

Episode #29: A Conversation with C. Grace Whiting

SPEAKERS

Rosanne, C Grace Whiting, Disclaimer

RESOURCES

Caregiving.com

Daughterhood.org

Leezascareconnection.org

AARP Training videos: <https://www.aarp.org/ppi/initiatives/home-alone-alliance/>

How Crisis Impacts the Way We Care: Understanding COVID-19's Impact on Family Caregivers &

Lessons for Future Challenges: <https://bit.ly/3JVCbVk>

Caring For the Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the

Treatment Team: <https://bit.ly/3teqlzt>

Disclaimer 00:02

Content presented on the following podcast is for information purposes only. views and opinions expressed during this podcast are solely those of the individuals involved and do not necessarily represent views of Whole Care Network. Always consult your physician for medical and fitness advice. And always consult your attorney for legal advice. And thank you for listening to the whole care network.

Rosanne 00:42

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 frontlines 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 a love. We want to help you see your efforts are not only good enough, they're 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 Daughterhood. I spoke with C Grace Whiting, while she was serving as the president and CEO of the National Alliance

for Caregiving. We spoke right after the infrastructure bill had been passed but the provisions that addressed caregiving and other social services had been removed. We had such an extensive conversation covering many issues and emotions that caregivers deal with including where caregivers can find support, the range of emotions and trauma we experience in our journey and even how Wonder Woman fits into caregiving. I hope you enjoy our conversation.

Rosanne 01:52

For you, this has to be frustrating to do all of this work that you're doing, and then have yet another bill not be passed. And then for members of Congress to actually come out and say if that \$1.85 trillion dollars social safety net, as they call it wasn't in that bill, it would have passed. For me, it frustrates me. I can't imagine how it makes you feel. Because you're you're in this every day. you're slogging along trying to get these things done? And I don't know how that makes you feel?

C Grace Whiting 02:21

Yeah, I mean, I think it's one of those things where it's an editor. It's an iterative process. Because if you think about FMLA, you know, those conversations started very much, much earlier than the early 90s. And in the same way, the Paid Family Medical Leave proposals have really been out there for probably five or six years. And so the fact that it's in the public consciousness that people are talking about it that they like it, I see it as it's just part of that journey. I don't I don't think it's the end the end of the road. And I also think, you know, I think paid leave is at least an interesting issue, because it's sort of wrapped into parental issues, as well as other types of caregiving. And for some people, that's like, why the dollar sign amount is so big, you know, and I think there's some concern with that. Now, I think those arguments aren't great, but I can see, you know, I could see some of the challenges there. I think the other thing is, the pace about caregiving is also tied into this theme for better long term care, or need for other types of support like that the, you know, better access to health insurance, for example. And so it is part of this larger conversation. And I do also think it's still momentum. It's sort of like one step forward, two steps back, but I would say it's the reverse. I think it's two steps forward, one step back, but we're still on the right path.

Rosanne 03:49

Well, it's, it's a challenge. And like the the \$5,000 tax credit is great. It's wonderful. But it doesn't help that caregiver at three in the morning, who still hasn't had a break in, you know, a zillion days, it's those practical supports that aren't there. And and it's, you know, how do we find those supports? Because there are many organizations like yours, that are trying to provide that support, and I found your momentum to movement, but how do we get caregivers to know that this is out there, that there are the supports that they can access?

C Grace Whiting 04:22

You know, I think that's a really important question, because it is something so did you get a chance to look at the new Raise Family Caregiver Act, the the plan?

Rosanne 04:31

I did

C Grace Whiting 04:31

So I think that's gonna make it a little bit easier to sort of centralize some of that information, but it's still you know, it's not perfect. And I also think there's this piece and, and you know, this better than others, but it's sort of like when is the right moment to reach out and to connect with someone, you know, is it in that moment of crisis or a moment of crisis or pupil so up in a crisis, they're not really able to respond or some people talk about The idea of sort of reaching out to people before something happens, I think the problem with that is, it's really hard to predict before something happens if you're going to be in that role, or what's going to happen, you know, right. So, but I'd love your thoughts on it just based on your experience.

