

Daughterhood the Podcast BONUS:

Working While Caring with Karen Kavanaugh, Rosalynn Carter Institute and Anne Tumlinson

[Rosalynn Carter Institute](#)

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SPEAKERS

Rosanne, Disclaimer, Anne Tumlinson, Karen Kavanaugh

Disclaimer 00:02

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Rosanne 00:39

Hello, and welcome to a bonus episode of Daughterhood the Podcast. I'm your host Rosanne Corcoran Daughterhood circle leader and primary caregiver. At Daughterhood, we hear your challenges in navigating the healthcare system and how it can be both frustrating and disheartening. In each of these bonus episodes, I have the pleasure of speaking with Daughterhood founder Anne Tumlinson where we will bring the caregiving conversation to a different level with change leaders and policy experts. I hope you'll join us. Karen Kavanaugh is Senior Director of Strategic Initiatives at the Rosalynn Carter Institute for Caregivers. She leads the development and launch of the institute's initiatives designed to expand supports to strengthen caregiver health, resilience and well being. Her portfolio includes Working While Caring, and initiatives designed to deepen the research on effective workplace supports for caregivers and to expand access to those supports. She is also leading RCI's caregiving, typology and bereavement initiatives. Today we discuss the challenges that affect caregiving employees, employer viewpoints and ideas and policy changes that can help. I hope you enjoy our conversation. The Rosalynn Carter Institute has gathered substantial research both through their Invisible Overtime Report, the Working While Caring report and countless other cohorts and research that they've done. The elephant in the room seems to be the lack of policy for caregivers in the workplace. There's maternity leave, there's paternity leave, but there is no leave for caregiving. Can you talk a little bit about what you found and how that can change going forward or what we can do to try to change that going forward?

Karen Kavanaugh 02:26

And nice to talk with you Rosanne and Anne I just want to start with the famous quote of our founder, Mrs. Carter, there are only four kinds of people in the world, those who have been caregivers, those who are caregivers, those who will be caregivers, and those who will need them. And so essentially, that's all of us. This is a universal experience. Caring for someone who is aging, ill and or disabled is a life course event. And it's an experience that many of us will have more than one time. Sometimes we'll be the care recipient, and sometimes we will be the caregiver. However, it's systemic treatment and public policy, health care and employment does not recognize this. It's still treated very much as a one off somewhat unusual experience and siloed. And insufficient, insufficiently considered, despite its prevalence and the fact that we are aging, and as you have previously discussed we were right there kind of on that cliff, I think 2030 is the year right. So that's the context that I just wanted to set here. So it in many ways I don't want to, to point a finger or blame employers, it is every single system that we have has been either ignoring this or, or another way to say that is putting our collective heads in the sand about what is already the case but what is about to be an even larger issue for families, government, employers, the health care system. So I can start by just talking to you about Working While Caring our initiative and sort of our theory of change, not our truth of change. I just want to say that we have a great deal of humility in this. So what we have designed here through working while caring is really an our approach is partnering with employers, and particularly small and medium sized employers, employers where the workflow and operations is such that you know they need people doing the jobs on the floor in a clinic with a concentration perhaps of hourly versus salaried workers, and those that do not have the kinds of resources that very large organizations have. This doesn't mean we would exclude large organizations because some large organizations are characterized, characterized by what I just described. But we're not talking about those really well resourced organizations, we're trying to help the others. And so this initiative was really designed to advanced three objectives in service of two goals. And I'm going to quickly talk to you about those objectives. The first one is to raise awareness of employee caregivers and we define that as someone who is caring for somebody who is aging, ill and or disabled while working at a paid job. They are a significant cohort of the workforce, one in five US workers is providing this type of care. So that doesn't include child care, unless the child is ill, or disabled. Number two is to begin to fill in the gaps on what is empirically understood about effective support for employee caregivers. And we define effectiveness here by keeping someone attached to the labor market all kinds of negative outcomes into if someone has to separate from the labor market, even for a temporary period of time. And most people, most employee caregivers want to provide care and work they don't want to have to choose, they just need more supports, and also to help them feel supported in their caregiving role in order to reduce the stress of balancing both our own survey, and many, many, many other surveys that look at this have found that the number one challenge for employee caregivers is the stress and strain of balancing both. And then third, and I can talk more about this is to really engage employers in the broader context of care, they don't often spend a lot of time thinking about the fragmented and as Anne loves to call it the dysfunctional long term care system in this country to the extent that we have such a system, but they should, because they are already paying for the costs of that fragmentation. So our theory here is that could we over time, first by engaging them in their own self self-interest around workforce recruitment and retention but then could we help to connect the dots for them between what they are seeing within their workforce, and this larger fragmentation in order to organize them cultivate them to become much more vocal and visible champions for reform at the federal and the state level. And there's a question that at some point in this conversation, I'd love to ask Anne in terms of her history with long term care

