

Daughterhood the Podcast

Episode #55

Finding Meaning in Caregiving with Dr Allison Applebaum

<https://allisonapplebaum.com/>

[Stand By Me A Guide to Navigating Modern, Meaningful Caregiving](#)

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SPEAKERS

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Disclaimer 00:00

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Rosanne 01:06

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 front lines 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 alone. 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. Dr. Allison Applebaum is a writer, speaker, researcher, advocate and caregiver. She is an associate attending psychologist in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center and also the founding director of their caregivers clinic. The first of its kind in any Comprehensive Cancer Center in the US. Dr. Applebaum amplifies the voices of family caregivers in her scientific journals, editorials, and her research which focuses on developing innovative ways to identify, prepare and support caregivers. Through this work. She also addresses the distress experienced as a result of increasing responsibilities. In Allison's new book, Stand By Me A Guide to Navigating Modern, Meaningful Caregiving. She brings not only her professional experience to the subject, but also her personal journey of caring for her beloved father, Stanley Applebaum. In our conversation today, we discuss her book, the experience of living in the in between as a family caregiver, and how caregivers can find meaning and purpose while juggling the responsibilities and emotional ups and downs. I hope you enjoy our conversation.

Rosanne 03:05

Allison, in your impactful book Stand By Me, you captured all of the facets caregivers deal with throughout the caregiving experience. Most importantly, it captures what is not apparent to the outside world about caregiving, the heaviness of living with uncertainty, and in that liminal space, the time between what was and what's next. Can you explain how that affects caregivers?

Dr Allison Applebaum 03:27

Absolutely. I mean, I think this is something that characterizes all of our experiences, family caregivers, regardless of the illness that our care partner is living with, regardless of what our responsibilities are. And that is a fact that the reality we once knew before we were family caregivers is no longer here. And we don't have a crystal ball. We don't know what the future is going to bring. In fact, we cannot plan for the next year or month or week and in some cases, even the next day or hour, because of caregiving and because of illness. And so limit living in this liminal space is in between space is really one of the primary tasks that we all have as family caregivers, learning to sit with uncertainty, learning to not know what the next moment is going to bring. And dare I say, starting to become comfortable in that space in that period of in between.

Rosanne 04:21

It's the part that's overlooked the most because people don't understand that, that that's a huge part of it. Aside from medication management, aside from going to the doctor's and and the practicality of caregiving, that piece adds to all everybody's stress.

Dr Allison Applebaum 04:38

Absolutely. You know, I think there's so many facets of our responsibilities that are invisible, and are hugely burdensome, and this is one of them. This is one of those emotional elements that in order to be that physician or a social worker, case manager and all the other things that we do as family caregivers, it also means that we are living in perpetual uncertainty. And that shapes all aspects of our lives, both in terms of our family caregiving responsibilities, and everything else, like our potential paid employment, which we're trying to maintain and our other responsibilities that are deeply impacted. But this is an invisible burden, and very much shapes the experience of all caregivers.

Rosanne 05:18

You know, we hear a lot about holistic care and psychosocial support. What exactly does that mean? And how would that help a caregiver?

Dr Allison Applebaum 05:25

So grateful that you're asking this question, because I think there's so many phrases and terms that are thrown around, and not everyone understands what they mean, or they can mean many different things. So when I speak about holistic care, I speak about treating the patient as a full person, as a human, not just as a diagnosis, not just as a medical history, but an individual who has a set of goals, and not just goals for care goals for life, an individual who has a personality was parts of themselves that are important to convey. And so holistic care means attending to all parts of that self, when developing a care plan. And that care plan can be a medical care plan, or the reference psychosocial care. And that's the care of emotional well being and spiritual well being. And I often use the word existential well being that we're really providing support for the whole person, not just how they're doing medically, but in order to provide holistic care providers and health care providers, health care professionals of all all sorts need to know who the patient is outside of just a diagnosis outside of what they might just be reading and that medical record that is, you know, very limited in terms of what information is required.