Rosanne 05:15

Well, I mean, I, I did call my local area on aging when when I moved my mom in, and it's a frustrating sort of trail, because you feel like you're picking up breadcrumbs from each person that you talk to, but you have to talk to the next person, and you have to go through your story every time you talk to that next person. And then at the end of it, you find that unless you are Medicaid eligible, there isn't a lot to be found, which was my finding. And that's frustrating. And you, you know, I kind of thought that before I even made these calls, so I was preparing myself for that. But it was so frustrating. And it was still defeating for me. So I think I come I come to this, from that perspective, from that person that was dreading making these calls and trying to find information on things that I didn't think were out there anyway. But I was going to try because that's what people had told me. And it just, it's, it's just defeating in the midst of trying to caregiver and trying to figure out what is happening and how you can help, you know, I would have done anything, and I did do anything that I could to help my mother and trying to find those those resources was just a struggle. It was just a struggle. And I don't know, every time I see something come up, I see that, well. We're talking about Medicaid expansion, which is trying to get blood from a stone at some point. Because even if it's passed federally, it's the states that have to pass it. So you're waiting. And in the meantime, you're waiting in this in this stew, hoping that something someone's gonna throw you a line, and the line never comes. But you're still caring every day, and you're still carrying everything that you're carrying.

C Grace Whiting 06:54

Yeah, well, you know, one of the things I've been thinking about too is this idea of sort of moral injury and trauma from seeing somebody love go through this, because one of my colleagues is working on in the rare disease space, this new grant program, where she's got these trauma counselors and the trauma counselors, they've done work with people coming back from combat zones, and having them provide some assistance and support to caregivers of kids with rare disease. I think it's a really brilliant idea, because I think nobody approaches it like that. But you and I know what I don't know is like is that is that rude for me to say, caregiving can be traumatizing?

Rosanne 07:37

No, I think it's real. And I think that's part of the conversation. Because until we elevate what caregiving feels like, it's very, when you're trying to explain to somebody, well, what do you do as a caregiver, nobody can really understand it. And I think this is part of the reason that nobody really understands it until they get in it because they don't know what it feels like. And those feelings, you can't disassociate, you can try, and there are times when you need to. But those feelings add to your stress as a caregiver,

because you are no matter who you're caring for husband, wife, parent child, who no matter who you are caring for you, you have an attachment to this person, and they're changing in front of you, and they're suffering in front of you, and that affects you. And that's part of your everyday caregiving life. So that's I think that's brilliant. I think it's absolutely brilliant. And anybody that's on the other side of caregiving can tell you they are traumatized. We have trauma with PTSD. It's it's a fact,

C Grace Whiting 08:35

Do you feel like there's something that can help on that other side. Because I also like one of the things we've talked about before, it's like how hospice has a benefit for the family to get counseling, but how most people like don't even realize that that's something that's available to them.

Rosanne 08:50

Yes, I think. I think what happens is initially, after your person dies, hospice reaches out to you and says, Do you want to help? I think that's too soon. Because I think you're still in shock. And I think you're still trying to figure out what the heck just happened, depending on the situation. I'm sure some people are very open and welcoming to that call. But I know a lot of people that couldn't even think about talking to anybody in those first weeks or months even. So I I think the bereavement benefit of that 13 month program is fantastic and really should be utilized. I just don't know how you get more people to utilize that because of that trauma and everything that you just experienced coming through. Yeah. Yeah, if that makes Do you know what I'm saying?

Rosanne 09:42

Do you mean like they're, like, resistant to take advantage of it because it's too close. Or,

Rosanne 09:48

Well, I can only speak for myself. I mean, hospice called me about a week after my mother had passed. And honest to goodness, I don't, I didn't know how I was even thinking functioning in that time span. I had no idea. And I was totally numb. So for me, it wasn't a Yeah, I'd love to come in and talk about what just happened, that that wasn't even on my radar. I was still in that just got through the funeral, having to do everything that goes with death, that all the paperwork and all of that I wasn't in that spot of sitting in my chair like, Okay, I think I can talk about this now.

C Grace Whiting 10:26

Yeah, yeah, I can see that.

Rosanne 10:29

There has to be some some lead time. But I think that's, and this is all part of, I think, and you can tell me because you, you study this, you're in this every day, it's not just one thing that's going to fix this system for caregivers. We can't just say, Well, if we if we provide a tax credit, it'll it'll help or if we expand Medicaid, it'll help. It's not just one thing. It's a, it's a huge compilation of things. And that being in the position of being in caregiving, when you look at that, it's very easy to get discouraged.

C Grace Whiting 11:05

Yeah, I can see that. I can see that. And I think that piece of how do you how do you honor and celebrate the person, but also grieve and grieve the impact it's had on your life and your relationships and your identity? And that's really hard to it seems?

