

Daughterhood the Podcast

Episode #51

Why Daughterhood? With Anne Tumlinson and Andrea Cohen

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SPEAKERS

Anne Tumlinson, Rosanne, Andrea Cohen

LINKS:

[Daughterhood Circles Calendar](#) – Topic Circles – presentation on a specific topic with Q&A after.
Connection Circle – A chance to connect with other caregivers and talk about what’s on your heart or in your mind.

The Hill – [America’s long-term care infrastructure: A road to nowhere](#) by Anne Tumlinson and [David Grabowski](#)

Roz Chast – [Can’t We Talk about Something More Pleasant?](#)

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Rosanne 01:06

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. The challenge of carrying through a broken health care system is something every caregiver lives through. My guest today daughter hood founder Anne Tumlinson and Daughterhood interim CEO Andrea Cohen know those challenges personally and professionally. Anne Tumlinson has spent over 25 years working to improve how America delivers care for our oldest and frail us adults. She's worked in government participated in policy research, and worked with hospitals, nursing homes, assisted living providers, and home care companies, and is the founder of ATI Advisory a national research and consulting firm dedicated to making health care work better for everyone. And she's also the founder of Daughterhood. She created daughter hood in 2015 to provide support and resources for caregivers, as we face confusing options, lack of information, and all of the feelings that come with being a caregiver. Andrea Cohen is Daughterhood's interim CEO, and was also the founder and CEO of Houseworks, one of the nation's largest and most forward thinking home care agencies. Andrea is a social entrepreneur, dedicated to transforming the way that care is delivered to seniors at home, a visionary leader and nationally recognized expert in care delivery. She has spent her entire career in the aging field as a creator, innovator, and influencer. Today we discuss their personal experiences as caregivers, what drives them to create change, the importance of being able to find practical resources and support and how daughter hood can help. I hope you enjoy our conversation. And you wrote an opinion piece with David Grabowski for The Hill, June 11, of 2021. It's called the America's long term care infrastructure, The Road to Nowhere. And in it, you stated The problem is that families with aging loved ones have no easily identifiable place to turn for help in navigating and accessing services. Instead, a crisis is followed by a period of calm until another care emergency arises. And then the panic begins again, the stress that this place is on families is unsustainable. They are being forced to create and manage an entire care network on their own, over and over again. It's more than a full time job that often takes the place of paid employment, especially for women. You and Andrea, were both professionals. I'm going to put in air quotes in the business for all of these years. Can we discuss what your experience was like being the caregiver in that system that you knew about professionally, but it was different when you were in it? Andrea you first?

Andrea Cohen 04:29

Sure. I appreciate being here with both of you. And I'm really looking forward to this discussion. Because it's not that often when you just have the opportunity to talk about family caregiving in a way that's meaningful. So thank you for the opportunity. Thank you. I, I have to step back a little bit because, you know, I'm not going to tell you my whole life story, but I am going to just tell you a little bit that sort of got me to where it was. So I actually grew up in New Jersey and I had parents who are older, my mother was over 40 When she had me, and that was back in 1957. So it was like a grandparent age and my entire life growing up, they told me, you know, how how much older they were and how I should be their first client. And, you know, they should be my first client, etc, etc. So I grew up with this whole sort of idea that I'm going to be a caregiver for them, in some way, shape, or form. So funny enough, I went off to graduate school and college and graduate school with the idea of being a social worker, you know, I wanted to help people. And that's actually where I landed. And when I, I went to college, they didn't really have a degree in an undergraduate degree. But I do remember working in a nursing home and saying to myself, got to fix that it was really a scary place, a scary place

