

Daughterhood the Podcast Episode #27: Rajev Mehta and the Atlas CareMap – Finding Your Support as a Caregiver

RESOURCES

Atlas of Care Website: <https://atlasofcaregiving.com/>

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SPEAKERS

Rosanne, Rajiv Mehta, Disclaimer

Disclaimer 00:02

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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 are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in Daughterhood.

Rosanne 01:29

Rajiv Mehta is the CEO of Atlas of Caregiving, a nonprofit, which envisions a world where caregiving is valued and is supported as a fundamental to a healthy society. Previously, Rajiv led innovation and new business development at technology companies such as Apple and Adobe, and built upon his work as a research scientist with NASA. Rajiv holds an MBA from Columbia, Ms from Stanford and

BSE from Princeton. He sits on the board of Family Caregiver Alliance and is an advisor to Quantified Self. He was recognized as a 2018 influencer on aging by PBS affiliate Next Avenue, and is a Salzburg fellow. Rajiv and I discussed the Atlas Care Map, which helps caregivers better understand their current situation, plan for potential difficulties, identify missing people and services, and provide empowerment going forward. I hope you enjoy our conversation,

Rajiv Mehta 02:22

The organization got founded about five, six years ago. Now it's a nonprofit that's been focused on both doing research on how we people care for each other on family caregiving, and then developing kind of practical tools, and and so forth, to help people do a better job of caring for themselves, their families, their friends, their communities. And one of those tools we've developed is one called the Atlas CareMap. And basically, what it looks like when you've drawn it is sort of a stick figures and little symbols, squares, triangles representing different kinds of things, with arrows showing who is caring for whom, and to some extent to how intense that caregiving is in that particular relationship. And end up you draw essentially ends up being a web of relationships, as you say, one person process that they show themselves, and let's say their mother with dementia, where they came for, and their sort of big, heavy arrow going from the caregiver to the mother, but then sometimes, you know, they might put a little arrow back saying, Well, my mom still cares for me. And I find great benefit in her presence, at least at certain times of the day. And then they include their sister and their neighbor of the spouse, and so forth. And they start seeing that it's a web of relationships that have often mutual care. And not necessarily even. Because that's not the way life is at any given particular point in time. But essentially, it's a diagram of your care ecosystem in the value of it. The drawing itself turns out to be handy. But deeper than that, it's the questions you ask yourself, as you're drawing this thing, who all do I care for who's caring for me, that raises a lot of awareness of what your situation really is those sort of self reflection questions. And then once you have the drawing, talking with other people about your situation, it turns out to be a great tool for sparking conversation. Somehow, it's a lot easier to talk about the situation when you're talking about the map as opposed to just talking about it in abstract. And so this particular tool both in its ability to help people see their reality and in helping to sort of Spark and support conversation has turned out to be enormously helpful.

Rosanne 04:44

And it's not you don't have to be Picasso to make the map it stick people and and arrows which is which is wonderful

Rajiv Mehta 04:52

Yes it's designed for my drawing skills.

Rosanne 04:56

I'm with you. And it's more of like you said it's a web It's a web of these people that are in your life that you may not really notice or recognize as people that can help you.

Rajiv Mehta 05:08

Yeah or people that are helping you. So just as an example of that the value of the CareMap is not necessarily instantaneous. And I'll give you an example. There was a woman in one of our workshops,

who told me afterwards her story that she had left the workshop, she had drawn a CareMap, but she left it with this feeling of being more overwhelmed that when she came in, because as she drew the care map, she realized how starkly alone she was that she was doing everything. She's raising the kids, she's caring for her mom, she's doing all this work in the community. And she's feeling like she's at her wit's end, what can she do, and she didn't really know what to do. But essentially, with our eyes opened to these questions. Over the next few days, she started seeing things that innocence she had seen, but never paid attention to before, of how her children were sort of hyper attentive to their grandmother's needs, that they would get up and change TV channels, or get her a blanket or Get her a glass of water, often without being asked. And it made her aware that her kids were, in fact, actively involved in the care of her mother. And she told me afterwards that it made a huge difference, even though it didn't make any difference in the sense that everything on her plate was still on her plate, but no longer feeling like she was actually alone. Right made a huge psychological difference.

