caregiver, it can be such a gift just to call and invite them to share a little bit about their story and just be really ready to receive the story without trying to fix it or make it better. You know, waiting for someone to invite some advice, or waiting for someone to ask for something more than just that experience of giving them your full attention so that they can process, you know, their caregiving experience through story

Rosanne Corcoran 33:30
Well and that's what makes it so isolating, is the fact that sometimes you feel like you're a downer. Sometimes people don't want to hear about what you're doing. They don't understand what you're doing, or you just, you're just too tired to share. Like it just, it's, it becomes another

barrier for you, which adds to the isolation and the stress. And I mean, we see it all the time here at daughterhood, too. It's, it's not just the reality of what you're doing physically, it's all of the emotions that you're carrying. And you brought up an interesting term, which I wanted to go back to, which was emotional resilience, because at the end of the I mean, we know our caregiving journeys are going to end, but between the start of it and the end of it, there is so much that we're trying to manage and we're trying to do our best with, but there's so many guilt laden things that you're doing in the meantime, whether they're small decisions that you have to make, or big ones, like, I can't care for them in my home anymore, or I can't care for them in their home anymore, and they have to go to a community. How do you deal with those types of they're really big guilt bombs here,

Roy Remer 34:47
Yeah.

Rosanne Corcoran 34:47
How do you deal with that?

Roy Remer 34:49
Yeah, what a great term, guilt bomb. It can feel like that. Well, I think maybe the first thing I want to say is, I think. It's helpful for caregivers to acknowledge that they're going to cause pain in some regard, or they're going to face the resistance. But that doesn't mean it's a bad decision, that it's a necessary decision, and you can't control someone's response to a decision that you think is in the best interest. And you know, there's the suffering of the individual, but then there's the suffering generally. And if we can minimize suffering generally, I think that's a positive thing. So can we just acknowledge that we may make people unhappy with decisions that are sound, or can we acknowledge that we may screw it up and make mistakes and recognize that all we can do is the best we can do, and that has to be enough. I think one of the most difficult things for family caregivers is to step back and remind themselves that, you know, as much as I love this person, as much as I care about them, I can't fix this for them. You know, they have lived this long life. They're on this journey, and while there is this entanglement that all families experience. Because, you know, family dynamics are complex. I can't make this better for them. And so when we make these decisions, if someone is resistant, you know, we may need to accept that they're just going to be unhappy about this and move into them, and then we go back to the self compassion, right? Like this feels really horrible. We just went through this with my dad. You know, he's been living in the house that I grew up in, and he was by himself. And whenever we would raise our desire, our suggestion that he go live in community with other people, because we knew he was lonely,

Rosanne Corcoran 37:09

Right.

Roy Remer 37:10
And we knew that he was living in a very dangerous situation, he still resisted, and he had all his reasons. You know, all of them are quite understandable, but at the end of the day, my sister and I and my brother, we said to him, Dad, we really want this to be your decision, and this has to be your decision. It is no longer tenable for us to stand by while you live alone in this house, you know, and he had some resistance, but you know, ultimately we wore him down, you know, and and we noticed the benefit of for him and living in community where we knew he was cared for someone was going to be there whenever he needed someone. So these are difficult moments, and they're going to be uncomfortable. And I think the the more tools that we have at our disposal to, you know, manage the difficulty, the better off we are and guilt. You know, it's, I don't know if it's possible to go through such an intimate experience of caring for someone without holding some guilt around the way you're doing it. So can we normalize the guilt? Can we, you know, generate some forgiveness for ourselves, or, at the bare minimum, some self compassion for ourselves, and recognize that that's probably part of it. And there's something else I'd like to say about this.

