

Curatio Connects podcast with Tanya Yarkoni

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[00:00:02] (Robert) Hi, welcome to Curatio Connects, a podcast about health, wellness, and staying connected. So, what happens if you find yourself suddenly in the role of full-time caregiver? The advent of the Covid-19 pandemic has amplified the situation and our guest Tanya Yarkoni knows firsthand what it means to face this challenge.

[00:00:23] (Tanya) Look, for the next 10 to 15 years, you're going to be looking after someone who has a chronic illness that's going to be getting progressively worse. They're living in your home and you are going to need to manage that along with everything else in your life, right? If I said that to you at the beginning, what kind of tools and what kind of mindset and what kind of support would you think you need to put in place, to do that role effectively?

[00:00:55] (Robert) More from Tanya Yarkoni on the challenge of full-time caregiving in just a minute. This podcast is brought to you by Curatio, the private social network for health used in over eighty-five countries. Find out more about our app called Stronger Together, designed to help you cope and thrive during Covid-19. You can download it for free from iTunes or Google Play. And for more about Curatio, visit us online at Curatio.me. Now, let's hear from Tanya Yarkoni, I spoke to her at the Kibbutz, Givat Haim Ichud, north of Tel Aviv, Israel.

[00:01:29] (Tanya) So my background is that I'm a family caregiver. I have a child who is 13 years old, I have three children and she's my middle child. And really, through the process of taking care of her, she has special needs, requires 24/7 care. I found myself after a few years sort of sinking into a pretty deep and dark place and wasn't equipped or had really any understanding or awareness really of what was happening. I just felt miserable and started on this very non-linear path, that I wasn't even aware that I was on the path. But I was on a path to help myself. And after a few years on this path, started to sort of look at myself and my situation and think, wow, I'm actually doing better today than I've ever been and isn't that strange? That's not at all what I thought this story was going to be about and it's just happened here. And that was really the beginning of thinking about the company that I formed a couple of years ago, that was really actually based on, more than anything, a premise about challenge. And why is it that when we go into these situations or when these things happen to us in our lives, firstly, you know, it's not an anomaly. Like every single human being on this planet pretty much experiences a challenge in one form or another, certainly some more than others. But we're not a small group of people here. And why is it that challenge is viewed as something sort of surprising? And why don't we have the tools in place to help us go through this process? And why isn't it more sort of widely accessible? And that was really the beginnings of Resilient, which today is behavior change, coaching platforms for family caregivers of people with chronic illnesses and disabilities. And we're currently running an eight-week program that really guides the caregiver through a journey that helps build self-awareness, puts them back on track and start to feel that they have some control of this situation. That's the beginnings of it, really.

[00:04:14] (Robert) Well, that's an incredible turn for you to go from being the caregiver who was thrust into this situation, obviously not by choice, and then having to sort of fight through and figure out how to manage all that and then turn that around into a tool for other people to help them figure out how to manage it and deal with it. That's quite the trip.

[00:04:35] (Tanya) It is quite a trip and definitely still on it. And I feel like I'm on a mission, now actually. It just feels like this is what, I clearly was put on this planet to do this and to now help others do this and I feel that that's my responsibility.

[00:04:57] (Robert) Okay, so let's just talk about what that situation means for people, because I think we're really now in a situation where we have, we're really kind of talking about two different things. We're talking about people that may find themselves in a situation like yours, where a family member or someone close to them either gets sick or has a disease that means that they need care, sometimes constant care, but also where because of the pandemic now, we're finding that all sorts of people are having to care for people in one form or another and in kind of very restricted or an odd situation. What advice do you give people who are finding themselves suddenly as a caregiver and they didn't plan for this, it just happened.

[00:05:38] (Tanya) The fact that we have now all become caregivers in one form or another is to me a fascinating experience. And I and I keep referring to it all the time, that the people who aren't necessarily even taking care of someone with a disability or illness are experiencing many of the symptoms that caregivers experience. And many of those sort of symptoms are things like, you know, being in a very unpredictable situation where they just don't know what's going to come around the corner and all this, you know, words like uncertainty that have been thrown around endlessly. Isolation, paranoia, fear, worry. You know, all of those things are endemic to the caregiver experience. And now we have caregivers who are, you know, well, as I see it, there's going to be more caregivers over time because, you know, not only, of course, we're now actually also going to unfortunately be facing some major economic downturn, which is going to mean that the onus of care is going to fall more and more on the families because there just won't be the money to pay for home based care.