Rosanne 06:31

Yes, yeah. Well, and yeah. Because you're right, it didn't change anything, but it changed her perception.

Rajiv Mehta 06:39

Yeah.

Rosanne 06:40

And sometimes that's what we need, we need to change our perception and our expectation to make things I don't know, feel better seem better?

Rajiv Mehta 06:47

Yes feel better, just feel better. And of course, there are plenty of times where actually does the people to real change. So kind of the parallel story was another woman at the same event, who again, went home feeling like oh, my gosh, this is impossible. But she then shared her drawing and her thinking with her husband, and her and her daughter, and it was the most important change was sort of her acceptance, that it was impossible. And therefore, help would be good. And in fact, as it turned out, her husband and her daughter were ready to step in, but kind of refrained from it from not wanting to insult her, you know, because, you know, mom will feel like, you know what, I'm not good at this if you step in. And so she was essentially able to ask for help, realizing that it was impossible, as she said, she no longer needed to be super Betty and other people were able to step in, and it made a huge difference, as you can imagine,

Rosanne 07:47

I'm sure.

Rajiv Mehta 07:48

Yeah

Rosanne 07:49

That's wonderful. I think it's, it's for information. And we always say, you know, information, knowledge is power. And information is helpful. Whether you like it or not, the information is helpful to you. And I think this really spells that out

Rajiv Mehta 08:04

You know what's also interesting is that it kind of gives people an opportunity to rethink. And, you know, that just makes it a difference. But it also gives people language and a tool a visual to be able to advocate for their needs, which they lacked before. And that's been true for innocence. We've we've developed over the years a collection of these paper and pencils, very easy to draw tools that help people look into other aspects of their lives, you know, of their, their work colleagues, and how is that impacting their well being? How is that the spaces that they regularly live in, whether it's their home, or their office, or the subway tracks or what have you, and see how that's impacting their well being, and so forth. So helping people come to a deeper appreciation or awareness of what their own life is like, which, of course helps them kind of get grounded on what is it gives them clarity on what they could do to make things better, but also real clarity on what is simply outside of their capacity where they really need help on, there are certain things we can do better. But honestly, there's a lot of things that society needs to do better. And so it gives them greater ability to advocate for their needs. And just to be frank about it that you know, it's, as you well know, so many people that are caring for others, they have this sense of guilt that if they could only do a better job kind of thing. When you come to appreciate No, this is about as good as it gets. Other people need to help, it makes a huge relief. So it's a collection of tools to help people kind of see the invisible of care and well being in their lives.

Rosanne 09:48

Absolutely. And it's validation.

Rajiv Mehta 09:50

It's validation. Absolutely. And you know, on the validation front, it's odd. So, there's so much of language around here. Giving that sort of speaks about it heroically, or speaks about, you know, isn't this a joy to care for your loved ones, and so forth. And honestly, it is nice when it's those situations. But for most of us, it's just what we do, because that's what family members and friends do. And we don't want the world painting some, you know, rosy tinted picture of what our situation is, nor hold us up to some heroic standards that we're, you know, some great being we just want acknowledged and validated. This is this is human, this is hard. This is not always nice. And somehow that validation of just being part of common humanity, is what we really want.

Rosanne 10:48

Absolutely agree. Absolutely agree. Because it makes you feel bad then when you don't feel that way.

Rajiv Mehta 10:55

Right. Right.

Rosanne 10:56

When it is hard when it is four in the morning, and you haven't slept and you're at your wit's end, when it's the 14th time you're getting up when when whatever we're trying to balance. Yeah, I mean,

anything, we're trying to balance your life with your caregiving. There's so much that's intertwined. And there's so much guilt and responsibility that goes with it. This is this clarifies a lot of things, which is just wonderful.

Rajiv Mehta 11:23

You know one of the places that clarifies is oddly with the people who try to help us if you think of, let's say, doctors, or nurses or social workers say you're a caregiver for someone with Parkinson's, dementia, what have you, or, you know, a child with type one diabetes, or what have you, the doctors, in a sense, the patient's doctors, that to the extent that they view you as providing a valuable resource to their patient, and so forth. You know, they, let's assume the best of them are trying to praise you, and to help you and so forth. But they want you to do the best you can for their patient. Right. And that's not your life, your life is juggling a lot of balls. And oftentimes, sharing your cam app and stuff with these folks just opens their eyes to the reality that, yes, you have to care for your father with Parkinson's. But honestly, you're going through chemo yourself, and you're trying to raise a child, and you have to do all of the above. And so no, you will not be doing the perfect job for their patient. Your dad with Parkinson's.