Rosanne Corcoran 38:51
Sure,

Roy Remer 38:51
I think a really helpful reframe for caregivers is and I talk about this in the book a bit, but you know, I view caregiving as an initiation of sorts, and as humans, we have been practicing and experiencing initiatory rites for as long as we've been around this is what helps us transition from one stage of life to another, and the people who have studied initiation rites around the world throughout time have found that the more intense the suffering, the greater the transformation, and the transformation that one goes through while experiencing a difficult event can actually be beneficial for them and the people around them. So when we come out that other side, we come out with gifts, gifts of wisdom, just gifts of knowing. And our community, our families need that wisdom. And so if you're a care. Giver who feels highly burdened and you feel like you're doing the impossible, which is what we do as humans. We make the impossible possible. I hope you can please trust that when your caregiving ends, you know you've made this huge sacrifice, but you come away with something that is so needed by others around you, those who will someday be in the role, and then you ideally give away these gifts for the benefit of others who will also be in a similar experience. And I think it helps restore for people who maybe feel like this is their undoing, that they're not going to survive it or there's no bigger sense of meaning. It restores a sense of purpose and meaning in the experience. And it doesn't make it any easier, necessarily, but it, I think, offers a slightly

different perspective on the experience, so we don't get so trapped in the emotional weight of the experience,

Rosanne Corcoran 41:07
Right. Well, it's it's the living in that and of caregiving, right? I adored my mother, and it was the hardest thing I ever did. Like they both existed at the same time, and I feel like you may not be able to see there's meaning in it while you're doing it

Roy Remer 41:26
Right

Rosanne Corcoran 41:27
Because you can't see anything when you're doing it. Do you know it's like, it's like, you know, trying to, it's like drowning in somebody saying, kick harder, like I'm trying, so trying to hold both of those truths at the same time. Does that go back again, to taking that moment, to being present in the moment? Is that would that help in that?

Roy Remer 41:51
Absolutely, and I think, you know, even in the midst of high stress situations, in the midst of just you know, the the exhaustion, the physical exhaustion, the emotional, mental exhaustion, if we can pause and come back to present moment, it actually allows us to see what there is in Our life that is worthy of our gratitude and grow and sitting with people at the end of life, not always, but sometimes you get this opportunity. So you know, here you are. This is the way it is. And is there anything still that is worthy of your gratitude? And people always have something always, always. And you know, this may sound like a small thing, but it can be so comforting. And so I think really what we're talking about is just finding these momentary, fleeting opportunities, just to remove ourself from all the stories we tell ourselves about just how difficult this is, and that doesn't make light of the experience. It's just that we get so stuck in these stories, and if we can't find a way to drop into the truth of what's right here, right now, in the body, in the environment around us, without story, then they do become incredibly burdensome, and we do get stuck. And it doesn't deny the truth of what someone is experiencing, but it provides a little break. And then we're training the brain to keep coming back to these little breaks, and it provides some freedom. And I think it's also useful to be able to remind oneself that I do have agency here. It may feel like I'm trapped, but I'm not. You know, you do hear these stories where people are they find out that a spouse or someone close to them is, you know, has a particular illness, and they're like, Yeah, this is not what I signed up for. I'm not doing this

Rosanne Corcoran 44:13
Right.

Roy Remer 44:14
And the people who are showing up for your circles and who are listening, you know, they're making a choice, like, I'm going to stay maybe there's no one else to do it, but you could walk away from it, but you're choosing not to, because you know you have this big, compassionate heart. And I think just recognizing or reminding oneself of that agency can be really empowering, and again, can offer kind of a shift in attitude for folks.

Rosanne Corcoran 44:46
You know, there's so much grief in caregiving. It's kind of inherent in caregiving. We don't acknowledge that. And then, of course, the anticipatory grief as you move towards the towards the end of. Of their life. How does you know all of that? The anticipatory grief, grief itself, all of it. How does that impact the caring, with trying to blend mindfulness in, to try to tamper that, or make it more even, or something?

