Introduction to Sarah Teton Canter

Welcome to this episode of the Reverse Alzheimer's Summit. I'm your host, Dr. Heather Sanderson, and I'm so delighted to introduce you to Sarah Teton Canter.

She has a Ph. D. and she's using that degree on this mission of helping people embrace the gift of growing older. She's the CEO of Positive Caregiving, an organization focused on helping caregivers and care receivers.

These care partner dyads favor their experience while finding opportunities for personal growth. She's the author of Positive Caregiving, a book published just this month.

As we're recording in 2023. And she's also a developer of the positive caregiving mobile app available for both Apple and Android users. She holds a doctoral degree and a master's degree in gerontology from the University of Nebraska and Omaha, where her research focused on the emotional experiences of people living with Alzheimer's disease and related dementias.

She's a dementia friend and certified caregiver advocate, and prior to pursuing her passion in gerontology, she was the chief marketing officer and chief customer service officer at Connect the Now, an IBM company.

She lives in Lincoln, Nebraska, with her family. And you can see why I am delighted to introduce you to her. And so, so grateful to have Sarah with us today.

Welcome. Thank you for having me. So, you know, we were chatting just a little bit before we hit record about caregiving and what that can mean. Both the ups and the downs and the joys and the and the heartache and stress and how this can actually put caregivers at risk somewhat.

So I'm curious and I'm curious how you approached that and what that means to you. Yes, I think well, the narrative in America especially is that caregiving for our older loved ones is is a burden and stressful and scary.

And that's actually true. Caregiving is often scary and stressful. And you're caring for someone that you love.

Reframing Caregiving as Growth

And when you see someone that you love that is adapting to an illness or an age related change or an injury, of course, that's scary. And and what we try what I'm trying to do is tell the other side of the story, because when you actually talk to caregivers and caregivers, caregivers especially, that have gone through the caregiving experience, when you come out on the other side, they're so thankful for the experience and that they had that time with their loved one.

And so it's we're trying to tell the story that caregiving is also an opportunity to savor, a time to build bonds with our loved ones and the time for personal growth.

Well, so, yeah, what I'm hearing is this sort of this choice that we can really reframe that caregiving experience where if we're feeling overwhelmed and burdened by caregiving.

Where do we start in that process of reframing it. And the great question in the book, we talk about perspective as being one of the pillars of positive caregiving.

So perspective just giving us the space to take a step back and look at the experience and look at our lives and our care receiver's lives in perspective.

And it gives us an opportunity to reassess what matters most to us in life and to recognize our own personal worldview, how we approach experience is in hardships in our lives, is dictated by our own personal worldviews, which have been, you know, just created over our lifetimes, from our own personal experiences or personal. These are genetics, etc.

But from a positive caregiving standpoint, we always try to tell people that there's additional lenses that we can put on to help us reframe and change our worldview.

And so in the book, we talk a lot about using gratitude and empathy, forgiveness, love and awe as not only emotions that we want to foster, but also as lenses that we can use to approach our our caregiving duties and our relationship.

Is there any simple kind of daily practice that you would recommend our listeners. Start today? Well, I think you know, I think one that I love to suggest to caregivers and their care partners at the beginning of a caregiving relationship or even if people are finding it difficult moving forward in their caregiving relationship, is to take a deep breath and create a clear mission statement and so on.

Positive caregiving become the website. There's a framework for people that they can download, but it's just three simple questions. You know, both parties, what matters most to you?

What are your shared values and what does success in this relationship? Or what does the what's the best outcome in this relationship? Talking about those things and crafting a caregiver mission statement similar to what organizations do all the time to get people aligned and motivated and crafting that for you and your care partner is a great way to reset or to get set up for success and having that where you can always return to it on a regular basis if things feel overwhelming going back to same, you know, going back and rereading your caregiver mission statement and getting back aligned together with your care partner.

And it sounds like for someone who's struggling with dementia, of course, you would want to do this early on in the process and really helpful.

Mission Statements and Early Planning

I've seen so many, if I call them dyads, right, this care partner duo where when it takes so much burden off of the caregiver, when they really understand clearly, though, the wants and the values and the idea of what this disease progression might look like of the person suffering with dementia, that when those when those wants and needs and desires are expressed really clearly and cleanly ahead of time, ahead of that demise of cognition and judgment that is so freeing for the person who's caring for them, even though it can be a really difficult conversation.

Right. Right. And, you know, one thing that in my research is that just as people if people living with Alzheimer's disease or other dementias, they may you know, their cognition changes, but they don't lose their ability to feel.