Rosanne 11:26

Oh, yeah. Well, because you're so intertwined, of course. Yeah, absolutely. But I think the the thought of someone is going to help us. And in the past, it's been, you know, will a bill be passed? Or there'll be provisions? I think that has, it's almost, it's almost like yeah, all right, well, let me know when that happens. But in the meantime, I'm still gonna care for my person, and saving the healthcare industry billions of dollars, by putting everything on our own backs and caring. And I don't know how to. And that's, I guess, that's my question to you. How do we make that change? How do we how do we help caregivers get resources to help them throughout this process?

C Grace Whiting 12:09

Well, I think one of the questions that I always have is, where are people going for information? You know, because I do think part of this is that frontline physician should be aware of what's out there and how to help people. I also feel like the internet is really in an imperfect place. Everybody wants to put stuff on the internet. But that's not always the best way to reach people.

Rosanne 12:31

No, no.

C Grace Whiting 12:33

What do you feel like it's been helpful when people reached out to you.

Rosanne 12:36

I try to send them for the support, it's the underlying support, it's not the overt support, because that's not there. So it's the underlying organizations of, you know, like the National Alliance of caregiving, like our daughter hood website with support groups like Leeza's Care Connection, like those types of organizations that can provide support directly to the caregiver, so they can find the strength in themselves to keep going, because that's what it comes. Everything comes down to the caregiver. And I understand the person who's receiving the care is the key point. I mean, that's the medical key point. But the spokes that come off of that person, always feed back to a caregiver. And the caregiver is the one that's that's driving the bus here. And for us to be invisible in this system, like how do you think things get done? It's the caregiver. But I don't I just don't know how you get those supports to them.

C Grace Whiting 13:29

Yeah.

Rosanne 13:30

And from that, from the national lines of caregiving from, you know, the, the Elizabeth Dole Foundation from AARP, AARP has videos on their website, I don't know if you've ever seen them, they're called home a home alone. And it gets I mean, it's a fantastic resource. So I try to, you know, provide those

types of resources when people reach out to me go on there, you know, find the videos, but but Isn't it a shame that that's where we have to find our information?

C Grace Whiting 13:57

Yeah.

Rosanne 13:58

Isn't it a shame that it's not a provided that a doctor's office isn't providing these this training, or someone isn't providing this training for us

Rosanne 14:07

Did you see we have a new paper about billing codes and how providers are reimbursed for services to family caregivers? And

Rosanne 14:15

I didn't see that, that

Rosanne 14:17

Let me see if I can find it and send it to? I think that's a big part of it is that we have bizarre incentives that drive strange behavior. And I think that that's part of this. Let me send you this paper because I think there are providers that are trying to do that um.

Rosanne 14:34

Thank you for sharing that grace. I'll include it in the show notes. And all of this leads to compassion fatigue, which is also a very real part of caregiving.

C Grace Whiting 14:44

It's been such a year of ups and downs, because I like many people, I think that work and charitable organizations, the sense of fatigue and exhaustion is real because you have been trying to help through the pandemic and there's a sense of is it ever going to be over? You know, I, every time I put on the mask, I think to myself, Oh, my goodness. And I think that kind of trauma day in and day out that we're all experiencing is really hard. And then you look at research from places like University of Pittsburgh, and you see that it's that much more for caregivers. Yes. And so I've been thinking a lot about this question of how do you restore that sense of compassion? How do you address compassion fatigue? And it's a really hard question for caregivers, because to do that, so often, you you know, the way that you would do that is to find the silver lining and to look for gratitude. But sometimes the people you're taking care of can't or won't or aren't able to express gratitude. And so it sort of feels like you give you give you give, and then you don't always get anything back in return. And that drains you over time. Yeah. So it's a really challenging problem. I think. I, I think there's also this piece of, not that you want to tell yourself stories, you know, but it's almost, I almost think it's, if you're in a situation where no one can or will express gratitude for what you're doing. Maybe the approach then is almost one of forgiveness, where, where you're saying, you know, what I do I do, willingly. I always think of Wonder Woman, what I do, I do freely and with a clear conscience. Yeah, so I think about that, and I think there's this piece of, okay, I'm caring for someone I'm giving, giving, giving. I've done this, like Wonder

Woman, you know, freely with a clear conscience, and this person may never be able to say, thank you. And because of that, I, I forgive them that limitation. And I forgive myself, that I couldn't be the perfect caregiver that I might want it to be. And I think that's really important, too. Because I know, you know, from a leadership standpoint, that's something that, you know, people struggle with all the time as you make a call, or, you know, you start a program or you end another one, or and you're sitting there regularly, like Did you know, did I do the right thing? And, and it's hard to tell sometimes. And I think there's a piece of, you know, I did the best that I could and that, and that's good, you know? Yeah. But it is, I think, to me, that's the biggest issue that's going to emerge in caregiving is this sense of how do we address compassion, fatigue? And how do we get mental, emotional, behavioral health support to family caregivers, because it's the one that we haven't paid as much attention to as the other aspects of caregiving?