finance reform, and again, our theory here is that employers were not sufficiently engaged in that conversation. And we all know the type the political clout and influence that they have. Could we help to do that over time? Gonna stop there?

Anne Tumlinson 08:03

Yeah, no, I was thank you so much, Karen, I want to say that I have high hopes for employers to get more involved in changing some of these systemic issues, because this really isn't something that they can really do on their own. And no matter

Karen Kavanaugh 08:25

Yes

Anne Tumlinson 08:26

How many wonderful programs that they offer or services that they offer, it's just a little band aid on a bigger problem. And so, you know, like, health insurance as like an employee benefits. So in many respects, employers are a little bit less motivated to save, for example, push for national health insurance reform, because they still use health insurance benefits as a way of differentiating themselves in the market for talent. This isn't going to be one of those things like, Hey, we're just way better for caregivers. I, you know, to some extent, it's there's you see that with parental policies, but even then, there's just there's a limit to what employers can do to make up for the gaps in the system. So what I have seen in the past is that when the issue is framed, or has been framed, just in terms of financing, like we need a new social insurance program that will pay for long term service and supports, the employers tend to kind of back away that is scary to them. That's like, you know, social insurance like is not really our thing. We got a lot of fish to fry from a policy perspective but I do think going forward if we can begin to frame it more systemically and make it Yes, financing is a piece of it, but infrastructure and you know, funding for the area agencies on aging funding for free public services, better health care service delivery that's less siloed and fragmented and is all of those things because I think what they're gonna find over time is that is the stress of balancing both is created, in large part because a lot of the work that the family caregivers are doing is essentially kind of correcting for helping to correct for systemic problems. So if we can address the systemic prompts, there's always going to be work for family caregivers, we're always going to be taking care of each other, and there's more care to be provided, and there's nothing that's going to change that. But if we can address the systemic problems, that reduces a lot of the stress and the burden, and, you know, you know, gets us out a little bit out of this world in which it's so family specific and individualistic. So I do think if we can frame it to employers that way, and we and they start to really when they start to really feel this and like within the next five years, I think we could get some good engagement.

Karen Kavanaugh 10:54

Well, that's our theory and I love your framing and in fact, we're seeing a little bit of that through the first innovation lab. So I'll talk to you about how we are engaging employers sort of that central piece, and that is through organizing and supporting employer innovation labs. And our first one is in the homestretch and this includes five employers in Southeast Michigan, largely in Southeast Michigan, and they represent the retail manufacturing and nonprofit sectors. Most have workflow and operations cannot be done remotely or many of their employees cannot do the work remotely, where they need to