And so the emotions are really important. And that's another reason why putting gratitude and empathy, forgiveness, loving are at the center of our caregiving relationships are so important because or.

Even all relationships. That's right. So and I guess with caregiving relationships, it can be even more challenging, particularly if it's a family member that you're caring for because there's so much dynamic that goes into that relationship.

Rabies, these memories from 20 years ago, these, you know, the judgment or the kind of ingrained dynamic. Right. Right. So do you have any suggestions for people who are running into that?

Yeah. So the first part of the book is really focused on explaining to people how to reframe the situation and how to use those additional lenses. But the second half of the book is more like almost a cookbook full of little recipes of your activities that you can do with your care partner.

They include questions and discussion topics that you can have, and then personal practices for the caregiver as well that they can do on their own to help build their own resilience.

But there's really practical things that people can do, different activities that they can do everything from, you know, creating memory boxes to walking a labyrinth as a path for forgiveness.

So there's there's a wide variety of activities to help foster those emotions of gratitude, empathy, forgiveness, love and all. And I think that having that list is so helpful, right?

Because many of us, we get to that spot in our day, we're like, okay, I got it. I got the dishes put away and I got the laundry done and now I have an hour.

What am I going to do with it? And it's so easy to scroll and to turn the TV on. But when we have those activities, top of mind makes it a little simpler, and especially if we've decided ahead of time sometimes that decision making rate, it's like it's like looking for the movie to watch.

You never like it. You spend an hour deciding which movie to watch, but if you have sort of a list of these things that you can do and maybe you've started the ones that you're really interested in, then when it's time to go do them to walk that labyrinth, you can put that at the top of the list and say, Okay, this is my hour.

I get to go do that thing that was in positive caregiving. Yes. Yes. Do you have examples or anecdotes of people who have been doing this? Sure. Well, I think that yes.

One part of the book, too, just before we move on to that, is that we emphasize the power of micro moments for caregivers, too, because sometimes people don't even have an extra hour to go and do an activity, you know.

Emotions, Family Dynamics, and Practical Activities

So when you were mentioned, when you were talking about doing the dishes, it's, you know, a suggestion of, you know, while you're doing the dishes, kind of take stock, look around and identify five things that you're grateful for in the moment.

So little things like that that help build that resilience is really helpful. But one thing that even my mom and I do is go in for walks and identifying things that we're grateful for on our walk.

So it's just adding instead of, you know, doing something out of the ordinary, taking something that's ordinary and adding the gratitude or empathy or forgiveness a little bit into the activity and everyday activity.

So even having. So, for instance, having dinner instead of just having dinner one evening focusing on forgiveness, maybe there's something that has been said or maybe once a week you decide that we are going to talk about anything that hasn't felt good for the week and we're going to light a candle and we're going to candlelight dinner.

And at the end of dinner, we're going to blow out the candles. That's going to be our release and our forgiveness practice. And I love that. What a great idea.

And so you've worked with people who are suffering with dementia, also people who are caregiving. And what have you seen? Give me some examples. You. Yeah, many stories to share because they always do inspiring people.

Well, let's see. And there's there's quite a few and there's quite a few in the book. And of course we change names and everything just to keep people's privacy.

But there is a mother and her a mother and her daughter. The mother was still living at home. A lot of people obviously live alone for quite some time living with dementia.

And the daughter was visiting her one day and they were sitting out back and the mom just said, isn't this sunrise

beautiful? And just took the daughter back so much because she hadn't been as communicative lately? And I think it's important to realize that those esthetic experiences, those natural experiences are so important in life.

And for the caregiver to recognize that those things are still so powerful for everyone, even when you have a cognitive issue or a decline. So there's there's those, you know, obviously when we're caring for people we love, I think taking rest is really important as well.

So taking respite for ourselves that we can take care of ourselves and we can take care of our care partner better. And that's a really important lesson that I've learned as well. So.

Oh, I've got to pick your brain about this because what I tell my care partners, who I coach and work with, is my goal is for them to have one day to themselves, one day of the week where they they're not running errands.

They're not caring for anyone. They're not responsible to pick anyone up or drop anyone, offer answer phone calls. But they have one day where somebody else takes all the responsibility.

And sometimes that's an adult sibling or it's a spouse or it's a niece or nephew or it's a hired caregiver. But one person who can give you back a full, complete day.