[00:07:05] Certainly sort of the magnitude of what we're dealing with now has changed. And we're looking now at sort of care, the subjects of care. What is needed to manage care? I feel it's going to become a topic that is going to become more and more relevant over the next few years.

[00:07:26] (Robert) So if I'm one of those people who has suddenly been thrust into this situation, one of the things you said was you identify these feelings that I guess what you're saying is that's normal. You're going to feel those things. Those are going to happen, so what do I do?

[00:07:40] (Tanya) So one of the things that I didn't, I was absolutely unaware of, when I went into my caregiving experience was that I had become a caregiver. And it sounds extremely obvious, you know, and actually, I think that is perhaps, you know, there is more discussion about it today than there was, let's say, when I went into this situation more than a decade ago. But, you know, I certainly didn't view myself as a caregiver. I was the mother of a child who needed help and I didn't think of it in any other way, and that's normal. But caregiving is a role. And the biggest or the first mistake that people in this role make is that they don't actually identify with themselves in this role and because they don't self-identify and because they're not really aware of the demands that are going to be placed upon them. And again, this is not something that, how would they know? Here we are with Corona and we just don't know what's going to come around and we don't know how long it's going to last, and we don't know what the impact is going to be. The same thing happens to a care giver. There's many, many pieces to this that are just unknown. And at the same time, they are being required to manage something that is challenging not

only from, you know, on a task level or on a sort of knowledge base level that you suddenly have to sort of learn about something that you knew nothing about, but obviously from an emotional point of view as well. And so here you are; and if I was to say to you, look, you know, for the next 10 to 15 years, and let's just say the average caregiving role is, you know, let's say around 10 years, you are now going to be looking after someone. I mean, I'm not talking about someone who's like, in my case, with a disability. But, you know, with someone who you're looking after, who has got a chronic illness, that is, you know, that is terminal ultimately. You are going to be looking after someone who has a chronic illness that's going to be getting progressively worse. They're living in your home and you are going to need to manage that along with everything else in your life, right? If I said that to you at the beginning, right? What kind of tools and what kind of mindset and what kind of support would you think you need to put in place, to do that role effectively?

[00:10:33] You know, if I threw you into any other kind of work situation and said, "okay, I'm going to need you to do X, Y and Z now. This project needs to be accomplished by a certain amount of time and you need to do it, you know. And what do you need? What do you need to do this job?". And that mindset is not at all applied to the caregiving experience. And instead, we're sort of thrown, you know, things like take care of yourself and take care of yourself is just such a useless statement in the middle of a crisis when you're just trying to sort of stay afloat. It just doesn't carry any weight or any value. So, most people just go, oh, they don't understand. They don't get what I'm talking about and ignore that piece of advice. But actually, what, "take care of yourself", means is you're in something now that if you don't manage this properly, we know what the statistics are. We know how people burn out. We know about decline of health. We know the impact it has on the family. We know the financial impacts of it, too. Like there's a whole domino effect in the same way as look at the domino effects of things that are happening right now around this virus. So, this is you know, this is the reality that caregivers should be presented at a much, much earlier stage, ideally at the beginning. I'd like to say one more thing about that, actually. At the beginning, a caregiver is in a very high state of stress usually. And it's actually physically extremely hard to be coached or taught anything when you're in a high level of stress, when you're in a high level of stress, you can't take in any more information that you're already having to deal with. So, this is where the catch-22 begins, because they're in the war zone, the bombs are flying. They're just trying to stay alive. And yet at the same time, actually, they need to have someone supporting them and guiding them who can navigate with them through this path of, you know, uncertainty and fear that they're experiencing at the beginning.

[00:13:08] (Robert) Yeah, and I think you've said a couple of things that really resonate. One of them is the idea that you don't really prep for it, like it happens and then you just are in it, you don't take the time to prep. As you describe that job to me, I mean, I smiled because, you know, we're using Zoom to do this interview and there's probably 30 pages of help information on how to use Zoom. You know, but is there is there the equivalent of how to care for a person? So, there's that. But then the other thing you said that really resonates for me, is this idea that because we all understand the pandemic now, we all understand the restriction, we all understand the financial implications. We understand all the nuanced pieces that fall out of the idea of a pandemic. So, when I go back to when they first said a pandemic, I just went, yea okay, fine, it's a disease that's you know, it's an influenza that's worldwide. I didn't put two and two together and think about the social effects and the financial effects as the spill out effects. But I understand that now and I think a lot of people around the world understand that now. And what you're saying is that in a personal caregiving situation, all of those same fall out things occur. So, what do you, what's your advice to people when they find themselves in that situation?