Rosanne 17:47

I agree with you, I fully agree. Because it's, it's just, it's just hard. And I think the other thing is that both of those things can exist at one time, it can be the hardest thing, the most draining thing, the most emotionally overwrought thing that you may ever do. And it can be the most rewarding and they can exist in the same space. It doesn't have to be either or. Yeah, I think that's right. Now, the, like you had said bizarre incentives to make things worth the billing incentives. Is it a matter of changing codes? Like there are programs across the country, memory centers have great ways of incorporating the caregiver and getting a social worker? Like, wouldn't it be great if every doctor's office had a social worker, I mean, so that you could have this information, you could have the resources that somebody can say, Here's your resources, you don't have to reinvent the wheel, I'm going to give you the wheel, and then you go on your way. So at least you have a shot? Can there be something like that? Is there something available like that?

C Grace Whiting 18:45

Yes, or No. Um, so. I mean, here's what I here's what's weird about the incentives for providers is we think about, you know, when you're a human, and you're moving through the healthcare system, it's not like you're on a train. And there's different stops where you say, Okay, this is acute care, you know, next up post acute care, next stop Home and Community Based Care, right, but policymakers because healthcare so complicated in the US specialize in each of those train stops. And so the incentives are different at each of the train stops. And depending on who's running the train, whether it's Medicare, or Medicaid, or, you know, a private insurer like United are Humana, and that creates this situation where, you know, as a passenger, you have a sense of, I want to get from A to B, you know, maybe I have a hip replacement, and I want to live safely and independently on my own, but the incentives aren't structured to do that. Because every every time you stop, it changes a little bit. And it makes it really confusing. And I think one of the things that we've discovered is that even when there are places that providers want to be able to help Someone that they may not have the right billing codes to do that, or the billing code that might be available to get reimbursement is so low that you, it's almost not even worth it to bill it because you could make up that money somewhere else. The other thing, I think, sort of apart from that billing codes issue is, sometimes there aren't words to describe what caregivers are going through. And part of this is that, you know, if we go back to the training examples of the caregivers along for the ride, but those systems don't recognize that the caregivers there, it's almost like the patient has a spot to sit on the train and the caregivers, they're, you know, holding on to the

holding on. Yeah, just like, you know, everything that comes along, you know, so. So, you have a provider who recognizes, okay, I have this person in my office, I know they're caring for their dad, I know they're in a bad situation, I'd like to get them help, but I can't bill it to this patient, because the caregivers, not my patient. And so that adds complexity. So the the short answer is, yes, in many, in many facilities, in particular, there's going to be a patient advocate or social worker that the patient or the caregiver could ask to speak to. And that's a great way to kind of find out what's out there. But ultimately, that caregivers, because they're not the patient, they may not be able to get access to what they really need for help. And so it's almost like two strategies, like you want to find out is there a medical social worker that can help through this person's medical provider, but maybe there's also a medical social worker through your EAP program, or your human resource department, or through your own health insurance? And you kind of have to do both tracks to really get what you need.

Rosanne 21:52

Doesn't that seem crazy?

C Grace Whiting 21:54

Yeah. Yeah, for real? Yeah, absolutely.

Rosanne 21:59

So isn't there a way? I mean, it really does come down to insurance, and what insurance wants to pay for because it also sounds like, depending on what the doctor is going to get reimbursed for is also what they're going to recommend? Yeah. Which is a little frightening when you think about it.

C Grace Whiting 22:16

Yeah. I mean, absolutely. And we have a health insurance system that incentivizes it, what they call fee for service. So every time I hand you a tissue, I get to bill you X dollars for the tissue. And so that also creates strange incentives, because sometimes there's an over reliance on medication, when something like physical therapy might actually be better and cheaper, and, you know, more person centered. So I think it is really hard. And I do think part of what happens though, is it gets hung up in this bigger philosophical debate about how we feel about healthcare as a nation. And that's one place where the US is so different from our global partners. Because, you know, our constitution is really a constitution of negative rights, meaning that our constitution is basically a list of like government, you're not allowed to do this, you know, stay out of my hair, here, here, here, here. Whereas if we were to go to Europe, for example, the way those constitutions tend to be structured are more like Affirmative, like, I have the right to health care, I have the right to education. So because are just the inverse of that we have a lot of uncertainty about whether people have a right to health care. And you see that every time we debate, the Affordable Care Act, or if we debate, you know, Medicare for all, or any of those kinds of proposals, you see that come up, why should I have to pay for their healthcare needs with that, and what's driving that is that we don't have widespread recognition that it should be a fundamental right, that we have access to health care, and that that's part of, you know, health, happiness, that's in the preamble so