Rosanne 12:31

Absolutely. And, you know, you've said before, that the health care system sees the patient as the hub. It's it's the patient is the center and everybody else. But the the care partner, the caregivers, anybody who provides care needs to be in there with the patient. And the healthcare system doesn't view us like and we've seen that over the last year. But how does this really illuminates that? It really, here we are, we're all on this page together. And how can you help me? And how can I do this in a better way? I guess.

Rajiv Mehta 13:06

Yeah. And I think in a sense, the the language change of perspective, change needs to be all around that all of us live in these complex lives. And so the perfection for one particular person is just not going to happen. I mean, likewise, the doctors and nurses and all they have however many patients on their duty roster for the day. And that's why they rush through things, right. And recently, there are a lot of challenging issues to improve upon. And our fundamental point is, first, you need to see what is at the moment to be in a position to be making improvements.

Rosanne 13:43

Right. Right. Agreed. And it's and with that language, sometimes it feels like it's us against them, where we are the caregivers. And then then there's everybody else. And that doesn't help.

Rajiv Mehta 13:56

In fact, in our in our work with, say the professional healthcare system, almost all of it has been focused on helping them as people see care in their own lives. Because you know, even the most brilliant surgeons happen to have friends and family that are ill, and they themselves have health issues. And so we help them see the complex care and wellbeing situations in their own lives. It opens their eyes to the fact that other people are dealing with the same. It's when we are working with health systems. We

begin by helping the people help themselves before we start thinking about what can we do for your patients, your clients, etc.

Rosanne 14:34

Now, the Atlas of Caregiving website has all of this. I mean, the the information that's on the website is I could spend hours on it. It's it's fantastic. And aside from the Care Map, you have the body connection, you have the daily activities, you have engagement, you have the social network, as you said, everything, everything that we do in our lives. It sounds really silly to say this Everything we do in our lives is connected. We're all it. Whatever we do if you if you decide to skip breakfast and you know not eat to lunch, you're going to be affected if you decide that you're not going to interact with your friends or your people, it affects you, everything that you do affects you. And this website lays that out for you. And it gives you concrete information so that you can try to make those changes, but it it shows you where those issues might be. Can you talk to me about how you developed this? And how this, how did this come to be?

Rajiv Mehta 15:34

Yeah, yeah. So yes, all of these tools, but we call them tools, because that seems to be the most appropriate word for them. But they're paper and pencil tools, they're paper and pencil by design. And yeah, they're all available on our website, people can download the information, they can do it for themselves. I can guarantee you that at first glance, they will. It'll be like learning a foreign language there. It'll, it'll seem like what is this, this makes no sense. But I will also guarantee you that if you take a little bit of time and trouble to learn them, in retrospect, they will seem easy. I mean, we've had second graders do this stuff. So it is very doable. And as you will learn as you use the tools, they are intended to be very flexible, intended for you to change them for your circumstances, because we cannot make a tool that will be universal. Our lives are so different today is so different than tomorrow. So they're meant to be. But to your question, yeah, the these as simple as they look as because their pencil and paper in hand drawn, and they seem like they might be simplistic, they, in fact, are the result of a lot of deep work. So my own background, you know, once upon a time I did, I was a scientist for NASA, then I led innovation in Silicon Valley for many years. So I had bring this background of science and so forth to this. And I've been part of a global community of like minded people called the quantified self. For the last well, from the very first meeting, so for the last dozen years or so, it's a global group of people that are all individually interested in examining their lives and seeing what they can learn. And so we've picked up a lot of ideas and methods and tools from these people. We're also connected to some of the most brilliant information designers in the world, people who work with, you know, the big corporations and banks and world organizations on data analysis, and so forth. But we have, as a group have deep interest in human scale data data at a personal level. And so these, these tools that we've developed are based on these decades of experience and experimentation with different things. And so what you see now is kind of the synthesis of that, which is no guarantee to say that they have been perfected I, it's almost like, I can guarantee you them that in two or three years, all the tools that we have on there will have been changed and improved. But they weren't made on a whim. There's a lot of background behind them.