Roy Remer 45:18
It's huge, as you've discovered, Rosanne, you know, the book is divided into these four sections. So the first section is the foundation. It's mindfulness, and that section has, I don't know, 810, chapters, something like that, short chapters. And then the second section of the book is compassion, and the third section is loss. And just to say the fourth section, I titled intimacy, and it's really it's a place for the chapters that didn't fit so neatly in the other three sections. But in any case, this section on loss is so important. You know, when we talk about loss, the mind may immediately go to say, end of life, but as you well know, as a family caregiver, loss is being experienced constantly. You know, there's such an opportunity cost to being in the role, giving up time for yourself, time to spend with friends. You know, maybe you're you've given up certain health routines, etc, and there's this whole anticipatory grief piece where we see where this is leading, and grief begins to arise. So I make the point in the book that as a caregiver, if you haven't been willing to really look at your own story of loss and the corresponding grief, because a lot of us just want to push grief aside, because it doesn't feel so great and it can be all consuming, so we tamp it down. We pretend it's not there, etc. Or, you know, there are pressures around us to get back to our routine, when really what we need is just more time to be with our own grief. If we've succumbed to that, if, for whatever reason, we haven't given ourself enough time to be with our grief, we're probably not going to be so great at showing up to hold the experience of loss and grief for the one we're caring for. So it's also true that as a caregiver, is experiencing their own loss, witnessing what their loved one is going through. Their loved one is trying to catch up and process so much that's falling away. So once again, it's this entanglement, this reciprocity in the caregiving relationship. So my what I offer in the book is a way for caregivers to really think about and process their own loss so that they can better show up for their their loved one. And I think that, you know, giving the person we're caring for the opportunity just to talk about, well, what's, what are some of the changes you've noticed that you're going through because, you know, especially in a familial

relationship, the person we're caring for may not be comfortable talking about loss, or, You know, their own mortality with us because they don't want to cause us pain, right in those situations, I think it's really important to recognize that dynamic and then maybe call somebody else in you know, to have that kind of conversation. But if that's not possible, I think the more a caregiver can display their emotional resilience, their presence, their groundedness, the more likely their loved one is going to be able to raise with them. What can be for some people, an uncomfortable conversation. So there's a chapter in the book that's titled mindful communications. How do we integrate mindfulness into our conversations with people? And I reference a close friend of mine who's a hospice physician, Scott, and he uses this metaphor of the vessel or the container. And can we know our story of loss and grief so well that we basically can empty that container so that the person we're caring for can fill it with their own story. And really what this means is, have we spent enough time with our own loss and grief so that when someone's sharing. Their own story, we're not getting triggered emotionally, and we're not surprised by the emotions that are arising for us. So this is really rich territory, and what I've noticed in my life is, because I have experienced a lot of loss, like so many others, when we don't resist it, can be so enlivening, and we can learn so much from the process. And I talk about a mindfulness based approach to grieving, and this is the idea that we honor the emotions that arise. We actually get quite close to our grief rather than push it away, and then it just allows us to more readily move through the grief experience, not to suggest that it's ever finished, but it becomes easier just to and we see this in the elders around us, to wear the grief like a cloak. It's just there, and it doesn't stop us from doing what we need to do, and when we're more comfortable paying attention to our emotions, we can carry on with our activities, with the presence of emotions, and they don't prevent us from doing what we need to do. They don't debilitate us. They're just kind of along for the ride. You know.

Rosanne Corcoran 51:19
It's so interesting because the whole idea of being present from the beginning of caregiving through the end of caregiving, through end of life and death, and the after it's it's the thread that runs through, but we fight it because of all of the things that we're doing, and then when caregiving ends, it's like, wow, what am I supposed to do with all of this now?

Roy Remer 51:47
Oh, yeah, that's right, that's a great point. And you know, caregivers are busy, yeah, and caregivers make themselves busy, because when we're busy, we don't have to think about or acknowledge these heavy grief emotions,

Rosanne Corcoran 52:05
Right.