Rosanne 23:53

Well, and it's and you add that along with non patient centered care. And it's, and this is where we're at, this is what happens. Yes. So then how do we try to get out of that?

C Grace Whiting 24:06

I think part of it. There's a couple things. There's some things that are in the healthcare system now that we thought were going to be good ideas that are actually terrible ideas, one of which is the idea of the electronic health record is important access to your information. Absolutely. The problem is with the implementation, and that is you don't go to medical school to learn how to do data entry. And a lot of doctors aren't very good at data entry, and they're annoyed at having to do it, and it disrupts the flow of the meeting. And so that's the kind of thing where you're looking at that going. The idea is good, but the implementation is not working. We need to rethink that. I think that would help. I think the other thing that would help is a lot of times, you know, policy nerds like me will say the solution is we need to do more training for the physician. But when you come back to how do we actually pay for health care, you know, to be able to stay in business, a lot of physicians essentially how To get their visits down to about seven minutes, right? So they're not going to be able to ask you about, you know, every person you've ever kissed every type of alcohol, you ever drank all of your chronic conditions, all of your acute concern, you know, it's just impossible. And so I think part of that comes back to the idea of an interdisciplinary team and physicians that say, you know, what, I'm not a behavioral health specialist, or I'm not a physical therapist, but I know how to get you to the right person, and to have that general practitioner or family doctor really be the middle of the information center, and then to say, okay, understanding that those are your concerns, you need to go here, here, here. And then that handoff process to be a little bit simpler than it is now because, you know, I think if you're, if you're in an open system, it then becomes now you've got to find a specialist. And you know, exactly, so I think a lot of that, you know, we see what's called accountable care organizations, or these these groups where the practice sort of groups together, it does reduce your choice a little bit, but the advantage is that you have easier access to these other sort of components of the healthcare system.

Rosanne 26:08

Okay, well, and then if you have an HMO, trying to get out of that practice to get to a specialist is like mother may I.

C Grace Whiting 26:18

It is, it is I mean, I so I'm a proud member of Kaiser Permanente, which is closed system, but they do a couple of things that are slightly, I mean, essentially, it is an HMO. But a couple of things that work really well, most of your core services are all on the same building. So and even that is huge to think about, I can go to my primary care doctor, he writes me a prescription, and I could go downstairs to the lab, get my bloodwork done, and in the pharmacy is right there. And it's all in the same facility. And I think those sort of almost like community centers, like that is an excellent innovation. I think the other thing is the telehealth has potential. Absolutely. Although it's sort of it's like electronic health records. We're not quite there yet, you know?

Rosanne 27:07

Yeah, well, and it's great. If you don't, if somebody doesn't have to put their hands on you, or look up your nose, or in your ear or something, or look at something, you know, it's like, it's great. So, but I can

say that, and the last time I when I was at my general practitioner, I mean, what she did, I could have done, I could have taken my own blood pressure, I could have taken my own temperature, because she was Tap, Tap, Tap, Tap Tap in on that stinking computer. And it starts to wear on you as a as a consumer even of what what's happening here. What is happening and things changed grace. I mean, I don't it I think it adds to that frustration. And then when you know, when you're a caregiver, and you have to call the office and you're waiting on hold and that in that music, is it music, is it real music, what is it? And then you're waiting and waiting, and then you're you finally get to somebody and then you have to tell them your story. And then yet, it even happens if you have to send a message. Yes. Like, it's just, it's so difficult, on top of everything that you're carrying as a caregiver, and then you know, you're not going to get anywhere. It's like, let me just go bang my head on the wall. It'll be fun. This time, it'll be better.