And even better, if you can get 24 hour full hours. And I recommend that people do this before they think they need it. Because one of the heartbreaking things I've seen is people getting backed into a corner after there's a fall or a stroke or some event that sends people downhill and in need of more and more care.

It's not sustainable for one person to care for them around the clock anymore, and they don't have that option of finding someone they trust. They just have to take the first person that that answers the ad or shows up.

And I hate to see people compromise in that way. And it's so nice when they have had an established relationship. Somebody already knows the person and then they're able to just sort of like expand their responsibilities and lean on them temporarily a little bit more.

And then in addition, I think having that day off, although it maybe is preparing for the worst, it's also giving that caregiver that ability to like put their oxygen mask on.

Yes. No. And I would suggest looking at that through a lens of love, because, I mean, so many caregivers that I've talked to, caring for people who are living with Alzheimer's disease is that there's so much love there that they want to do everything.

And but you're right. I mean, all of a sudden you get depleted when one of a person that I interviewed when we were doing a study looking at people who had to move their spouses into memory care, eventually he used the frog in the boiling pot.

You know how concept that all of a sudden he didn't even realize that the water was boiling and that he you know, so it was very, very difficult. So I think looking at self-care and time to yourself is an act of love, not only for yourself, but an act of love for your loved one, because it gives you the recharge you need to continue to be able to care in a healthy way.

And so I agree with you 100% that giving yourself time and thinking about it early and again with a different lens so that you can build that into your caregiver journey, as is a natural part of that's what you do.

I take a day every week rather than waiting until it's too late.

Micro-Moments and Everyday Practices

Well, then I think we can all experience and appreciate you're a CEO and I don't know if you're a mom, but yes, it doesn't take being a career partner to have that experience of like if I'm doing the seven days a week, 24 hours a

day and I don't get a break, I'm more irritable, I'm not creative, I'm not appreciating, I'm not slowing down.

Notice those moments because I haven't gotten a break that I desperately need. And so getting that ahead of time is important. The other really important piece that you bring up and is reflected in the literature is that you're not as good of a care partner if you are depleted.

And so when we can reduce that burden by getting you a break, by making sure you're getting restless sleep, then you actually take better care of the person you're caring for.

And this is measurable and it's like a safety issue, right? You're the person that you love is is going to be better cared for when there's balance in that.

That's right. So what are their advice? You give caregivers who are struggling to maintain positive perspectives and balance in their journey? Yeah, I think, again, those micro moments are so powerful and so everything from just learning how to breathe, how to, you know, regain perspective quickly.

One of the things I love to tell people is just to look up. Just tilt your head up. And whether you're looking up at the sky or the stars, it's it helps your body to regain a new perspective and helps to induce a feeling of all which can bring you back to here and now pretty quickly.

So there's little things like that all through the book and again, and then taking care of yourself above and beyond, giving yourself time, making sure that you don't miss your appointments for your help, your regular checkups, making sure you're eating healthy, as you know, feeding yourself with loving foods, easy junk foods, you know, those kinds of things all can take care of our are ourselves so that we can be a better partner for our loved ones.

Amazing. And so I can't wait to read your book. It's not out quite yet. A very creative mess, but I have ordered it because I love these ideas and I just I want more of them from you. So.

Any other quick tips or and more? Definitely go and get the book, but any other quick tips around things that we can do day to day or activities that we can do with our especially with our care partners?

What can we do together? Well, there's everything all of the ideas in the book really are centered on that dyad and then the caregiver personal practice is just in addition to the the diet, you know, the cared for more activity.

But I love the ones, especially things about just everyday activities. So we talk a lot about, you know, there's a lot of waiting that goes on. We're waiting for a doctor's appointment or we're waiting for our prescription at the pharmacy or we're waiting, you know, so what are things that we can do to induce gratitude, empathy, loving in those moments?

So even just simply holding hands and thinking of that as an act of love and then, you know, or using your drive to the to the doctor's office or to the grocery store or to church or whatever, wherever you're driving, using that as an opportunity to take notice of how the seasons are changing and what you love about the season, or what you love about your community.

Just asking those kinds of questions to bring those emotions and to just everyday activities. I love it. Yeah, just that refocusing. Yeah. Think you have four pillars of positive caregiving.

I'd love for you to take us through each of those. Sure, sure. So we talked a little bit about the first pillar, and that's perspective.

The Four Pillars of Positive Caregiving

So, you know, regaining perspective on your caregiving role and in life in general. And then they're savoring because I think and this is one that I think is so important, is that even amidst the trials and of life in general, but especially as we age, we face potential illnesses or injuries or cognitive disorders.