to be. And then I graduated from college, and I actually became a home health aide, you know, just because you needed a job out of college before you figure out what you want to do. And, you know, I just wanted to see what I wanted to do. And so I became a home health aide. And that was a very interesting experience, then went to graduate school, then went to work at a not for profit, I worked at a AAA or Massachusetts, it was an area agency on aging and an ASAP. And it was at that point, I was in my early 30s, that my parents both died within six months of each other. And so it was a really, you know, I mean, for so many reasons, it was a difficult time having parents die at a young age, like that was really hard. The other part that was hard was that I was already working. I mean, I was working in a not for profit to support people to stay at home. So I was living and working it at the same time. And, and so anyway, well, I, I remember sort of calling up doctors, and I remember trying to figure it out and getting diagnoses and you know, one was diagnosed, and the other one was diagnosed, and then one of them died. And you know, it was just really off. I remember trying to get home care. And I just I remember one time I got off the phone with a neurologist, and he was so cold to me. And so difficult. I just started to cry. And I just said, Oh my God, how can people who don't know what they're doing? You know, I worked at the information referral department in a AAA, right, how do people who don't know what they're doing do this? And I think that's sort of what spurred me on to just say, it was really a pivotal moment, when you look back on your life and say, What are pivotal moments that was a really pivotal moment where I said, I gotta, I gotta make this better for people who are going through something like this. And then I sort of, you know, that's when I found it house orbs, which is a private homecare company in Massachusetts, which has grown quite a bit since it started in 1999. But, you know, during that time, yeah, all I did was solve problems for family caregivers. And I, you know, yeah, it's just like, every day is another problem every day is a new problem. Every day, I would have families calling me with fear, you know, fear, like they, you know, and I got to a point, I got to a point where I realized, yes, you have to help people, you have to provide them with an answer and a solution. But what you really have to do is be a coach, you really have to be, listen, you really have to be able to really understand what's going on inside their head and not just give them a solution, just just hear them. And, and coaching is really different than managing coaching is allowing people to, to really make their own decisions versus you tell them what to do. And so anyway, that's sort of how I got into it. And we'll get into more of that later. But I just, I think it's important to understand the context. So I feel like I bring I bring to all of my work, sort of the the importance of what the family you know, what family caregivers do to hold it all together. You know, I brought in professional help and how important it is to integrate the informal network, which is a family caregivers with any professional help you might bring in, and how do you do that? And so that's what I spend a lot of time on now.

Anne Tumlinson 09:39

I just have to say, Okay, this is I'm just having such a, like goose bumpy God moment, because that I'm on this podcast with Andrea Cohen. It's like, I mean, I know. Like I when I founded Daughterhood, in 2014. Well, 2015 really in 2014 It was like this little tiny germ of an idea that, that I was I was, it wasn't my own personal caregiving journey. Actually, it was that of a family member. So not it wasn't directly but it was, you know, they call in, this still happens, by the way, all the time, you know, people will call me and obviously through daughter had, but also family, friends, neighbors will call and, you know, what do I do? How great that I have a friend who's an aging expert, and I'll always just say, like, um, I don't have a great solution for you. And in 2014, when that happened, kind of it was trying to have them kind of for the first time in my life, because I was entering into my, I guess it was in my mid 40s, that I

felt like, I'm a deeply curious person. So I was like, why is this like this? Why do I know all of these things about this system and the payment and the providers. And what's, you know, I thought the big problem was just that we didn't have enough kind of financing for the long term services supports that we fixed that everything would be fixed. And then I started to realize it was so much bigger than that. And I was thinking through what I want to do, and I was leaving my job. And I ran into this guy who was in Massachusetts, it's all leading to how Andrea's an inspiration that I met, and I was like, I want to do this thing. We were having this like late night cocktail, talking about life, and what we're gonna do, and I said, you know, I want to start an organization that will net build a bridge between caregivers, family, caregivers, family members, caring for their loved ones, and to how the system works. I'm really fascinated by this. And he was you have to check out houseworks because you need to check it out. Just go look at it. It's unlike anything else out there. And I remember going to the website, Andrea, and I was just like, Whoa, it was like I was like, This is what the company I wish I made up to and and I never imagined in a million years that I would meet you or get to know you. And then we and then I got invited to be on the board of a caregiver Action Network. But you were odd, and I was a little bit like just starstruck for a while. And now here we are working together. So I just wanted to say that out loud in public.

Andrea Cohen 12:19

Thank you.

Anne Tumlinson 12:20

So you know, Andrea, yeah, so you've just really, you're so kind of integral and so many of these conversations going on around how to support family caregivers, but more importantly, how to just support caregiving in general and caregivers in this country. And for me personally, more recently, I think if, for those of you who've read the blog, my father died a year and a half ago, and we had a very intense caregiving journey for about six to eight months before he died, I would say probably longer than that. But COVID was created all kinds of challenges, but very intense in the last six months of his life, and just all it's all kinds of challenges with our healthcare system. I've read, I've written about just all the surprises about how unhelpful our home health agency was. I felt like a switchboard operator. You know, my mom was, we were trying to figure out how to do these really complicated medical tasks at home, and then also manage all of the people coming in and out of the house and take care of my mom and her health and also spending all day every day at an infusion center with my dad, it was just it was so lonely. I remember Christmas day, I was with my dad, I was not with my children or my husband, I was with my parents. And I remember taking the dog out for a walk and just looking around and seeing all these other families. Like having a normal holiday and feeling happy. And like they're all like, you know, multi generations and they're all walking and their outfits Florida, so it's very warm. And it's lovely. And everyone's so happy. And I mean, I'm just we're not you know, my dad was having a really bad day. There was no celebration, it was just like, how are we gonna get through this day, and I felt so profoundly alone, even though I wasn't but I felt that I think that feeling of aloneness is such a core piece of this experience that we all kind of weirdly share. And we, but we are like we share that experience, but we still feel alone. It's hard to it's hard to put into words.