C Grace Whiting 28:18

Well, you know, part of this, I got to blame lawyers. And I feel like I can blame lawyers because I was trained as a lawyer. But I was thinking about how, you know, there's all this research that if somebody has an issue with malpractice, and the physician apologizes, that greatly lowers the risk that the physician is going to be sued. But of course, from a legal perspective, if you apologize, you admit that you did something wrong, and it creates, you know, more evidence for the other side? I think part of this is, you know, ultimately people go into health care and medicine because they want to help people. And there's been a lot of fear around how do we have a you know, if you talk about person centered care that requires you as the medical provider to be willing to trust this other person. But it also kind of means that the patient has to be open to that a little bit. And understandably, so many people had such bad experiences that it becomes more antagonistic. You know, down in Texas, they just passed a law that said, if you have a loved one in a nursing home, then as a caregiver, you have a right to go and see them. And that's like a perfect example of that, where it's like, as a staff member, maybe when I see this caregiver walk down the hall and groaning a little bit, but that caregiver is taking a lot off of my plate, and then to immediately shut them out, kind of puts us in that antagonistic position. And they did it because they're worried about liability, and they're worried about contagion and all that, but there are ways to mitigate those factors. And so you see sort of that reaction where patients and caregivers just say, Well, no, like, I'm not a visitor, I need to be here. And so they push for You know, litigation or legislation, and sometimes that that undermines the trust. But sometimes you have to do it. Because otherwise, if you don't, people will kind of shut you out. So very precarious.

Rosanne 30:12

Right. So how do we turn this around for caregivers to give a ray of light or some hope and not just the status quo.

Rosanne 30:22

So my colleagues in the UK had this really innovative program that I love, that's called the carer passport program. And the idea is that you essentially have like a physical badge almost that identifies you as a caregiver, like in a hospital setting. And what that does is it immediately recognizes that you're not there just as a visitor, that you have a defined role, and that it gives providers a way, it sort of formalizes what the caregiver is doing without turning them into like an employee of a hospital. But it also gives the Provider A way to instantly recognize, okay, that's who this person is, and why they're

here. And to be able to contextualize information along those lines. You know, the other thing is, there are groups like, for example, Rush University of Chicago, they're working on how do you make sure that medical records do capture information about the caregiver? And I think there's some of those pieces that the academics are working out, which is like, how do you actually get it so that like, if I am type typing, I'm also putting in information about the caregiver, and then a section where I could actually find it if I needed to find it. And those are tricky problems. But there's a lot of big thinkers that are working on that suit. So I do think there starting to be some progress there, especially around implementation of the Care Act.

Rosanne 31:45

Well, that's a plus and your 35 page document of the United States strategy that you have on your website?

C Grace Whiting 31:52

Yes.

Rosanne 31:54

That that is something to be seen.

C Grace Whiting 31:56

One of our lighter reads.

Rosanne 31:58

Yeah, I thought that, yeah. Tell me a little bit about that. How did you come up with this? And what went into it? Because it's very comprehensive Grace.

C Grace Whiting 32:08

Well, first off, I can take no credit. It's the brilliant people I work with, who said we should do this. And I said, right on, let's do it. And I think part of it is, if you think about other areas of advocacy that have been really impactful, they have multiple streams of effort. So they have, for example, a national plan, they have state and local plan, they sometimes have global benchmarks that they're working from. So one of the things that we have thought about is, look, we've got global engagement and benchmarks that we work from, and then the national plan is in progress. And what we really need is a corresponding movement among states to implement family caregiving plans and to identify what other states have done well, there's this whole idea in policy about states being sort of laboratories for different approaches. And that's been very useful in a lot of different new innovations. So I think that was kind of the thought here is can we give people a recipe for here's everything that's in the gumbo of caregiver support, and you know, pick and choose what might be a good starting point for your state. There are a handful of other efforts, the National Association of State Health Policy, which supports the race Council, they have also started to do some state specific work, and then the Retirement Research Foundation is trying to build infrastructure and support for family caregiving coalition. So so we see a lot of that sort of bubbling up. And I think it's such an important part of informing what happens nationally, because, you know, everybody's life is very different depending on where you live, what state you're in, what benefits are available.

Rosanne 33:48

Right no that's great. And it seems to me, it's it's very separate from the policies, because it's very important, who we vote for in these roles that will then turn around to support these types of systems.

C Grace Whiting 34:04

Yeah.

Rosanne 34:05

And, you know, I always hear the, you know, write your congressman, write your representative, write them, call them tell them how this is. I feel like that there was a groundswell of that, before this federal law, was defeated, was taken out was not passed the Policy Act. Do you feel that that's still something that we should be doing? Or do you feel like it's falling on deaf ears?