think about flexibility in a more creative, thoughtful way. They all offer some level of paid leave, but are located in states that do not presently have a state paid family and medical leave policy. So it's largely FMLA. And then the whatever they offer through PTO, so we've been working with them and we are going into our seventh meeting with them, we spent about 90 minutes and I can tell you that they agreed to join this innovation land because they are very aware of employee caregiver, within their own workforce, but they're not really sure what to do, how to support them. Many of them talked about the fact that during the pandemic, they heard over and over from parents, especially of parents of school aged children, but while they knew that many of their employers were or employees, were also caring for someone who's aging, ill or disabled, some in skilled nursing facilities, by the way, even if someone you all know this, but even if someone is in a skilled nursing facility, there's a great deal of care that happens via family members, but they were quieter, they didn't raise their issues with them, unless it was an absolute crisis. So they've also, some of them already have an employee resource group that's focused on this type of care but again, they're quieter. So one of the things that they asked us to talk to them about are what are what are effective supports for caregivers, writ large, whether that is within the workforce or not in the workforce and as you know, there's there's just not a lot of empirical evidence about what is effective within the workforce. However, there are five things that show promise for supporting caregivers and particular employee caregivers. One is a caregiver friendly workforce and want to talk a little bit about later. I wish it had a little bit of a sort of more robust title there. But it's really about normalizing this type of care within the workforce, having leadership talk about their either their own stories or elevating it, training supervisors and managers to have these types of conversations, shouldn't an employee bring this issue to them, recognizing some of the signs, those are just, you know, some things, employee resource groups, but also importantly, it's not just what you say, within the workforce, right, but you have to have concrete support or tools to then support people. Another piece is flexible scheduling, which is, you know, a challenge in some workplaces, especially the for the employers that we are working with in Southeast Michigan, but there are some opportunities through such things as job sharing, use a little bit more scheduling control. Another is psychotherapy, cognitive behavioral therapy or counseling. A fourth is connecting caregivers to at least one form of support, particularly for those who are caring for someone with dementia or the frail elderly and then the fifth one, that's the one that is sort of the the one we're not paying the most attention to right now, because the one that employers have the least ability to affect right now and that is embedding caregivers more robustly within a care team. So sharing that they have information that they feel supported in decision making, that they're not just off to the side and well, this type of care will be required, we're just going to assume you're going to pick it up, but know that they are part of the team. So in our innovation lab, these employers are actually looking at those four out of the five things that they can do. So they are either well, they are doing both, they're looking at their existing offerings, and where they may be able to build those out where they may be able to take a look at, okay, do we really have the types of services available for caregivers, so people who are trained and understand what the issues are for employee caregivers, and then can connect them to services. So one example there is EAP's they're also looking at a little bit, you know, where could they tweak their flexible policies where they might work. And then in terms of connecting to formal support and services, they are really interested in innovating here and piloting, this is not going to be a surprise to either view, but potentially sharing care navigators who are trained, and have deep knowledge in Medicare, Medicaid, private insurance, and importantly, the local landscape of home and community based services. So what we think will happen

there is that these navigators could be very helpful to employ caregivers, but it will also at the same time, right, reveal the gap.

Anne Tumlinson 16:55

Yes.

Karen Kavanaugh 16:56

And that is where we can begin to connect the dots, and the public policy context.

Anne Tumlinson 17:02

Oh, it's brilliant. That's such a brilliant design, because that's exactly what I was just thinking was that you're gonna have this rich source of data, from the questions, you know, for the problems that each of these care navigators solve on that are able to solve and are unable to solve are able to support you know, you know, both well, and not well, depending on what's available in the community. And even just the time that they have to spend on the the nitty gritty of the day to day for caregivers, you know, like, like just the the kinds of things it takes for ever you're working. But your mom's prescription was supposed to be filled yesterday, but the CVS is out of medication, but they didn't call and tell you, so now you got to find you got to call around a whole bunch of other pharmacies, and then somehow you have to get off work to get to those pharmacies, before they close. The doctrine, as you know, like, that is an hour of work, where I'm also supposed to be on a call, or I supposed to be on the floor, or I'm supposed to be producing by according to a quote, you know, and then you're asking me to also have to be doing this. And then oh, by the way, my kid, you know, teacher called, and it's just, you know, at a certain point, you're just like, why am I even bothering to work?

Karen Kavanaugh 17:06

Yeah

Anne Tumlinson 17:25

What is the point of it, you know, obviously, to make money and that's the inability to just quit is the reality for most people. So we when these care navigators getting involved, those that kind of almost, I want to call it ethnographic anthropological data is going to be so illuminating and valuable I feel like to the, to the employers and employers more broadly.

Karen Kavanaugh 18:57

Yes. And it reminds me of another conversation we had. The employers also asked for a presentation on home and community based services within Southeast Michigan. So we engaged a wonderful nonprofit provider, the Hammond Center in Detroit, and they primarily serve caregivers of older adults. So I just want to recognize that and recognize that there are other types of care to know, middle aged spouse with a cancer diagnosis or a sibling with a mental health diagnosis. But they were the employees were very engaged in that conversation. It was a very deep conversation. The woman had very, very extensive knowledge about home community based services and Medicare and what it doesn't cover and Medicaid and private insurance, as well as the barriers to talked about transportation, the lack of transportation. And she even talked about some of their clients were being they were using their respite, but that their caregiver had to take unpaid leave an hour of unpaid leave on either end to

drop them off, and then to pick them up. So that was a really rich discussion, how to begin to like, and and I would say that many of these employers who are participating have their personal experiences, very eye opening, and

Anne Tumlinson 20:36

It's always that.