Andrea Cohen 14:39

I would totally I mean you're you're you're you're talking and I'm remembering even though I was young, which sort of brings its own set of whatever. It just, you know, I felt like I was living in a different world. And I mean, it was just like I was outside the world. And then occasionally, when you get that look into the world that you used to be, you're just like, I don't want to be in here because I need to be back in my other world of caregiving, because it's not fair that I'm over here when I should be over here. And, you know, so many families that I've talked to over the years, as a person goes more into that space, where it's clear, they're just the decline is really fast. You know, I've talked to so many families, should I move there should I be there should I want you know, I mean, and you just don't, you don't know where you belong. And I remember the it was one of the last times and I still have this note, like, I remember leaving my parents house because they're in New Jersey, I was in Boston, I just gotten married, my mother didn't want me to basically screw up my marriage and keep, which of course it wouldn't have. But so I flew back to Boston, and I was sitting in the airport, sobbing and wrote, wrote her this note, and then I decided, when I got home, I was just gonna go back there and live there until, you know, she died because she had ALS. I mean, she wasn't going to get better. And so, but, but by the time I decided to do that she died. You know what I mean, she didn't want any part of me. She didn't want any part of me being there. So she didn't want to be dependent on anyone. So like, I really do believe that people have the will to die when they want to not everybody, but someday she was pretty strong. And, but that was such an eye. You know, like, I think for all of us who have done caregiving, like what you said, just triggered my feelings of, you know, like, you sort of bury them. And then they come back, and then you bury them the first year that you're, they just keep coming and going and coming and going. But then after a while, it's been 30 years for me. You just buried them, but every day I think of them.

Anne Tumlinson 16:49

It's trauma not there's trauma, it's trauma, there's trauma, and you're making me be like, one time I gave a talk, this was me, you know, part of the caregiver Action Network work, where we did this lunch and learns, I guess, just kind of giving a talk about caregiving, and it was in a community center. And this one woman raised her hand and she said something, it just really stuck with me. She's like, every time that I hear a siren, or like, drive past the emergency room. She's like, I like my the, like, my veins run the blood in my veins runs cold. She's like, she's transported back into that tear. I love how you said that areas like the other world, the other world, and Roz Chast to if anybody has not seen her book, she's a she's a

Rosanne 17:38

An illustrator, cartoonist.

Anne Tumlinson 17:41

Yeah, does. She wrote a book like, Can't we talk About Something More Pleasant than

Andrea Cohen 17:47

Such a great book.

Anne Tumlinson 17:48

It's a great if you don't have that book you should get that book Because it will it is. But one of the things she talks about, and at least I've seen her interviewed is like, she's like, it's, it's, it's this whole

other planet. I call it like planet caregiving, like what happens on Planet caregiving? And it's helpful to me to think about it that way. Because it's like, okay, just recognize that we are living on this different planet. And you're right, Andrew, you're kind of peering into this other world, like, you're behind this glass, like looking out, like, wow, look at all those other people having normal lives. While I'm doing this crazy, not normal thing. So.

Andrea Cohen 18:30

What's interesting about it, from my perspective now, and just watching it, like it almost used to be a counterculture thing, right? You know, there are these caregivers, and you know, and then as you get older, there's more and more caregivers of your peer group. But it's not counterculture anymore. Everybody's doing it. So now it's kind of like, okay, everybody's doing it. You know, you can walk into a room, I remember I used to give lectures, you know, in companies without family and family caregivers have come. And I would ask everybody to raise their hand and say, how many people review are in the midst of caregiving? And I would get about half, maybe less than half. Maybe it was a third. And yeah, and it was just like, now it's like, if you went into a room and did that, it would be everybody. But there would be if you could raise two hands, you'd have two hands because oh, by the way, there's so many different iterations of marriages now that you've got, you know, they're they're now saying that you have instead of having like two parents on either side, if you're married, it's like eight parents because of all that. So it's a whole different ballgame. Now.