Rosanne 18:07

Right and the research, research changes and and I would think the data that you're looking at will change in some way

Rajiv Mehta 18:18

In some way. Yeah, the interesting the, our research these days is much more ethnographic or as an anthropologist would do, then as a data scientist would do, because all these tools that we're developing these paper and pencil tools, make it essentially impossible for us to gather data in a numerical sense, right? We're not like some app or website where you can gather data, but it's more observing people talking to them hearing their stories, like the two stories I shared with you earlier, that help us kind of understand how these tools are helpful, how they need to change, and so forth.

Rosanne 18:57

Well, and, you know, coming out of 2020, with the isolation that was happening.

Rajiv Mehta 19:01

Yeah.

Rosanne 19:02

How do you see? I mean, we all know that isolation is just, it's so detrimental. And I don't think it was realized, until everyone was isolated. How does having something like this help in in those factors in real world experiences?

Rajiv Mehta 19:19

Yeah. So two things, I start off with the small one, and then talk about the big one. So the small one is simply that, for example, when you try to draw the care map, or when you think about drawing, the conversations tool, and so forth. It shows vividly that you're interacting with so many people, so you become aware of that. Now, you know, over the last year, your interaction may have been limited to the postman at the door or the UPS driver, or the clerk at the grocery store, from a physical person. There's lots of interaction by phone and chat and so forth, but you become more aware of the connections you do have. And so at that kind of individual level, the tools help If you see the ecosystem that you're within the the much more important thing, and very much in the design of the work that we do is we have really discovered and emphasize the value of collective self reflection. So we really encourage people to learn these tools not kind of isolated by themselves, but with along with their peers, family members, friends, co workers, whoever, just others. And in the process, learn by sharing with each other, your experience of both of using the tools and how easy it was, how hard it was, and what you learned. And that collective self reflection ends up leading people to get more that validation as they discover how common their challenges are, even if each person's challenge is different. But the commonality the themes come across, in the process, they discover how much value there is both emotional and practical, from talking about these things from each other. And, as it turns out, which is somewhat by design, but nevermind, as it turns out, because we're human, are bonds of connection get much stronger, when we share our lives with each other in this kind of open, empathetic way. And so we have very actively designed our work designed our programs for being done in community with community rather than as a group of isolated individuals. And recently, one of the things that we did that really speaks to this was, we worked with a group of long COVID patients. So for people who aren't

familiar, long COVID refers to people who've had COVID, maybe were never diagnosed, but never mind, they had it theoretically recovered from medical perspective, but then weeks, months, even a year later, are still dealing with often debilitating symptoms. And so there are now it's estimated that 10 to 30% of people who've had COVID, end up with long COVID. So this is we're talking to millions of people around the world. And it's quite challenged. So we were doing one of our workshops, one of our mapping ourselves workshops with a group of people with long COVID. And in this case there, they didn't necessarily know each other was on Zoom, but they were all part of this online community. So in that sense, they had some ties. And we went through this five week program of teaching them these tools and having them talk to each other. And they said that in addition to finding the tools valuable, and the learning they did, it was that camaraderie that came through which was so valuable, you know, the isolation this last year has been hard for almost all of us, it but for people who have had long COVID It's been horrendous, not only were they isolated, they had most of the world believing that they were making stuff up, even including their doctor. So it's terribly isolating. And so it's going through this experience as a group was enormously valuable to them because it was in community.

Rosanne 23:08

Wow. It's amazing. And, you know, and on top of it, they don't feel well to have to make this like no, really I don't feel well.