And so how do we, you know, accept and adapt to those changes and then continue to savor the things that matter most to us in life? How do we continue to enjoy the things that bring us joy?

And so that's the second pillar. And the third pillar is reminiscence. And reminiscence is so important just as we age. I think, you know, we talk a lot about it in older age, but reminiscence is important throughout life to kind of constantly remember or to be able to think about what has happened to us and how that is held or how that has shaped who we are and to create meaning in our life and for people who have memory disorders or issues.

There's so many things that we can do as partners to help aid in that. So music is one of my favorite things that can bring people's can bring some meaning back to them and photographs and telling stories to our loved one as well.

So that reminiscence is important. And the fourth pillar finally is growth, and it's personal growth. And that's not just for the the caregiver. The care receiver has potential to grow, obviously, as well throughout their lifetime.

So having perspective, continuing to savor the things that we love and reminiscing about what we've done and to make sense of our our life and our roles currently.

And then to the natural outcome of that is personal growth. So I'm saying, yeah, this certainly is a ripe for personal growth, right? Because we are we're hitting up against really challenging things and things are changing.

And so it is this really beautiful opportunity to to step into that. What makes these elements particularly effective in promoting a positive caregiving experience?

I think you just touched on it. You know, when we're caring for someone that we love and especially when they're facing your age related changes and cognitive issues, there's a lot there's a wave and constant kind of negative emotions that might arise and be around.

And so it's almost like having to welcome them into our lives, but then using the positive to balance ourselves. So balance out some of those negative emotions with the positive emotions so that we can build our resilience and continue to move forward with courage.

And I think that that's one of the most important messages is that we don't want to ignore the negative, we don't want to suppress the negative. We need to feel those things because it's life, right?

We're caring for someone. We love them and it's hard to go through that. But being able to use the positive emotions that are available to us in those lenses is really important to to continue to build and continue to grow even through tough times.

I hear you kind of there's this theme of like we have a choice, right? And yes, that things are going to happen, that they're going to be sad and they're going to be emotional and they're going to be stressful.

And we can allow that to move through us and process. And then when we are given the opportunity, when there are these moments that are sort of benign, right, like a meal or a drive or waiting, that we can use them as an opportunity that like amplify the good and that over time, I mean, that's even a way to rewire the brain towards less stress.

And we know stress also the literature is very clear that dementia is associated with stress, anxiety and depression. And so if we can make decisions about the tracks and the wiring of our brain day to day, then we're going to have a big impact on our risk of developing dementia later.

And caregivers are at higher risk. And so these these day to day, I always think like it's those decisions that you make every day, those minor little things that you do that become that habit.

And that's really what affects the trajectory of your health, both mental health and physical health. Yeah, just overall wellbeing for sure. So I want to put this into the context of like just the larger society.

Right. And you mentioned how in Western culture, American society, there is this kind of expectation that caregiving is going to be very burdensome, sad, and how can we help to shift that narrative?

That's a great question.

Shifting the Cultural Narrative

And I think that that's really my mission because, again, when you ask people and when, you know, I've been a caregiver, you know, you come out the other side and there's a thankfulness there, you know, most people would say, I wouldn't trade it for the world, even though it was hard.

And so I think that that's like an important message to to get out there so that that people don't enter a new caregiving relationship or experience or caregiving journey already with a pretty determined mindset that this is going to be a burden in a difficult, horrible situation, because that's not the case in most situations.

There's going to be tough times, but there's a lot of joy to it as well. And so just making sure that people hear that message is step one. And then maybe going in with a mindset of like, wow, I'm going to be so grateful I did this.

Even when it's hard, I'm going to be so grateful. I had this time with my mom or my spouse or whoever it is. That's right. They can really see that. Wow. What would a phenomenal opportunity.

And then do you see people who, you know, financially, they just don't because this is a physical burden, right? Like moving someone around in and out of wheelchair, in and out of bed.

You know, sometimes as people age, they become a little bit more combative. Like there is a physical stress that can happen. There is an emotional stress, of course, of losing a loved one very slowly, particularly if they have Alzheimer's and they're there.

Their character is changing and potentially they're you're losing kind of some of who they are. And then there is also financial burden often for people, and particularly if they were expecting to continue working and then no longer able to.

And there's this push and pull rate of like, I would be so grateful to have that time with my mom, but I don't know. It may be less expensive and less financially burdensome on my family if I pay someone else to do it.