Rosanne 19:38

It's so fascinating to me, because you two are kind of a match set here. And it's it's quite a power duo for me. And in talking to both of you, because I feel like you both know everybody in in the world of caregiving, and then and you get that policy part that's so I mean, it makes me just want to, to be able to wrap your head around that. And, and Andrea, you're you have that strategy that operating that. Okay, how are we going to do it and both of you together is, is just it's it's a beautiful thing to be able to be part of.

Anne Tumlinson 20:16

We're a power couple Andrea.

Rosanne 20:19

It's amazing to me so and that's why you created daughter hood, from that experience way back when before you even were in it your personally. Why did you call it Daughterhood?

Anne Tumlinson 20:30

Yeah. Because I felt like so. So this is a little woowoo. But I think it's important for everyone to know, when you I was writing, because I just think this is important. This is, you know, I had been thinking about what was to become daughter had for a really, really long time. And I didn't know I still was struggling with like, what is this thing going to be? That's going to build this bridge. And a friend of mine said, you just need to start, you just gotta start like just start. Melanie is her name. She's amazing. She's like, just start start writing. So I started writing. And the first paragraph I wrote was something like, I was thinking about motherhood, I was thinking about parenthood. And I was like, when you're writing, it's like, where did the ideas come from? Right. It's like, all of a sudden, out of nowhere, the

word daughter hood, it was like, daughter had makes motherhood, look like a cakewalk, or something like that. It just, it was like and then kind of guiding, I'm a nice struggled for a little bit of time about whether or not this organization that we were creating or this platform at the time website, you know, calling a daughter had felt a little exclusive. And it is painful to me that people would feel excluded around something that they are struggling with. Having said that, ultimately for me, while it you know, one, one reason is that it is women who are doing most of the caregiving in this country, the research shows that they're doing, they're more likely to be doing the really hard day to day work. So even when men do caregiving, it tends to be managing the finances or helping to coordinate since not that that's not that's, that's not nothing. And there are so many men that I know who've devoted their lives to caring for their loved ones and like, made huge sacrifices. So I just want to be so careful in the way I talk about this, but and respectful. I think the more important reason, though, is that it gets to this, the system that we're doing this work in and the reason why the work is so hard is because the system is broken. It's a broken system, it's not. And what I've observed, and what I was observing was that the women tend to personalize a broken system. So women encounter a broken system, and they say, I'm doing something wrong. And men encounter a broken system. And they say, that is a really messed up system. So for me, what I wanted to do is to create a space where women come together and men if so welcome. But especially where we're we are very conscious all the time of helping to normalize this way, or contextualize this experience. So you feel if we can just solve for one thing, it's that you're not the failure, you the caregiver or not the failure, it is a failure of society and systems. We've sort of just rapidly outstripped kind of our abilities to meet the needs of families around this much longer life that we all get to live. So it's like a good problem that we have, but it is a problem. So daughter headed is the is kind of about that being in that role, where you're balancing so many different things, and caring for loved ones, while also dealing with th is broken system. That was a long answer.

Rosanne 24:17

I love that answer it's a great answer.

Anne Tumlinson 24:18

I still struggle, like should it be called daughter hood? Should we come up with something else? I think when when the gods decided to give me a new word, that's better. We'll know.

Rosanne 24:19

Yeah, but I mean, I can tell you from personal experience, after I moved my mother in and I was up at 2am trying to figure out how to find resources and what the heck I was doing and where I was going with this. And I mean to be clear, I I love my mother I adored my mother. I knew I was going to if there was something that ever happened to her I knew I was going to take care of her. I knew that already. But sitting there at 2am and finding your blog and and reading. It was like you were reading my mind. I had no idea I don't know, I don't know where I need to go with this. I know I want to do the best job I can do. And I know that I know how to, you know, find things on the internet. But I didn't know what to do with these feelings of failure of isolation of, okay I don't know how I'm gonna continue this at this level with my children and my husband, and we're all under the same roof. And my life is out there. And it's different now. I can't access what I was doing. I can't access my life, and it's completely changed. And here was this place, and I love the Daughterhood, because I daughter, but do you know what I mean? It spoke to me on so many different levels. And I thought, okay, I found my place. And that's

how I felt. Because it's not just about going to the doctor and getting equipment and, and managing the medications and talking to the godforsaken insurance companies. It's not just that it is all of those feelings that we bury, and we bury them because we're, we're caring, we don't have time for these fields, we gotta get back to you. And they keep popping up. And you keep saying, I'll get back to you. And that's part of that trauma as well. So I think it's spot on, quite frankly. And I get that, you know, we don't talk we don't like men. It's just that You know, I mean, that's just where we're at. When you looked at the idea of providing resources, you started with local resources and circles. I'm trying to provide that information to caregivers, again, because it's so hard to access. What what is the importance of those circles, and providing resources and support? What what is the importance of it? And how did you come up with circles?