Karen Kavanaugh 20:37

Yeah, and again, and like we, you and I have talked previously about one of the employers went to well, you know, I've been thinking of establishing a childcare center for you within the workforce for my employees doing, maybe I should be thinking about building other types of care. So, so again, like I think it does feel to me, at least through these conversations that our employers, it's not, you know, disparate facts that we're trying to connect, but it's right there.

Anne Tumlinson 21:10

Right, right. Well, I wouldn't just interrupt really quickly emcee this, and then Rosanne I'm gonna because I know Rosanne has many observations as well, this is a little bit so bear with me, everybody's listening. So I was in Atlanta, I think I told you this Karen, I was actually at a conference about that was about brain health. And so it so the sort of thesis of the conference was about how employers in the private sector can and support healthy brains, both optimizing brain health and preventing cognitive impairment over the lifespan. So this isn't just like, you know, how do we deal with somebody who's 80 or 65, or whatever this is sort of like when you're 40, what can employer be doing, both in terms of their, you know, sort of reducing stress in the workforce promoting, you know, healthy lifestyles, all of the things that go into good cardiovascular health, but also, anyway, so it's very, very exciting and interesting conference, and, but one of the things that came up was caregiving, because of course, one of the most stressful as you all have proven, and other research that you've done at the Rosalynn Carter Institute, I think, and CDC has been that, you know, the act of this, the stress involved in this burden of the dual roles is, is actually damaging to not only your physical health, including your brain health, and then when so I think I brought that up, or someone else did, and I amplified it, and then like, the floodgates opened, and, and all of a sudden, these employers were saying, like, they feel like for them, all of a sudden, kind of out of the blue, this issue of family members in these caregiving roles has become, like sudden, and extreme. You know, they're like, all of a sudden, all of our employees are absent are leaving our, you know, less productive are less, you know, the well being is going down all of those things. And it's all because this. And, wow, I do think that we're sort of on this cusp and the fact that you're doing you're just this work is so important that you're doing and it's so well designed as just beautifully designed and thoughtful. That will give us a lot of information, which will be very well timed, because I think we're we're really at a point where employers are starting to feel feel it in their workforce on a day to day basis. And I'm curious Rosanne and all the many conversations you have, oh my goodness, so many people and your own personal experience. And

Rosanne 24:01

Absolutely. Well, it struck me when you said they have a fear of speaking up. And I believe that because then you're that person that they can't depend on. You're that person that may or may not be coming in because you have to do this this work yet you can say to anybody, I'm caring for my mom,

and it's so hard. Oh my goodness, me too. Or, oh, my sister's doing this or my cousin's doing whatever we everybody is doing it or has been touched by it, but are afraid to then bring it forward because let's be honest, if your manager or your supervisor doesn't have that experience, it's going to be a little bit different because they don't get what that means. So you're you're hesitant to put that out, because you don't want that to come back on you. Right. So I don't know if there's a way that you're finding how to reach out to more people like it's really okay, you can tell us

Anne Tumlinson 24:59

Building the trust Yeah. How do you build that trust? Right.

Karen Kavanaugh 25:02

Yeah. And also people are reluctant to come forward because they don't want to be viewed as less engaged or committed team member. Exactly. They don't want to let down their team, they don't want to be passed over for promotions or more responsibility, like, and, and so, there, you're right, this sort of gets to the whole conscious conversation around psychological safety in the workplace. So it's in and it's multi level. So there's, there's the organizational culture, which is critical. And you know, also, like any other culture, it's hard to change but it can be changed. So that's, that's one piece that employers look at is how are we even recognizing this type of care? Are we talking about it? How are we talking about it when somebody's on boarded? Are we proactively saying, we know, some of our employees are also caring for someone who is aging, ill or disabled, just like parents, and we have these benefits, these tools that we can offer. Or to be very specific about, we want you to we want to help? If this gets to be a particular strain, we want we want to first work with you to see what can we do? What can we prevent? Or could we prevent you from having to reduce your hours, or leave the workforce altogether? So that's really important, having leadership or CEOs share their own caregiving stories is really important as well. Also important, as you all know, like the key to employee satisfaction often comes down to the their relationship with their supervisor or manager. Right, absolutely. So ensuring that supervisors and managers are trained, that they have the tools and that they have the support. I mean, oftentimes, they're resistant because they are responsible for the work product. So that that's a really important component of this and in time, we helped to do more sort of focus groups and understanding about that aspect. So and then in general, Rosanne, you know, some things that are good for caregivers are good for all workers. Right. And we were also asking the employers, let's do an evaluation of what you already have to see. Do you consider it a tool or support for caregivers? And if not, why not? And could it be? Could it be and or could it be tweaked a bit to become a tool.