How how do you how do you support people in navigating those decision? Of course. I mean, I think that like everything in life, I mean, everyone has their own individual experience.

And so some people are I mean, there's all different kinds of caregivers. There's part time caregivers, there's full time caregivers, there's caregivers.

Just because someone you love is living in a care community, whether that's memory care or assisted living, you're still a caregiver to your your loved ones.

And so a lot of people care for their loved ones from afar as well. So they might not be in proximity to their loved one that needs assistance and that doesn't make anyone less of a caregiver.

So I think that that's important is that there are all different kinds of caregiving relationships and it really needs to make sense to you and to your loved one, which is why I mean, the sooner that people can talk about these things with their loved ones long before a caregiving need arises is the better.

So, I mean, I definitely always tell people to how do these conversations and talk about it and start talking about it and thinking about it again through a lens of love.

So how do we do this as a gift to our loved ones so that they know what our wishes are and so that, you know, and

vice versa? So I think that's really important.

Really important. Yeah. Well, thank you so much for making the workbook available so that people can navigate that and know that you are not alone out there. And I feel because I'm a mom so that moment I see a lot of people going through Alzheimer's and it's kind of like that moment you become a mom, you take that newborn home like you don't really know what you're getting into until you're in it.

And caregivers, especially those supporting them with dementia, it's like you don't want to know anything about dementia until you have to know everything.

And it can feel really overwhelming and like you're alone in it. And sometimes there is stigma. Oftentimes a person struggling cognitively, cognitively doesn't want their social network to know, and so they aim to hide it.

And then it's harder to get support because you're not allowed to tell anyone else. And these things are challenging to work through, certainly. But you are not alone.

There are a lot of people out there and it sounds like it.

App, Support, and Hopeful Stories

Tell us more about your app. I know we've been talking about your book, which is going to be available by the time the summit hits in June. The book will be available. It's being released in May.

So go out and get the book Positive Caregiving by Sarah Kanter. And and then tell us about the app and is there a chance to connect with other people going through this on that?

Yeah. At this time, the app is really just for download for people on their phone and it's again there's self self-care for the caregiver. So some tools, some micro moment ideas daily that come across there are caregiver reflections to keep the five emotions gratitude, empathy, forgiveness, love.

And at the center there are caregiver affirmations daily. And it brings with me to all those things to help the caregiver. But then there's also caregiver activities or care partner activities that are that people can do together.

And then there's a care album. So if you want to record some of your activities that you do with your care partner, take pictures or take notes so that you have that for future reminiscence that's available as well.

So it's it's a very simple too. It's free to use, but, you know, for people who are feeling isolated and maybe they are in a situation where their loved one doesn't want to be talking about it.

There are some ongoing support groups that are you can remain fairly, you know, confidential, etc.. So I would highly suggest that as well. But I also for the people who are living with Alzheimer's disease or related dementia, I mean, there are so many people that I know that have built wonderful relationships with new people that they've never known before through memory cafes, through activities in their community, whether that's at the art museum or the coffee shop.

I mean, there's it's really about exploring and kind of looking at as a new adventure where you get to meet new people and you get to explore different way of living.

So I really think that keeping a positive outlook on this is so important. I was reading last night, you know, I'm always reading about Alzheimer's and there was this account of a woman who became much more creative as she developed, like went down the path of Alzheimer's.

So she started to paint and she was this phenomenal painter and she kept getting better and better and better at painting. She was losing verbal ability.

And all of a sudden she was like this really phenomenal painter. And these are things like when I read that through with like what? Like you don't hear this.

That isn't part of the narrative. That's right. There is potentially this like hidden gem under there that could be exposed if it's cultivated. And, you know, and I've seen this over and over again as well, people even moving into Marama, the residential care facility, they develop these phenomenal relationships.

There's very close relationships with the other people who are there and they're celebrating together and cheering each other on and looking forward to things together.

And they're for each other when they're grieving or something bad happens, and it's really just really moving to see that connection in is so powerful.

Absolutely. Absolutely. I mean, there's a lot of parallels between the the make the narratives that exist between caregiving and living with Alzheimer's or dementia.

And we only hear often the negative side and there's a whole nother side to it. People do live well with dementia and they can live with passion and purpose and meaning.

And I think that that's an important message to give as well. Yeah, it takes a little bit of effort and creativity, but it's still possible for so many people.

So it's just a privilege to have you. Thank you so much for joining us and for sharing this very hopeful message with with people here on our in our summit.

Thank you. Thank you so much.