Anne Tumlinson 26:46

Yeah, so that's a great question. So I think that the time that I found it, daughter head was around 2015. It's funny, it's a little bit embarrassing, or weird to say this now, because it's sort of out of fat, it's very out of fashion. But you all may remember that book by Sheryl Sandberg called Lean In, they had these circles all over the country, lean in circles. And then there was another organization for women that also had circles. So I was kind of watching that. So I was like, that was happening, it was in my consciousness. And then at the same time, what what I was really struggling, what I really want and still still want to solve for seems like very challenging is, how can we create an entry point, like up here supported entry point into this system? What we what I was learning and doing my research was that at every single community is totally different. And so there's no way that sort of like if somebody calls me and says, you know, where should I go for transportation services in, you know, a suburb of Chicago? I'm not going to I'm not going to know, and I probably can't even really find out. But there's probably a caregiver in that community, who has already solved for that and can share that information. And can we create at the local level, like this network of support? And so I was thinking about this, I was watching these, like other circles that were happening at the grassroots level. And then these two really amazing women in San Diego, like Karen Van Dyke and Christine Lee, reached out to me, yes. Christine, Christine and Karen, that's how I think of them, Christine and Karen reached out to me. And they found out about me through some other thing anyway, they, they were like, had the same idea. They had the idea at the same time separately, we want to do something with this Daughterhood thing, we want to do something locally. So that so it just it just it was a very natural and organic, kind of immediate thing. And so we launched our first daughter head circle in San Diego, and then we started and then we worked really, really, really hard to try to recruit leaders in other areas to become circle leaders and eventually started kind of creating this leadership community of people around the country who wanted to be involved and wanted to make meaning out of their experience and, and bring caregivers together.

Rosanne 29:16

And then the pandemic hit.

Anne Tumlinson 29:18

And then the pandemic head, and then we learned so I should just say, we struggled on the circles like the local circles, we struggled on a number of levels one, Rosanne, I think you and I've had many conversations about this, even when you bring all these caregivers together, and they are you know,

bringing their experiences and their information working with different providers and they're like, Oh, I know transmit, there's you still don't know that it's impossible to really that we weren't solving for the problem that I was hoping we could solve for so we learned a lot about that. It's hard to get caregivers to go to an in person circle because they just getting in your car and driving somewhere and going. And that's like a pretty big bridge to have to cross. And so we were having trouble recruiting leaders, we were having trouble solving the problem, we wanted to solve every trouble, you know, really, you know, these leaders would go to all this work, and then they'd have five people show up. And then just sort of it was getting more and more unwieldy to manage, because it was a lot of people. And then my dad was getting sick. And so I took my eye off the ball, and it just sort of become a little bit unwieldy. So COVID hits, and everybody starts doing their circles virtually. And they start getting more participants. And learning that actually, this virtual environment was working, maybe better than the in person environment. But we still had the challenge of sort of now we're doing it virtually, but it's local. So that was confusing. And then, you know, we're still sort of struggling with all the other challenges. And that's where, you know, a number of our circle leaders were kind of frustrated. And we brought Andrea, it's almost like, Andrea came to me, she's like, this is amazing platform, let's work together, we can do so much together. And so Andrea came in and did a whole strategic overview and refresh and everything and started to think about, let's move our circles into a virtual platform that's national and make them more topic based, and less about what's happening in any one particular local area, because we're not really solving for that anyway. And it will make it easier for us to support leaders and manage and deliver a consistent experience for the caregiver. And so, next thing, you know, we're redoing that, and we're forming a 501 C three, and now, you know, we're getting ready to go into fundraising, right, like it just took on a whole new life.

Rosanne 31:46

Well, Andrea when you came on, what was your What was your thinking? Obviously, you like the, the idea of it, the whole platform of it, but what was your thinking? In in coming on board?