Rosanne 06:42

And you did that continuously with your father. And you described it beautifully in the book, you made sure everyone that came into that room understood what was important to him, and who he was as a person, as, as a person in the world and as a person in your life. And it was such a beautiful companionship. And it was, you know, I I felt connected to him and to you while I was reading this. And I know that throughout your whole caring with care journey with with your dad, you were able to explain that how do caregivers find their voice? Doing that through this journey?

Dr Allison Applebaum 07:24

Thank you for that. Just, you know, thank you for acknowledging that. And I guess mission accomplished. If you were able to feel connected to my dad, then my, my work is done sort of. Absolutely. You know, my dad suffered from a neurodegenerative disease, Lewy Body disease, and there were periods when he was not oriented. He was disoriented and hallucinating and unable to communicate with members of the healthcare team. And there are other times when he was so sick, from sepsis or other illness that again, he was not awake or aware. And so in those moments, it became so very clear to me, that without me by his side, there was no way for any member of the past few medical teams to have any idea who Stan Applebaum was and what mattered to him, and that I needed to be his eyes and ears and voice. And that responsibility continued when he was awakened oriented. And it's a responsibility that we all have as family caregivers, regardless of whether your care partner has Lewy Body disease or another illness that that impacts orientation. And that is the fact that we do need to speak up. We need to find our voice that means that we are asking clarifying questions the medical team, there's a lot of medical jargon that's that's that's shared in these brief, intense moments in emergency emergency rooms. And it's very important that you ask clarifying questions so that you know that you and your care partner actually understand what it is that healthcare professionals have shared with you so that you can make informed decisions. You know, finding your voice to means that you as a caregiver are getting your own education and information needs met. And I often go to this example, which is that we are increasingly tasked with taking on responsibilities that were once only those rescued, you know, taken on by healthcare professionals, by nurses and physicians, etc. But we as family caregivers are now being asked to do so many different things. And too often without training, education and support. And while we have the Care Act in this country, and it's a great direction we're moving in for those who are not familiar, the caregiver advice record enable act currently passed in 45 states and territories. And, you know, it says that hospitals need to be providing training and education to caregivers before a patient is discharged. But we all know everyone listening knows that that is not consistently implemented, I will say in my experience, and it was a pre Care Act experience that was never implemented. I never was offered training. So what I encourage caregivers to do to get their needs met, is to speak up and to ask a member of the healthcare team, a nurse, a physician, someone else to demonstrate for them that tasks that they're going to need to complete at home, so that they know how to do those things and can perform them competently and confidently. And then when they're home, oftentimes patients will receive visits from a visiting nurse. Well, that's not only an opportunity for that nurse to evaluate a patient, but for you to get additional training, and an all of these interactions, not only are you going to be making sure that you feel confident in your skills and your abilities, but that those healthcare professionals understand who the patient is. And so for me referenced the fact this was repeated, this was a daily, weekly monthly exercise for me, when I shared my dad's health history, and we all are asked about our care partners health histories, I always made sure to include elements of who Stan Applebaum was as a person, in terms of his personality, his drive for life, his curiosity, the goals that he had for the time he had

remaining. Now, my father was in his 90s, and ageism, very deeply shaped our experience as Partners in Care as it does for so many of us. And I found it's so important for me to be able to win, conveying who he was that that his age was meaningless to him, My dad didn't want it to live to at least 103. That's what he had his his goalposts, he wanted 103 got to 60s before his 97th birthday. But it was so important for me to do that. Because otherwise, those healthcare teams could not deliver holistic care, they could not deliver interventions that were in line with preserving my dad's capacity to, for example, get down to the boardwalk in New Jersey and filled with sunshine on a skin. holistic care meant understanding that that was something that he really wanted to do. That was important to who he was, and we needed to make sure that we could do everything we could to make that happen.

Rosanne 11:50

That's beautiful. It's It's so true. And there's so much that goes into this. And when you look at the Care Act, and then you think, Wait, you mean, this was happening? Like nobody got instruction? Yeah, that's right. That's right.

Dr Allison Applebaum 12:02

Nobody, nobody got instruction. And most often that that still is, is the case. And and so, you know, I often encourage the caregivers with whom I work to be as educated consumers as they can and to speak up and find your voice. And many caregivers will say to me that they have become so darn outspoken, because of their caregiving role, because they've had to be that person asking the questions, asking for training, saying, Hey, we can't leave yet, because I have no idea how to change this catheter bag. So you need to tell me how to do that.