Rajiv Mehta 23:18

Yes. And you know, it's even a sort of slightly less intense version. So, in essence, those of us caring for parents going through the illnesses of old age, again, we find we get isolated, there are still so many stigmas in society, around dementia, around cancer and so forth. So you as a person either going through it, or the caregiver of one, you often find yourself sort of constraining yourself in not bringing this up with others, whether it's your friend group or the people at your church or what have you. You don't talk about kind of stoically keep it to yourself, figuring that others don't want to hear about it wouldn't understand and so forth with some reasonable sense of that, you know, we're not making this up. And so again, when we've done these sorts of workshops, for example, with a group of Dementia Caregivers, you know, I remember one time we did that, and the group that was participating in the workshop, that one of them spoke afterwards and said that they had been meeting as a group for over two years, and learned more about each other in this two hour program than they had in that entire time before. Wow, partly because by you by learning the care map, they had kind of learned to see their lives more clearly, and had gotten the language and in a sense, the program was set up to allow them to talk to each other. And so in all sorts of places this opportunity to talk is so valuable, and yet what we're doing is somehow significantly different than normal support groups, because the tools come first to help you see

Rosanne 24:54

Right because they're there you're just not seeing them.

Rajiv Mehta 24:57

Yeah, you're not often you're simply unaware Which is not to criticize people are so busy and overwhelmed by the doing.

Rosanne 25:06

Listen, sometimes, you know, when you're a caregiver, you're lucky you can see your your feet sometimes like, I mean, you know, there's so many things that you have to balance that the very last thing on your list is yourself.

Rajiv Mehta 25:18

Yeah

Rosanne 25:18

Unfortunately, that's the reality of being a caregiver.

Rajiv Mehta 25:22

It really is. I'm full of stories because I've been at this for so long, but a share one other one was a woman who at the time was in her late 50s, she was caring for a son in his mid 20s, who had various emotional behavioral issues. And so the reality for life was, if you will, 23 and a half hours of each day, life is fine. It's just when disaster happens, it's you know, it's a five alarm fire instantly. And so effectively, she can't do anything. So she hasn't been able to, um, she was actually a practicing lawyer before she had to give that up. But so if you simply, you know, look through her window, she you see this woman simply sitting on her couch, flipping through the magazine all day, it's like, wow, what a life leisure. But no, she's trying to pass the time waiting for the next bomb to fall. And so in working with her, she was able to kind of diagram what her day looked like, what did I do all day long. And afterwards, she said this thing, which was both so sad and so funny, but she goes, I realized that I no longer need to feel guilty for being tired. Yes. And he was so sad in the sense that yes, this was the reality for life. And so affirming to know that being tired is like an absolutely natural part of this, you're doing as well as anybody could.

Rosanne 26:42

Yes. And that's the part that gets overlooked. Because there's a lot of times when, you know, and you've seen the charts, I've seen the charts, caregivers spend 4.5 hours dispensing medications a week, and you're like, Well, yeah, but that doesn't

Rajiv Mehta 26:58

It doesn't count

Rosanne 27:00

It doesn't, add up you know, or or providing care that caregivers provide 22 hours of care a week? Well, no, that doesn't count for the times that you can't leave your house and you're still on duty, you may not be actively doing something. But like you said, you're you're waiting for the next for the next emergency, or even it's it doesn't have to be an emergency. It's just the next thing you have to do in caring for your for the person that you're caring for.

Rajiv Mehta 27:25

Yeah. And you're just mentally exhausted from that because you're always waiting.

Rajiv Mehta 27:29

Because you're always on. Yeah, the waiting is part of being active, but it's not viewed as being active because you're not active, which doesn't make any sense to me.

Rajiv Mehta 27:37

Right. Right. Exactly. Yeah, one of the one of the things that we have been slowly pushing the boulder up the hill on his and we talked about this in a previous conversation about how we define caregiving. Today, we define it as only occurring when you're caring for someone who's very, very sick. And so we're, we talk about it in the sense that there are 43 million American caregivers or whatever the number happens to be these days. And I think this is a fundamental flaw in our thinking that almost all of us are caring for people all the time and caring for ourselves and benefiting from the care of others. And this is important, because then choose to step in to help caregivers. At the moment, it's only when you're in the middle of a crisis. But this is this is crazy. It's like only teaching bookkeeping to companies that are about to go into bankruptcy, or only teaching cooking to people that have been designated to make a gala meal, you know, for some for some lavish function. It's like, oh, my gosh, no, that is not the time to learn how to do scrambled eggs. And it's like, the time to learn is when life is kind of at its normal pace, and to become good at paying attention to care and well being when things are somewhat normal. And you're much better equipped to notice this when you get to crisis. So one of my friends, one of our advisors for Atlas for a long time, is Susanna Fox. She was previously the Chief Technology Officer for US Army Health and Human Services and has long written on peer to peer health and so forth. And so yes, she has been involved for a long time, she's been using the cam app in her own life for a long time. And every time she has used it with another family member, and so forth, she's learned so much more. So these tools kind of deepen over time as you become more and more skilled at them. And also, I mean, she, you know, given the pandemic she speaks of using these tools as kind of a vaccination that prevent the next instant from becoming much worse than otherwise. And so in that same spirit, I believe we would all be better off if we viewed care as a human activity that all of us are involved with, and something that is worthy. Have all of us being sort of empowered and equipped to do better about to both kind of recognize to celebrate, to improve upon our skills of caring for ourselves and others?