Andrea Cohen 31:58

Yeah, I mean, I, I had heard about Daughterhood, from a very dear colleague of mine, at Mass General, she said to me, you really need to look at this website, daughter hood, you know, this woman really gets it. And of course, like skeptically looking at it, because there's no one that really gets it. And I read it, and, you know, so I had known of Daughterhood. And I also sort of knew of, Anne in terms of her brilliance in policy. And so I, when I spoke with Anne about doing it, I felt like, you know, given what I've seen and, and what I know, we've got a really good infrastructure there that coupled with the fact that, you know, as a caregiver, a family caregiver advocate my entire life, right, I devoted my entire life to this, that to finally see family caregivers noticed, is, you know, I feel like I died and went to heaven, right. And so the idea of just focusing on supporting family caregivers, to me, and figuring out how to do it was was really a cool opportunity. And so, when I looked at it, you know, the first thing I had to do was really go in there and talk to all the leaders, which is I, I pretty much called anybody who would talk to me and, and I listen to them. And I have to tell you that every time I got off the phone, I was just like, wow, you know, everybody brought to it something different, but they they all brought to that same passion and the level of support. And then yeah, so I talked to all of the leaders try to figure out what it is that they see the value of, you know, how, you know, continual conversations with them. And then that's an, I think we just like it popped into my head, you know, how we all like, we get in the shower,

and it's like, boom, it's like, Okay, keep them virtual circles, but let's not, let's make them. So like, you don't all have to be from one geographical area. But like, you know, making sure that that we're prepared to be able to, you know, facilitate a group like that, because that's really different than meeting with a bunch of people from Atlanta. You know, what I mean? And then also, like, what are the topics that we're hearing over and over again, that are darker Hood community of which we have about six to 8000 people on our newsletter, you know, what are they telling us they want and, you know, and monitoring all the Facebook chatter, and you know, each each leader had their own ecosystem of people in it. So, you know, all the caregivers from different areas, were listening to that too, and sort of what goes into that, and you know, and then I would call up Anne and be like, wow, you know, let's do this, or Well, let's think about this and then but what's been interesting about it, because it's been almost a year, it's just like it keeps iterating and that's what's so great about it and that's what's so great about working with and and what's so good about working in the environment that I'm working in right now is, is that when I started Houseworks, I remember, like, Okay, well, we're gonna do this, this and this, and this. And then you know, of course, you know, 10 years later, it was all very different. And then 10. So I kind of learned that it never really works that way. So I already had that mindset coming into it. And you know, and the idea now that, I mean, the big thing, and everybody who's listening to this, and YouTube, especially understand this, that, by the time I left House House works, the level of complexity of clients that we were getting went from, like, you know, people need someone to go to the grocery store and do an errand with them to they are at home with equipment that like, I mean, the complexity and the quickness that were people were coming home, so that like, yeah, that's a whole. And so we had, like, so at Daughterhood, it's like, it's not like we can solve all those problems. You know, like, there's other, there's other we want to lead people to solve him for those problems. But those are really hard problems. And you talk about fear. I mean, it's just like what Anne said, when you were talking about with your dad, and all sudden you're doing all these medical things that you've never done before, how I felt my stomach hurt when I when I heard that for you. So now it's just you know, do we spend time training, you know, family caregivers up so they're able to do it better is that our job is our job support is our job, this is our job that but at the end of the day, you know, our job is really to be that place that people can go and step out of that scary place, and go to a place where they feel like they can be held and they somebody understands. And what I was gonna say before that I think is really important is I, yeah, I like and still get like 20 calls a week from people. And now especially because I'm old enough that it's not only their parents, it's their spouses of themselves, it's like, triple the number of the calls, and I can't ever, you know, sometimes when my kids are home, they roll their eyes, and it's like, Oh, my God, another one of this. They actually, they both do they both do good for the world. But like, I can't not answer someone because I feel like for some reason I was put on this earth with a gift to give what I know now, which I know, you know, like, I know that I can do something. But I think it's I think the biggest compliment or the most satisfaction that I get when I get off the phone with someone is that you made me feel better. You made me feel so much better. And you know, and I didn't really do anything except for say, then you're doing and I don't say it like this, but you're doing the best that you can or you know you're going in the right direction. Or, like, I might say a couple of things that that help them understand that I understand how they really feel like like we were talking before the call Rosanne. It's just like, so many people don't understand how you really feel until you're in it. I mean, when I was in my 30s. And I was a caregiver as like the first person of anybody that their parents died. And then little by little as my friend's parents died, they were like, I'm really sorry that I wasn't there for you. And I said to him, I said to them, there's no reason to be there until you have to be there.