Rosanne 27:59

Having the ability to have a care navigator, if if, if they can figure that out to bring that in as part of a service would be life changing. It would be life changing for for so many caregivers,

Anne Tumlinson 28:13

Just to have that it's that like, because so much of the time what we see and Daughterhood is that like that question? Like, where do I go? Where do I even start? There is a lot of time that is spent just trying to get a grip or a handle on this whole new world that you've entered into? What is it was it Raz Chast says, you know, what is this planet that we have now landed on or whatever she's the best quote. And I think that to have that impact that professional to help walk you through it. And somebody who's trained

and prepared for that is going to be really it's gonna be really interesting to sort of measure that impact. And yeah, you know, I was also thinking a little bit about public policy and all of this and sort of, you know, so in the way my brain organizes, it is like what we were talking about earlier, right, which is like the employers are doing these things to kind of patch up a broken system. So from a policy perspective, to me the most impactful and important work that we can do is to be working on improving the system funding our area agencies on aging funding services, and you know, improving the way that healthcare is delivered. So it's less challenging all of that infrastructure, systemic type work, but a lot of advocates family caregiving advocates do focus specifically on policies related to the workplace itself. So for example, you know, paid family leave, as a requirement was a really hot one you know during the all of the kind of COVID related lawmaking that happened in the last couple of years. And I was looking over your list your five, you know, things and like leave is definitely one of them. But it feels like everything else I don't I don't like flexible scheduling, mental health counseling, connecting to resources, tools to support I mean, I don't I'm curious, Karen, like your just your thoughts about whether there are also policy solutions as they apply to employers? Like, should we be forcing employers to be offering flexible scheduling? I'm making that up. But is there anything else that's like top of mind for you a policy solutions or with respect to working and caregiving?

Karen Kavanaugh 30:47

Oh, gosh

Anne Tumlinson 30:48

I'm sorry, I put you on the spot

Karen Kavanaugh 30:49

I know, you're not going to be surprised at my, my response. And it's not lawyers and mean, you know, I'm a broken record on this. If we had a more functional, coherent, responsive, high quality, affordable health care system for everyone this would put take, I think it's significant burden off caregivers, right? Because, I mean, they are the backbone of that system. Right?

Anne Tumlinson 31:19

Yep.

Karen Kavanaugh 31:20

So that will be my number one.

Anne Tumlinson 31:22

I that's what I think too.

Karen Kavanaugh 31:26

And with respect to employers, I don't I'm not sure. At this point, I sort of go back and forth, right. I mean, I mean, even within this work, I feel I feel this tug within myself, like, oh, employers, they have, you know, in terms of the power in this country, and political influence, they're sort of up at the top, and they're making record profits, they should be, you know, required through public policy to design higher quality jobs, and they should be, you know, they should be paying higher wages. However, with our

theory of change I have, I also have to really adopt some humility here and really listen, because the the five employers we are working with, they are committed, they are passionate, they are running a business. And I think they're really trying and I think, you know, I mean, others, I'm sure will call me naive but what I love about this work is where we are attempting to partner with employers, and many of them would say, you know, we knew that this was an issue, we didn't really know what to do, you offered us this opportunity. And so we took it, we were investing our time and some expertise. And this is not something we would have been able to do immediately. And one of them said last week, you know, I initially thought, you know, I don't think I can prioritize this cohort right now. And she said, now I think I can. So I love that. And I think over time, you might be able to give you a more precise

Anne Tumlinson 33:01

No, no, I mean, I think of the fact that you're, you're one of the top experts in this area, and you have a nuanced point of view. And I think that's, there's a little Anne soapbox, but I think nuance is missing these days. Every policy conversation that I'm involved in, and it's like, it's like burn the bridges, black and white, they're bad, they're good, they're good, they're bad. I just, I love what you're saying, because it's like luck, we all have to live in this country together. And we've got to figure out a way to work together. And we've got to bridge that what a lot of what you've been doing with these employers is essentially bringing them along, educating them in the in the value in the in the quality of what the caregivers receive from them, will be impacted by that, as opposed to a mandate of some kind that comes from a policymaker that, you know, kind of hits them on the broad side, they don't really know what to do about it. So I'm not making excuses for them, either but you know, I do think there's this. Yeah, there's a nuance here that, you know, we have to appreciate.