Rosanne 30:11

Yeah, I mean, that's beautiful. And I often wonder how many people don't identify as caregivers, but they are in fact, caregivers.

Rajiv Mehta 30:19

Yeah. Well, I, I, I think this campaign to get us to identify as caregivers is misguided. If all of us are, then we don't need to self identify it right is simply is, except that all of us are caring, yes, and recognize and help that. If we do, then we start seeing things differently, just as that woman in the first story recognize that our children were actively caring for the grandmothers, right, you know, bringing a blanket and getting a glass of water and help him it makes a difference. And so, you know, in this work, I've met with so many families, old and young, and so forth. And so many elderly, who have had the good fortune of having grandchildren attentive, and so forth, talk about how that's sometimes the highlight of their week. And we need to acknowledge those young ones as real caregivers in the family. And so again, it's that the term is problematic, not the fact that we don't identify with it.

Rosanne 31:18

Right. And it's, it's because we all are,

Rajiv Mehta 31:21

We all are.

Rosanne 31:23

In one way or another, we all care about somebody.

Rajiv Mehta 31:26

Yeah. And in fact, in our in our workshops, and stuff, people have been shocked, in a pleasant sense surprised to discover how actively, they are caring for others. So as I mentioned earlier, you know, I've worked with high school students and college students, and all sorts of folks. And so last year, we're working with a group of high school students in a rural community in Michigan. And it was, you know, as an adult, as a parent, it was just fantastic seeing kind of a glow in these kids, as they discovered both how many people in their lives were actively contributing to their sense of well being, is opening their eyes to that. But then even more so in discovering how crucial they were to their family and their community that, Oh, my God, I'm making such a difference. And so this is this really is universal.

Rosanne 32:20

Well, that's, that's beautiful. Now, to get these tools, they're all free. And it's on your website.

Rajiv Mehta 32:26

Yeah, as I said, all the tools are free and on the website, and it's so we do the best we can to make them available. Again, the reality is, as we have come to learn, they are so novel, that this isn't the ideal way to learn. So it seems to work so much better when a friend who has learned this teaches it to you, because they you know each other in your life, so you can talk about it. And so kind of friend to friend learning is the most powerful. So then the question is, how do you get that started? How do you get those ripple effects started. And that's where we as an organization have been working with different communities, different businesses, different organizations to kind of, to mix metaphors here to plant great seeds, to start with a group of people that learn these tools really well. And then they can help spread it in their community. And these ideas are, again, they're paper and pencil tools. So they might appear simplistic, but they're actually quite deep. And so you can imagine, it's as if you're trying to learn meditation, or yoga, or mindfulness or any other deep practice by simply reading a book. I mean, there are a lot of yoga books out there. But you know, a bit, they have their limitations, and so forth. And so these are the kinds of things best learned, through experience, especially a group experience, which we can't provide on the website, but what we can do is make all the tools available. And where I think it makes the biggest difference is that people who have already learned through some sort of personal interaction, then find the material really helpful and teaching it to their sisters and brothers and kids and so forth.

Rosanne 34:06

Right? Well, I know when I looked at it, I was I thought, wow, this is, this is deep, it's deep. And it's but it's, it gives you that ability to look at your your everything, your your interactions, your life, your daily schedule, I mean everything. But it's interesting, because you also say, You are the expert in your own life.

Rajiv Mehta 34:31

Yes.

Rosanne 34:32

And these tools are more of an empowerment for you than a service to plug into. And I think that's really important to to highlight.