Roy Remer 52:05

And we can tell ourselves, I don't have time for this. But then, right? You know, when mom dies, then there it is. You know, the busyness goes away, and here we are left to process this experience. And maybe for some people, that's an okay approach, you know, but it's not the only approach. And in fact, I talk in the book about setting an intention for our grief experience, like, if we can step back and think about our own grief, we can ask ourselves, really, how do I want to show up for this, and I work a lot with intention, because I think it's so useful. And so can we clarify for ourselves, you know, like a two or three sentence intention, a simple intention like this, is how I want to show up for it, and just hold ourselves to that as best we can, so that we bring some thoughtfulness, some mindfulness, to the grief experience, but let us not think that if we push it away, we're not going to have to deal with it at some point, because it just doesn't work that way.

Rosanne Corcoran 53:14
There are many guests that I wish I would have spoken to while I was caregiving, and many books that I wish I would have read during that time, and this is definitely one of them.

Roy Remer 53:26
Thank you.

Rosanne Corcoran 53:27
Thank you for putting it out, because it is so important, and it is so because it, you know, it filters back to you matter in this it's not just the provide you're giving. It's not just the care that you're putting out and providing. It's you too. And we get lost in it. We get lost in it, and it's so important. Yeah.

Roy Remer 53:52
You know, I would say, like the rest of you out there, like you Rosanne and your listeners, you know, and to some extent, I've dealt with this living with a chronic illness, but we will reach that point when we're really sick and we're going to need the care of others, and if it's my wife I'm talking about, or anyone else, I want them to be really well resourced.

Rosanne Corcoran 54:15
Yes.

Roy Remer 54:16
I want to know that emotionally, they're okay. It makes my experience with illness that much easier. So yeah, I agree.

Rosanne Corcoran 54:27

Is there anything that you would want to say to that caregiver that's listening today, that they're running around and they're harried and they're like, yeah, yeah, this is great, but I don't know how I'm going to do this, or I don't have the time to do it, or I don't know if I believe this. What would you say to them?

Roy Remer 54:48
I would say that doubt that resistance is okay. Just get curious about it. Notice it. Where does it show up for you? I would say I. If nothing else from this conversation, even if you don't buy the book, just try on. Take it on as a thought experiment. Just find those pauses in your day, and a lot of people already do this, but find those pauses in the day where you're just quieting the thinking mind, you're activating the sensing mind, and you're just allowing this present moment to be just as it is. And it sounds like nothing, but it's really everything it really is. And then the last thing I'll say, and this is a shameless plug, but pick up the book. It's available in audio, but if you're curious, you know, check out our website, Zen caregiving.org, and we have a lot of resources for caregivers. We have both our live remote courses so people can attend from anywhere in the country, and we have a self paced course that we've created so for busy caregivers, they can participate and acquire some of these approaches and skills in the middle of the night, if that's only what works for them. But there are resources out there, not just us. There are a lot of great resources that focus on these emotional skills and try it on, see what you notice.

Rosanne Corcoran 56:22
A big thank you to Roy Remer for being my guest today. For more information about Roy, his book, his courses, and the Zen caregiving project, visit zencaregiving.org I hope you enjoyed today's episode and found something helpful, whether it was information, inspiration or even just a little company. You'll find the full transcript and links to resources mentioned today@daughterhood.org in the podcast section. While you're there, explore more of what Daughterhood offers. We're more than a podcast. We're a nonprofit community providing free services and support for caregivers, including nationwide virtual support groups. We call circles. On our website, you can register for a circle, sign up for our newsletter and read our founders blog. Don't forget to subscribe and review us on Apple podcasts or wherever you listen. Your reviews help other caregivers discover the support they need. Follow us on Facebook and Instagram at daughterhood to stay connected, and if you know someone else who may benefit from Daughterhood, share it with them. Also. A very special thank you to Susan Rowe for our theme music, Mama's Eyes. This is Rosanne Corcoran. I'm so grateful you spent your time with me, and I look forward to being with you again next time here in Daughterhood.