[00:14:15] (Tanya) What we have at the moment are sort of bits and pieces that are sort of coming at you from different angles. But ultimately, I don't think there's a proper, proper consolidated answer for it. And again, it's difficult to do because, you know, not all illnesses are equal and even in one illness, there are many different symptoms, facets, you know, there's a spectrum, whatever it may be. So, it's not a clear-cut thing. So that's probably why it doesn't fully exist yet. But certainly, educating yourself not only on the illness, but on what I as a caregiver am going to, the kinds of tools and the kinds of awareness, and what will probably, if I know this is a stressful thing, then what am I going to need to keep my stress levels down, you know? And maybe as well as learning about the illness, I probably need to understand the impacts of cortisol on my body and I probably need to know that I'm going to have to increase exercise, eat better, you know, build my support network around me, have, you know, sources of maybe other kinds of income that can come in and help me, you know? So really make a plan, basically and the plan shouldn't just be around, how am I going to care for the patient? But how am I going to manage this thing? You know, I'm the CEO here, like, what do I need in this role to do this job well? And who are my people and what do I need to know? Do I need to get up at 6:00 a.m. and work out and then do an hour of meditation to feel my, you know? I know it sounds improbable, you know, but we need to be going in that direction.

[00:16:19] (Robert) Yeah, but I think the advice you're giving is really sound, which is you've got two roles. One of them is the role for taking care of that person and the other role is taking care of yourself.

[00:16:29] (Tanya) And everything else around you, which leads to this other piece, which is, when you don't manage your roles properly, you end up with role overload. And it you know, and that's when we start to see the fact that you start to feel that there are parts of your life that you know, you lose yourself. That's a common statement by caregivers. You know, I've lost myself. And basically what it means is I've become de-anchored from my other roles, like I'm just in this caregiving thing now. It's taken over my life and it gets very complicated because it's emotional. And because it's emotional and because it's someone you care about. That's where it gets murky because you feel that you are extremely responsible for someone else. And you may well be physically the person who is most responsible for that person. But there is enough knowledge out there today and there are also enough support systems out there today, to actually support a caregiver through this path. And the piece we've chosen to focus on is the emotional piece and this sort of, managing my roles and keeping myself on track peace. Within the sort of the ecosystem of offerings that are currently now available to caregivers.

[00:18:04] (Robert) I would think too, that as you're grappling with that role, that there must be some level of guilt where you say, well, if I do this for me, I'm taking away the time I could be spending with that person I'm supposed to be taking care of.

[00:18:17] (Tanya) And guilt is, you know, it's just another emotion, isn't it? So, when you start to observe your emotions, which is part of what we do, you start to realize that guilt is a habitual experience as much as any other experience is.

[00:18:38] And if you don't want to feel guilty, then that's a habit that you need to start to work on to change. And, you know, that's actually where, that's the point where it starts to become actually really interesting, from a personal point of view. And that's where I start, where I'm sort of saying, look, you know, this thing that I've just been through and I'm still in, has actually benefited me on so many different levels and it's not just because I'm a

nice a human being taking care of someone. It's actually because I've had to work on myself very deeply in order to do this role well and not allow it to take over and to manage it and keep everything else going at the same time. And habits are a huge and the routines that we create and the thoughts that we have and how we react to them and respond is a huge piece of the puzzle, actually. Certainly, from the emotional side, but also from all the other side keeping down to managing the pills of the patient or collaborating with the team or whatever you need to do. You know, if you're not building proper habits in place, it's going to be really hard to do all these things.

[00:20:03] (Robert) It's interesting that you would say that there's that positive side of that experience. Can you talk about that?

[00:20:08] (Tanya) So part of my journey was that I became a home schooler for my daughter for about three years and I attended this program. On the first day of the program, it was sort of a parent led homeschooling program. So, it was just all these parents who had arrived from all over the world to be trained on this specific methodology. And on the first day of the program, you know, the host or whatever, the teacher, came and sort of started speaking to us and, you know, started asking different members of the audience, you know, who are you? Oh, here's Judith, great Judith, where are you from? I'm from Australia. Amazing and tell us about your duties. Well, I got two kids on the spectrum. And I was sitting, you know, thinking, two kids on the spectrum! Wow! That must be really tough. And he just went two kids on the spectrum, wow what an amazing opportunity. And I was just so amazed by his response. Firstly, because no one had told me up until that point that I was in any way lucky to have what I have, and as soon as he said that, I immediately felt a sense of hope that I hadn't felt until then. And you can call that denial, but I can call, you know, that a changing of my perspective. And that was the beginning of changing my perspective about my role and understanding that, actually I had a much bigger say and a much bigger choice in how I view my role, than I had felt up until that point.