Rajiv Mehta 34:42

Yeah, that is that is really important. Thanks for bringing that up. You know, you are quite literally the only person that lives with you 24 by seven, so you're in a better position to kind of observe your life than anyone else. And assuming that you are not, you know, sort of mentally incapacitated in certain some way. You're also a sentience, thinking human being that is paying attention to the world, and just at a reality level, you are more expert in your world than anybody else could be. Now, if you've been married forever, you know, perhaps your spouse has a better sense of it. But you know, I mean, in general, we really are. And so when we think of ourselves and some professional, we need to recognize that there's kind of a symmetry of expertise, you are the expert in your life, that person may be the expert on ankles. So if you've broken your ankle, kind of that person's assistance is really helpful. But there's the symmetry of, of knowledge. Likewise, there's a symmetry of ignorance in the sense that you probably don't know a whole lot about how the bones in your ankle work. And so it's helpful to have that that doctor around, but likewise, the doctor has no idea what your life is. And so the doctor might say, Look, you need to stay off your feet for the next three months, and you're like, I'm, I'm caring for my dad with dementia, that's not going away, I will be hobbling around. So let's accommodate that. And so we are the experts in our own lives. And therefore, we feel we as athletes feel strongly that we need to help people sort of deepen their expertise, provide them tools, to see and analyze and visualize their lives, provide them tools to be able to explain themselves to others, and, and so forth, to deepen your expertise. Just as we provide doctors and scientists with tools and resources we need to provide us because our expertise is indispensable to our well being the reality is, you know, we spend close to \$4 trillion. Is it on the professionals and effectively nothing on us that really needs to change.

Rosanne 36:51

Yes, absolutely. And if it's not, you know, I don't think it's going to change soon. So in the meantime, we need to find a way to try to help ourselves, stay, stay up, stay moving, stay alive, because it's hard. It's just hard. Everything about it is hard. And, and in taking back some of that power is also empowering, is making you feel like okay, at least I'm, I'm working towards this, or I have these tools that I can try to implement into my life. And it might not happen 100% Every day, and that's okay. But at least you're trying and it gives you that that structure.

Rajiv Mehta 37:29

Yes, it does. It does. It really helps you cope as best as possible. And the other thing I would add to it is it allows us to recognize and celebrate that which is going well. Yes. Again, you know, back to the example of the woman who discovered her children were caring for their grandmother. It's only in seeing that the now you can say, isn't that nice that have a smile and a warm glow from recognizing that. And so I think when when people use our tools to examine their life, there's this tendency to think of them as kind of, let's find the gap. So we can do something about that. Because we kind of been trained into that, that negativity thinking, what's wrong, what can be fixed, but we encourage people to pay attention to what it reveals is good. And that makes a huge difference as well. Remember, one, just one little story, there's one woman who talked about kind of through this process, discovering that how much her brother had essentially kind of put his life on hold to care for their parents, whereas she and her other three sisters all lived in other parts of the world. And were always complaining about how poor job the brother was doing to care for the parents. And this made her recognize, oh, my God, look at all he is doing while the rest of us are flourishing far away. And so that moment of recognition of what an amazing job the brother had been doing. And in fact, how much of a sacrifice he'd made was something worth celebrating. And so often people find things to celebrate, to recognize are going well in their lives. And that's it's hard to quantify, but that turns out to be a real important value as well.

Rosanne 39:12

Absolutely. Absolutely. Because when you're floundering. Everything seems so so hard and so dark.

Rajiv Mehta 39:19

Yeah.

Rosanne 39:20

And then it's easy to say, well, this, and I'm and I'm not doing this, and I'm not doing this. Yeah, but what are you doing?

Rajiv Mehta 39:28

The 27 things you got done today.

Rosanne 39:32

Right, and look at what you know, that's that isn't a positive. It's a good thing. Yeah. Because that also adds to that heaviness.

Rajiv Mehta 39:40

It does. And I think we can improve our language on this, like we talked about, you know, from a political perspective, it's understandable why those of us who care about care, speak in language such as the caregiving crisis and so forth, because apparently things need to be in crisis to get response from some systemic improvements and so forth. And so it's understandable, but it also carries with it this sense that the crisis will pass. Right? And no caring for each other is part of being human. We will be doing this 1000 years from now as well. And so recognizing that kind of human part of it, and celebrating that is, I believe really important.

Rosanne 40:23

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