Karen Kavanaugh 34:07

Yeah, and I think about, for example, the mandatory leave in small organizations. Sometimes then the work just won't get done. So that said, I do think there's a lot of a lot of room for improvement in quality jobs. And this aspect must be a component of quality jobs, recognizing and supporting someone who is working while providing care for someone who is aging, ill or disabled.

Anne Tumlinson 34:40

It's a larger, I'm sorry, not not to wax philosophical here, but it's a larger, it's a larger sort of economic, yet a country where we have really prized productivity, and it has served as well and it has served us poorly. And we haven't organized this gets back to the larger work. You know, our businesses are responding to the economy that we are in and, and we and again, we, you know, we there are many good aspects of our economy, we, we produce and invent a lot of really cool stuff. But if you but if you were running a business in Europe, there's a certain amount of just like, you just kind of like, well, this employee is gonna be gone for a year, and we're gonna know about, maybe we're gonna be less productive, less profitable than I can do about it. Whereas here in the United States, there is a little bit of like, and I'm thinking a little bit as a business owner, myself, I have 30 employees, you know, and like, I do feel like we're on a bit of a run a bit of a treadmill.

Karen Kavanaugh 35:36

Yes.

Anne Tumlinson 35:37

Even if I wanted to kind of slow that treadmill down. It's, you know, we interact with other businesses that have expectations of speed. And so when somebody leaves to go out on maternity leave, that's six months long, it the impact on the business is very profound. And, and other people end up stressed out, and the to it isn't there. It's like this little domino effect all over the place. And it's hard to go in and just kind of crack for one thing when it's like, what I forgot what you said, like a family friendly, friendly. So that notion of normalizing care within the workforce, we kind of have to normalize care within society.

Karen Kavanaugh 36:21

Yes,

Anne Tumlinson 36:22

yeah. And so that, kind of as everyone adopts, and the larger ecosystem adapts, and we all just kind of take a little bit of a deep breath and and kind of accept a lower level of productivity, somebody, economists everywhere are twitching, you know, because we because we start to define productivity differently. It's, you know, tending to another person's needs is not part of the economic productivity engine. Yes, but it is absolutely productive work.

Karen Kavanaugh 36:56

Yes. So, yes. And there have been attempts to redefine GDP along those lines. So yeah,

Rosanne 37:03

Well, you know, everybody, I mean, we're living longer, right? People are living longer. It goes hand in hand, these people, the people that are living longer are going to need care. And I think it's coming to that head now, where before it was like, oh, that's fine. Oh, they'll figure it out. Oh, they'll just

Karen Kavanaugh 37:19

Its in 10 years its in 20 years. Anne's been on that other side raising the flag and ringing the bell.

Rosanne 37:29

It's coming, it's coming, whether you like it or not, yeah.

Anne Tumlinson 37:33

Back in the 90s. When I were I had been working on these issues since 1989. Even maybe 88. But um, and sitting, you know, there was the house aging committee at the time. And a new Congress as I was a staffer, and I wrote about the crisis, the aging of the baby boomers in 1992. You know, so here we are.

Rosanne 37:56

2023 2023.

Anne Tumlinson 37:59

And it's actually finally here.

Rosanne 38:01

Yeah. Well, in 2010, Rosalynn Carter needs to put out *Averting the Caregiver Crisis, Why We Must Act Now* in 2010.

Karen Kavanaugh 38:10

Right. And largely, we could read issue that change the date. And, yeah,

Rosanne 38:16

I'm sure you could

Karen Kavanaugh 38:17

And we had a pandemic.