Andrea Cohen 38:31

Don't feel bad? Because it really, it's really hard. And like it's like you just don't like why should you like you did the best that you could do, that's fine. But to have someone like an organization, like a daughter hood that like you can just know that, you know, and when we when we when we talk to leaders, we're doing a lot of work like to engage leaders to build community to build a community of leaders. Because, you know, if you look at it from a leadership perspective, you have to have the leaders and the followers in this sense, the leaders have to congeal, you know, from from every aspect of Daughterhood we're trying to get people to really think hard, we don't want them to spit out jargon. You know, we don't want that there's enough of that going on. We want them to be real and even authentic and transparencies becoming jargon now, you know, so that's why when people say like, you know, Anne and I talk about it, it's just kind of like, well, if you look on every caregiving site, everybody's saying they're transparent and authentic. So how do you really get across what what we are trying to do our daughter heard or what we as individuals are trying to do to support other caregivers, and it's just an interesting time for us, but I just feel like, you know, we're learning we're doing it and you know, like, I think just yesterday, Rosanne and I were on a call together and we decided we're having these we have these monthly circles on you know, dementia and grief for example. And we said, Okay, well, they're getting a lot of information on dementia and grief. But now we want to do a connection circle, which is a circle where just people, they don't come on to learn, they come on to just be with each other. And they're going through the same thing. And we're like, oh, we're going to add what we're going to add another circle, a connection circle for Grief every month. And that's, we just, we decided that yesterday, because we have been watching and going into the circles. And that's what's cool about this whole thing. So we want to hear from our community, and we want to hear the best way to do it. And we're listening as hard as we can.

Anne Tumlinson 40:34

It's pretty fun. I mean, because we're in, we are small, and we're nimble. But we're moving into this and I will say, like I ever been, anybody who knows me or knows anything about hardeners, I struggle with this decision like toddlerhood was something I created, and I felt very protective of and kind of ownership over and then make it into a nonprofit is to kind of like hand it over to the broader world. And that's scary and hard for me. And you guys are so patient and kind about it. But I but it's still. So first of all, sorry, what does it say is nonprofit, the key, the reason why that needed to happen is because we do need a funding model that will enable us to really support the operations on a going forward basis. But all of the funding models that are in the business world, for profit world, just are it's just very, very challenging. to first of all, they don't none of them worked very well. And people who have been trying to innovate and startups in this space have definitely struggled. But more than that, it ends up making something else that this the like, customer, right, so it's a it's an employer, thank you, okay, we're gonna sell it through an employer Well, now the employers, the customer, the Medicare Advantage plan is the customer or you know, the hospital systems a customer in your in your debt, now you're retrofitting all of the solutions, just to like, appeal to and suit that end user that isn't now the caregiver. So the nice thing about the nonprofit is like, it makes it simpler. Because we just in the top of our mind, it's always about the caregivers, funding is still a challenge, there's still we are still going to face this, right where like, even a philanthropic organization is gonna come in and be like, well, we want you to do this, you know, like, is that about the caregiver, like we we have our we have to kind of always be, I think, we're

gonna have to stay very focused, and principled as we move forward. But also, you know, we need to be able to sustain this on an ongoing basis. So these are challenges. I'm just sharing, I'm airing.

Andrea Cohen 42:55

But that's it. That's why it's good. Because we've got, you know, represented in the Daughterhood team, we have someone who understands policy, we have a sound understands not for profits, we have someone who understand sort of for profit, mission driven businesses, we have someone who understands really understand what caregivers are thinking and wanting and doing, like, we have all the right ingredients. And, and we have a huge opportunity here. And I think for the three of us on the phone. And, you know, and what I say for myself, personally, is that I am doing this because I want to make an impact. When I you know, when I was building house works and had the choice to either bring in investors and make it bigger, or make it sort of I was very comfortable in my own shoes and Boston make it a little bit bigger and a lifestyle kind of business. I chose the investor route because I'm wanting to make more of an impact. So when we think about where daughter hood was, you know, I give and a lot of credit, because it is like giving up a baby. And, you know, when she brought me in, I was so like, excited, but nervous because I didn't want to you know, like I I, you know, very carefully navigated, you know, well, what is your what is it that you really want? And what is your vision, and, you know, like, try to introduce new ideas, but like, with real deference to the person who founded the organization, and I think because, you know, and I really believe after running a company that respect comes from the top down. So if you think about Anne and I both being on the board, and then we you know, have a team and we write grants and you know that respect is going to trickle right down to the family caregiver, because of anybody I know. Rosanne and Anne both of you have so much respect for the family caregiver. And and you know, that's why we're set up To succeed, we just again, as Anne said have to figure out, you know, do we want to get some research for issues, you know, and fundraise for research issues we think are important to us. Do we want to fundraise to, you know, to build community with technology? Do we want to fundraise to better engagement, I mean, there's different ways that we can do it. So for us, it's a matter of both figuring that out and then prioritizing it. And again, with the end being what's the best, fastest way that we can support more caregivers than we do now?