C Grace Whiting 34:29

Definitely. I think people want to do something about it. And I think part of what's happening, I mean, it's interesting what happened with these two bills, because essentially, the President has come out and said, We have to Build Back Better program that's actually like several different pieces of legislation. So it's a little bit confusing. And essentially, what happened is that the sort of traditional members of Congress said, when you say infrastructure, we want it to be roads and bridges. on the progressive side side, well, infrastructure, you know, our role is changing. We're a service and people based economy and infrastructure needs to include these other components like, you know, the care infrastructure, the care economy, the Democrats in Congress had initially agreed to a compromise where the infrastructure bill would not pass unless this other bill would be, you know, sort of newer definition of infrastructure pass. But as the negotiations went on, There ended up being a divide. So the so the infrastructure bill moved, and the other one didn't. And I think what that's reflective of is the fact that you have a progressive wing of the party that is saying, These things are really important. And you have more centrist folks, some Republicans, you know, some sort of folks have been in Congress a long time to believe that those things are important, but they're not ready to make that big of a commitment. And I think that's going to change over time. I think the conversation is getting pushed down a little bit. But there is still a lot of sort of animosity between the parties. And that makes it really hard to compromise on some of these sort of big dollar items.

Rosanne 36:15

Right. So you just keep trying to push that up the hill?

C Grace Whiting 36:18

Yeah, absolutely. Because, you know, if we think about when Hillary Clinton ran for president, back in 2016, she had in her proposal, one of her proposals was for paid family medical leave program that would operate similar to the one in California. So in California, it's essentially like unemployment tax, and it takes \$1 out of your paycheck. Well, the proposal that Hillary had offered, and I say Hillary, like we're best buddies, I assume, in my mind, I'm friends with everyone. But she proposed something slightly more conservative even than the than the California law, and that you would pay a little bit more. And then folks in California pay for the state benefit. And I remember reading an article from an

analyst on it, and they said, basically, it will never pass, it will never pass. People view it as a new entitlement. And to think about, like, that's where we were even in 2016, that \$1 a week is too much. And to go from there to now, you know, people talking about paid leave. I mean, that's progress, it doesn't feel like progress, because the outcome is the same. But people I think are starting to change their mind. So I absolutely think it's, it's a marathon and people got to keep on, keep on and it will change. And then once it changes, you'll say seems like just yesterday, we were talking about this.

Rosanne 37:47

I hope so. I hope so let's go with that. I mean, and this goes back to it goes back to the 80s. It goes back to the 80s with Congress not wanting to pay for adult day services. So this isn't, it's that's the thing, it's not something new, it's not a new thing that keeps coming up, it's in it still goes back to the now. Because it's not, it's your job. It's not part of this. And that's the frustrating part, because we're drowning in the meantime.

C Grace Whiting 38:14

Well, I do think part of it is sort of the American personality of ableism. You know, we want to believe that everything that happens to you can be cured. And there is, I think, a huge success story when it comes to scientific progress. I mean, there are many, many diseases that thanks to innovation and brilliant scientists, and you know, capital investment, like we have medications for that we never did, or, you know, kids born with diseases that 15 years ago, never would have survived into adulthood that are now living into their 60s. And that's amazing. But part of what that does is it sort of draws focus from what about the people who are here now who have a disabling condition, who don't have that freedom? How are we going to care for them, and the Medicare and Medicaid program, you know, originally were intended to be that acute care, because the science wasn't very good. We weren't gonna live to be 80, we would die of a heart attack in our 50s. Luckily, that's not the case anymore. But I feel like it takes a long time for lawmakers to catch up to that. And to realize, not only is that not the case, but you can't just ignore long term care and hope it goes away as an issue it, it's there it's ever present and only gets more important as people in America get older and continue to get, you know, we continue to have sort of this imbalance of more older people relative to babies being born, which is not a bad thing, but it's also how are we going to improve quality of life and build a kinder society that allows people to have disability and still thrive? And especially after COVID That's going to be a huge issue.

Rosanne 39:55

I agree. And it's well yeah, because it's coming, you know, and you're right, you It doesn't just go away. It's not just by ignoring the problem doesn't mean it's going to be fixed. It gives me hope that you say that, that you think that it's, it's going to be a change, or that we're making progress. So I'll take your word for it there, Grace, because you know,

C Grace Whiting 40:16

Good. I'm thinking of Reading Rainbow and how LeVar Burton, you saw I say, But don't take my word for it. You know, I wish I could read the tea leaves on this, but I will say, I think it is. I think every person has some stake in caregiving. You know, as to paraphrase of First Lady, Rosalyn Carter and Carter. Yeah, yeah. And I think that that means, especially the pandemic, we're coming out of it, we're saying, like, what matters to us most, you know, and we want to be able to care for the people we love. We

don't want to live in fear that something bad is gonna happen to the people we love. And the pandemic, I think, was almost like an empathy machine for caregivers, because it helps people realize who were not dealing with caregiving day in and day out. But some of those fears and anxieties and challenges were, and I wouldn't be surprised if that doesn't help continue to shift the conversation. I think it already has been fun. I also feel like it demonstrated more than other efforts, how important it is to support caregivers, and how many people are in that situation. And so I think it'll be something that in the long run will help push for change.