Anne Tumlinson 38:18

Right. Well, and you know what, I'm glad you said that. Because the one other thing I just want to highlight that's been on my mind lately, has been, so we the the aging of the population, which is just dramatically increasing all this, we were talking about that, but also is colliding with what I call the increasing complexity of need in the overall population. Yes. So we all either ourselves, or our family members are much more likely today to be affected by mental health disorders, substance abuse disorders, violence in society and environmental challenges, the you know, sort of the degradation of our food supply, this making a stall unhealthy, and increasing our chances of having, you know, long chronic conditions mean, there's this confluence of factors that are contributing to actually the greater need for us all to be caring for each other, usually in family units, but sometimes also in front of groups and in other like kinds of community spaces, churches and otherwise. So we got the age of the population, and then we have this growing complexity of need in the overall population that is creating conditions that require support from another human being who loves you. Yes, yeah. On a day to day basis,

Karen Kavanaugh 39:41

Or maybe doesn't love you quite so much, but wants to help you do this.

Anne Tumlinson 39:46

Who is it was feels obligated to you?

Karen Kavanaugh 39:49

Yes, yes. I'm glad you raised that. And because we do have this other initiative that is in process to attempt to will create a new framework of caregiving typologies of profiles that really center first the the experience and the need of caregivers without negating that this is the dyad is really important the caregiver care recipient, but that is agnostic in some ways to disease condition or condition, but really looks at what is the experience? Is it short term and very intense? Is it longer term and, you know, the condition progresses? And so the intensity is going to get more deep? Is it, you know, intermittent, and then we're really interested in also what the how these social characteristics interface with this to either enhance the difficulty that challenges of the experience or mitigate against that. So factors such as family size and relationships, complexity of the role, race, ethnicity, do you live with the care recipient or

not in relationship to the care recipient? So, again, I, I sort of feel there's, as you know, when we talk about caregiving, oftentimes, you know, you're either thinking about someone who's caring for a child, or an infant, or someone who's caring for someone who's aging, but there's, as you said, and there's all there's so much additional care that goes on someone with a mental health condition, and who, who is really still dealing with a level of stigma, I do think it's changing, we've made some progress. And this was one of Mrs. Carter's pioneering issues, you know, 40 years ago, but that's, you know, that creates a different kind of experience mentioned earlier, cancer care, prognosis matters, you know, and, and also helping people to, in many of these situations, deal with inspiratory, grief, ambiguous, when someone has dementia or Alzheimer's, and then bereavement and, and the loss of the role. So all these huge, so it's complex, and I was just on a call this morning, actually, with Fidelity and they to have been like, you know, they're doing some great things for their employees. And they've been thinking about this for a long time, it's kind of part of their client customer service. But they also said, you know, we've been at this, and it's, it's complex. We're just trying to figure out also, you know, where can we add value,

Anne Tumlinson 42:39

It's so if this work you're doing on the, on the, on these on this typology and framing is, I just can't emphasize enough how important it is. And I think one of the misconceptions for people who haven't actually been in this situation is that they is that this is somehow very much akin to or similar to being a parent. And while they're both caring roles, you know, typically developing three year olds are all doing the same thing. Your family, you know, we could all have a 45 year old family member, and yours has cancer, and mine has a substance abuse disorder, and my mom has, you know, it's 85 and ran a marathon but yours, you know, so there's, this is, and then you know, and then the family dynamics to my Lord. So that in and of itself is a whole layer and, and so I just think our ability to respond will depend so much on understanding that typology and the need. And we it Daughterhood a little plug here for the work that Rosanne is doing on the content side and our programming around circles, which are now for those of you who don't know, we're moving more and more of those into a virtual environment so that we can be a lot we've been, we've been targeting by geography, many of the reasons we've been talking about right to do with helping people access the system, but what we're finding is that what's really needed and wanted and desired is being able to talk about this particular aspect of the challenge that this particular person is facing at this particular time. And it's all point in time, right? You know, like, technology, you're gonna move in and out of different types, you're going to be it into it, just as you said. So we're going to be moving into kind of developing the content in the in the programming in a way that is meeting hopefully, the needs of these individuals, and I'm sure it's going to evolve enormously over time and your work will inform it hugely.

Rosanne 44:39

What do caregiving employees what can they do now? In the meantime, before the employers catch up to hey, I've got people that work for me and they need help. What can they do?

Anne Tumlinson 44:51

I love how Rosanne always brings it back. I'm here to chat I'm like, you know, existential questions and academic this and that and frameworks, whatever and Rosanne's like okay, but we have people listening who are working today. What do they do? Here we're like oh...