Anne Tumlinson 45:36

Yeah, I think in some ways, the biggest challenge for Andrea and me, in particular, as a, as a duo, and you know, just to talk about the two of us for a second because, you know, we do have a nice, a really nice, bigger team is that is that we both do see so much. Like we said, we've got this nice new operating platform set up, and we've got a new website, and we, you know, we're like kind of marching forward now in a, in a, in a new and consistent way. So now it's like, okay, all right. Take a moment. And like, so now what, right? And then probably have is a good one, which is like, like, I've sort of been exploring, like how, you know, how can we partner with like, more than Area Agencies on Aging, to get people who are connected to infrastructure? And, you know, Andrea's really expert in like training and and then there's, and there's the technology? And what's the role of technology? And what are the private, you know, I think we probably want to build some partnerships, with some organizations that can give us a lot of leverage. And there are other nonprofits doing amazing work. I'm so excited about the new leadership at the National Alliance for Caregiving and caregiver Action Network. And I these are, like, the Rosalyn Carter Institute, there's so much there's so much opportunity for us to be part of a larger ecosystem and landscape where we were all working and kind of towards the same end. And

then also on the private sector, there's all these wonderful private, there's so many people doing so many amazing things, and we just kind of, I think Andrea and I are gonna have to, you know, we're gonna have to go back into kind of strategy mindset and, and get get a little clearer about where we want to prioritize, and what's it, but Andrew said it really well, like, you know, figure out where we can have a lot of impact and also, in be smart about it. But also we have to get him to get some funding. And so I have confidence in our team. I think we can do it.

Rosanne 47:37

Totally, totally. Well. And I think the the other underlying factor is daughterhood is made up of family caregivers.

Anne Tumlinson 47:44

Yes.

Rosanne 47:45

I mean, it is a direct line to family caregiver. So in that thinking, I mean, we hear from them daily, we hear from family caregivers. So it is that link, which which is helpful when reaching out for other for other opportunities. Now, I could talk to the two of you all day went really, really fast. I could I could talk to you all day. But if you could say one thing to a family caregiver who's listening, what would it be? Take turns I, whoever wants to go first,

Anne Tumlinson 48:16

The first thing that came to mind is just like I love you, we love you. So I think what I would say is all you have to do is shine the flashlight on the path right in front of you. Like just it's about taking the next right step. You don't have to solve the big problems today.

Andrea Cohen 48:36

And I would add on to that, is it okay, if I add on versus say my own thing? I'm just absolutely whatever. And I would add on to the like, what I tell people all the time is is that you could take that right next step and it doesn't work. So don't sort of say, oh my god, I can't do this to say okay, well, that didn't work. Now I need to try this. And you know, I mean I always tell families that there's always gonna be like one false start where you think we all think it's going to work and then it doesn't and that can be such a setback. So just know that that's possible. You know, and many times it works beautifully and sometimes it doesn't and you know, just keep you know, one step in front of the other one little bit it's like I always feel like it's steering a cruise ship. You know what I mean? But like, you can't get so overwhelmed by steering a cruise ship that you're not going to try to steer it at all. You just have to say okay, you just have to stick that put it into you know, one movable parts basically. And you know, understand that it is little by little but we are starting to recognize finally the world is starting to recognize what family caregivers are doing. No one will really get it except for Darwin, of course but no, I'm just kidding. No one will really get it as much as you will get it But at least I feel like maybe you wouldn't feel as alone as Anne or I did. You know, and and it's been a year and a half, I've been decades, but I feel like there is more awareness that's out there on the world now in terms of vulnerability, like people can feel more vulnerable in every aspect of their life. That's one of the things that's happening in the world. So wake up in the morning and do something and take a deep breath,

you know, I really actually do think, sort of even two minutes of a guided meditation in the morning to set yourself or, you know, I listen to music, or, you know, whatever it is, just take a little bit of that and you know, just do something that you can bring yourself inside yourself for a little bit before you have to go to the outside world and deal with that, but just, you know, it's like a hug. It's like hugging yourself.

Rosanne 50:50

To find out more about how Daughterhood can support you through your caregiving journey, including our circle, calendar, and blog, the podcast, and more, head over to daughterhood.org. 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 find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at [daughterhood the podcast](https://daughterhood.org). Feel free to leave me a message and let me know what issues you may be facing. And we'd 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. 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'll join me next time in Daughterhood.