Rosanne 41:32

I agree. I agree. And I just want to ask you, what drives you to try to make these changes and to push these things?

C Grace Whiting 41:41

Oh, my gosh, well, this is cheesy Rosanne, but you know, it's meeting, it's meeting people who are living it, you know, I always think about when I first came to Washington, and you know, I'm from the south originally, so I still had big Tennessee hair from law school. And practically a country bumpkin. And my boss had been invited to a meeting on veteran caregiving at the White House. And I was standing in one of the fancy blue room or something like this. And I was looking out on the lawn, so I could see like, all these other people and I, and I'm just like, bubbling over, like, so excited, like, I never thought I would be standing inside the White House and not, you know, outside with my nose pressed up against the gate. And there, there was a woman standing next to me, who was a caregiver for wounded warrior. And she'd been invited there on behalf of the first and second lady at the time. So Michelle Obama and Joe Biden, and she was one of these Elizabeth Dole Foundation, sort of hidden hero fellows. So there were all these caregivers there. And I said to her, Wow, can you believe it, I never, I never thought we would be on this side, you know, standing in the White House at a reception with the First Lady's and, and she looked at me, and she said, All I can think about is my husband back in the hotel room all by himself, and whether he's okay. And I think about that moment, probably every day that I'm working, because it really brought me back to Earth and helps me remember, you know, all the accolades and fancy receptions and dinners in the world. don't mean anything, when you're hurting for someone that you love, and you're advocating for them. And you can't even see the good you're doing in the world. And I really felt like one of the things I can contribute, is I can advocate for people who don't have the capacity to advocate for themselves, because they've given so much to this other person in their life. And that, that motivates me. I'm a fighter at heart. So it helps me, you know, it's like, Don't worry, I gotcha. I'll pick it up from here. And try to find ways to keep folks engaged and, you know, as they're able and as they want to.

Rosanne 44:05

It's beautiful grace. And I will say thank you, for all of for all of us, for all the caregivers that you fight for. Thank you.

C Grace Whiting 44:13

Absolutely. I love this work. And I will also say one thing that's nice is the people that I work with, and the people at our colleagues, organizations, they love this work. So that's the to me, the most exciting promising thing about this new national plan is you actually see it, you see that sort of shared Goodwill

for caregivers coming out. So there's lots of people like me, I think, and they're starting to find each other, which is an important part of it.

Rosanne 44:39

Yeah, well, and I see, you know, you see group after group and there's things that are being organized and there's resources that are being provided and I and for me, it gives me hope in looking at that that somebody is paying attention that there are people out there like you and your colleagues that are saying, we're working on this, like, you know, trust me, I'm working On this, and that gives me hope. Yes. Grace, do you have any final words or thoughts that you'd like to share with caregivers?

C Grace Whiting 45:06

If people can when they're sort of giving things for everything, you know, to just take a minute and give thanks for yourself and for what you do as a caregiver. And it's hard to do that sometimes I am totally, even as a child, I was always obnoxious, like, I'm fabulous. But it sort of take that on, even if you don't feel it and look in the mirror and be like, You know what, I'm fabulous. I'm, I'm doing good in the world, you know, and I'm upholding my values, and I'm caring for someone I love. And even though sometimes it's really tough, like, I'm thankful that I'm here to do this. You know, and I think making sure to recognize and thank yourself for all you've done.

Rosanne 45:49

A big thank you to C Grace Whiting not only for being my guest, but for her tireless efforts on behalf of family caregivers. To access the abundant resources, innovation and research the National Alliance of caregiving has assembled, visit their website@caregiving.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 also find us on the whole care network, as well as anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood The Podcast, feel free to leave me a message and let me know what issues you may be facing and would like to hear more about. Or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song Mamas Eyes, from her album Lessons In Love that you can find on the iTunes store. I hope you found what you were looking for today, information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you join me next time in Daughterhood.