Karen Kavanaugh 45:09

Well, certainly, they should. And this would not put them at risk, understand what what benefits are available to them. And they're going to be the experts and best, they're going to know what what meets their needs, right? If they have a relationship, that they feel secure and safe in with their manager or supervisor, talk to that person, you don't even have to disclose all of the details at all.

Rosanne 45:40

Sometimes less is more.

Karen Kavanaugh 45:42

Right. Right. There was always some level of unpredictability here. So maybe even just having that as a sort of table setting piece, you know, reinforcing if this is the case, I want to keep working, I want to be engaged, but I need some supports, in continuing to do that, and fulfill my caregiving role. To the extent possible, depending on if there are small teams, and you feel safe and secure, letting your team know, as you know, oftentimes somebody else will pipe up and say me, too, if there is an employee resource group, specific to this type of care. I, you know, while it's important childcare and parents doesn't, really encompasses this, and really also understanding the benefits, if any, that your care recipient has access to

Rosanne 46:39

Medicare, Medicaid, VA, Aid and Attendance.

Karen Kavanaugh 46:42

Yeah.

Rosanne 46:43

And the like. And what if the supervisor isn't a safe place?

Karen Kavanaugh 46:50

Well, I I would not give advice exactly on that. Other than to say, I do not advocate that people put themselves in unsafe situations or situations where they don't feel comfortable.

Rosanne 47:10

Fair enough.

Anne Tumlinson 47:11

Yeah, I think the, the reality is, unfortunately, so many people are not in a position to change jobs. But if you are, and you don't feel like you're in a supportive environment, I mean, in an ideal world, we will reward employers with talent, who make this range, it possible to work while caring. So if you have that kind of market power, where you can switch into a more friendly environment, and you can actually suss that out in that process, then that's a great thing. But, you know, I think I want to be realistic that that's often, you know, that's a pretty theoretical concept, as opposed to something that really is possible for many people. But this is, and this is where maybe we start to get into some, this is maybe

where a policy can be helpful. Yeah, setting, maybe setting some standards or legal protections or, you know, the Family Medical Leave Act that enables all of us to take 12 weeks of unpaid leave, when, in certain size companies when you know when we need it is as a really has been an incredible,

Karen Kavanaugh 48:23

Yes

Anne Tumlinson 48:24

Incredible gift.

Karen Kavanaugh 48:25

Yes. And I will say that, from my own experience, when I needed to take leave for a caregiving situation, my supervisor proactively said, I'm going to make sure that the paperwork is done. And I want you to at least take start with three weeks. Any more, you tell me. And don't I mean, so again, I am not suggesting that everyone has that type of situation. But that was really, really helpful to me at the time. And really, I did only need I needed a month. But that month was really helpful to help me to sort of readjust, understand what, what was coming. And also, I quite frankly, just could not have worked during that time. machine with the care recipient was changing. It was unpredictable. And so it got me through to a more predictable environment in which I then could better assess, that's great. And I guess I would also just sort of say that as as we've been talking today, a couple of things, employee caregivers, sort of on average, you know, they've got a second part time job with care. Part time if their lucky. The majority want to want to work and to provide the care but it is incredibly stressful and we need supports that address, directly take on that strain and stress to reduce it, and that there's not likely going to be one silver bullet here, right? Because caregiving is, you know, not homogenous, there likely needs to be a suite of different workplace supports, as well as non work, place supports.

Rosanne 50:17

It would be great if all of that could come together, across the board for everybody. And you wouldn't have to worry about it. You wouldn't have to make that choice.

Karen Kavanaugh 50:26

Yes, yeah.

Rosanne 50:28

Anne any final thoughts?

Anne Tumlinson 50:29

Not any, except just to say such a huge thank you to Karen

Rosanne 50:33

Absolutely

Anne Tumlinson 50:34

Thank you for being here. Thank you for your work and your leadership and your thoughtfulness and just everything about you. That's you.

Karen Kavanaugh 50:43

Thank you. Thank you to you both. Looking forward to working with both of you as we move forward. And I will say if there is a silver bullet, we will work to find it.

Rosanne 50:53

A big thank you to Karen Kavanaugh for being our guest today. For more information about caregiver employee initiatives and reports, visit [Rosalynncarter.org](https://rosalynncarter.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 Subscribe and Like us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood the Podcast as well as on daughterhoodthe podcast.com Feel free to message me on any of these sites 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 as Susan wrote for our bonus episode theme music, even my guitar. 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.