[00:21:55] (Robert) Yeah, I guess it's that and it's also the fact that you if you are open to it, there's the opportunity now to develop new kinds of relationships and new kinds of understanding with people that would never have occurred to you before.

[00:22:07] (Tanya) And with yourself! You can change yourself. You know, you don't have to be experiencing what you're going through right now, the way you feel right now, and I'm a living proof of that.

[00:22:25] The moment I started to understand that. That I actually was integral to my experience. That was the game changing moment, that was the aha. Then it was suddenly like, well, what does that mean? What part do I play in this experience and what where can I actually go with this experience? And what am I going to learn from this? And how do I want to make myself better? How do I want to improve myself as I go about doing what I'm doing as a caregiver?

[00:23:00] (Robert) So when you left that room with that optimism or that newfound idea that it could be an opportunity. Did that just energize you completely did that just give you a push?

[00:23:10] (Tanya) Yes, it was the first time that anyone had said to me that there was an opportunity here. And as I say, you know, you can say, wow, well, that just sounds very kitschy and fake. Or you can look at it and go, well, that's actually a very interesting idea.

And why haven't I thought about it like that until now? Why has no one spoken to me about it like that until now? Like why? Why is it only got to be about me being a victim here? And that was again going back to the beginning like why do we have a system in place? That's like when something, when challenge comes our way, why don't we have a system in place that kind of supports us and empowers us to actually become a better version of ourselves. And at the same time, you know, live with what we're experiencing in a much more sort of balanced way. It just doesn't have to be the way it is today.

[00:24:17] The challenge that caregivers face at some point after they've done it for a certain period of time, they just get to that point, it's just like I can't I just can't stand this anymore. I'm just so angry or I'm so fed up and I am so lonely or they're just filled with some negative feeling. And they get to that point and it's like basically that's the point where they realize that the old system is no longer working, you know? And the tools that they had in place, the habits, the reactions, the beliefs, all of that is no longer working. And they get it, they just realize it's not serving me any longer. And that's usually the point where Resilient becomes a value, because then they're ready. They're open, they say they're ready for change because they don't want to be in the place that they're in anymore. But I'm sort of saying, you know, why get to that point? You know, and that's also part going back to the opportunity. We as humans, and look at what we're, we're all going around going, "Oh but I just wanted to go back to being normal", right? "I just wanted to go back", and that's what we want, like, "I just want my old life back". I just want to you know, it was great, or it may not have been great, but it was you know, at least I knew what I was doing in my not so great back then. And now I don't really know what to do. And in that sense, you know, caregivers stay in that place for quite some time before they eventually get to a point where it's just like, I can't do this anymore. I'm really struggling. And so, I encourage people to think about this as soon as possible. But I'm aware of the fact that, you know, the opportunity to wake up only actually comes a few years later, usually.

[00:26:32] (Robert) So this seems like the perfect time then to ask you a little bit about Resilient. So, can people sign up now?

[00:26:39] (Tanya) Yeah, yeah. So, you can go to our web site, Resilient, which is with a Z, Resilient.co and sign up. We're currently running a pilot study which we're running for free. It's an eight-week program that allows the caregiver to be coached by an actual coach. They go through various video evaluations with the coach and then they are guided through this program that includes content, which they are asked to give their feedback and thoughts to the coach. They journal, they report on various metrics that help them stay on track. Over the course of those eight weeks, they start to build a level of awareness about their experience as a caregiver that they would not have had until that point.

[00:27:34] (Robert) So it's like having you in the room.

[00:27:35] (Tanya) It is like having me in the room.

[00:27:38] (Robert) What a great opportunity that is! That's fantastic.

[00:27:43] (Tanya) Right now I'm coaching as well, so they can help me too.

[00:27:48] (Robert) Tanya Yarkoni, you can find out more about her company, Resilient that's spelled R-E-Z-I-L-I-E-N-T at Resilient.co. This podcast and the Stronger Together app is brought to you by Curatio, the private social network for health used in over 85

countries. The Stronger Together app is designed to help you cope and thrive during Covid-19. You can download it for free from iTunes or Google Play.

[00:28:15] And for more information about Curatio, including links and show notes to this episode, visit us at Curatio.me for the team at Curatio and the Stronger Together app, I'm Robert Ouimet. Thanks for listening.