Rosanne 12:34

Right? These are big things, and they're scary things. And then you're in your house, and you're like, Wait, did they say left or right? Was I supposed to right? Was I supposed to do this before? After I pulled that? Like, it doesn't? It doesn't make any sense. I always say there's you know, and we know this, we know there's different language and everything. What are your favorite? I don't know your favorite three clarifying questions to ask that just cut through it that make them understand that you know what you're talking about.

Dr Allison Applebaum 13:02

I always ask, you know, and this comes from a, I'm a clinical psychologist by training and I practice psychotherapy. And I have a clinical practice with family caregivers. And this is something I asked as a psychotherapist, but it's Can you help me understand? Are you can you help us understand what you mean by? Because so often information is given in language that we you know, as lay folks don't understand it's not digestible. So can you help me understand what you mean by that phrase, that term? You know, I don't know that I have two other favorites for you. But I have one major general rule. Yeah, which is that direct

questioning is always a good thing. So being direct, not avoiding, not avoiding a certain topic, asking specific and specific questions. So, you know, when we think about prognostication, for example, no physician has a crystal ball, we got that none of us have crystal balls. If we didn't need to be we wouldn't even be seen here, sitting here right now, having this conversation? I'm not sure. But asking questions specific about what are the chances of this treatment working based on your experience with other patients like my father? If this treatment were to stop working, what are the other options available? Asking very directly and very specifically, I think is, is really the best route to getting our information needs met. And the reality is that most often healthcare professionals are not volunteering that information, we need to play traffic off and we need to direct the conversation and get that information ourselves. And so, you know, I this is why so many folks say that they've become so outspoken and confident because they've had to learn that the only way they they're going to get the answers is if they ask No, I want to make a point when I when I share this is that whenever possible, and I say that unless it's a situation where a care partner is not oriented or able to engage Of course, there's going to be a brookgreen of of what information you can ask between a patient and caregiver. In fact, very frequently we are in different pages and our care partner about what information is desired from a healthcare professional. And in fact, I oftentimes will encourage caregivers to have what I call a consent conversation, okay, in advance of meeting with a healthcare professional. So the consent conversation is basically, you as caregiver, getting on the same page with your care partner about what topics are and are off limits for the next meeting so that you can maximize that time because we all know those meetings with doctors go very, very fast. We're always nervous, our cortisol levels are high, we forget the six questions we wanted to ask. But the reality is that another impediment to maximize that time is being on a different page than your care partner. And so making sure that the two of you in advance of the discussion are on the same page about what can be asked is also going to help you to get as much information as you can.

Rosanne 16:00

Yes. And you never want to be in the appointment and say something and have your care partner look at you like what we didn't talk about that? Or what do you mean. And it's hard. It also adds to the stress of being the caregiver, because you have to have these difficult conversations, you just have to. And that's the hard the other hard part with when you're talking with the doctors, because you may not want to think about what happens if this doesn't work. But you have to.

Dr Allison Applebaum 16:32

These hard conversations invite an elephant into the room. And that elephant is death. And understandably, these are incredibly difficult, painful conversations for all of us to have even for those of us who speak and discuss for a career that you know that these are hard conversations for all of us to be having with those that we love. And so that said, having them

is so crucial, because if we don't have them, there is no way that we as caregivers, and in most cases, as healthcare proxies, will be able to bring our care partners voices into the room. If we are not having open, honest, vulnerable and very, very importantly, perhaps the most important part I'm gonna say repeated, repeated conversations about goals of care and goals of life, then there's no way that we can actually carry forward our work as caregivers, there's no way that we'll be able to make sure that our care partners receive holistic care if we actually don't know what matters to them. That said, you know, these are really, really difficult conversations to have, I'll give you another tip that that I shared with with many of the caregivers who come to see me and that is to practice opening the conversation through what we call agenda setting. So you as a caregiver might be ready to talk about the future talk about advanced care planning this umbrella term for all the things that we discuss around the care or care partners will receive in the future, should they be no longer able to advocate for themselves. But your care partner might not be ready to have that conversation. We don't know or they might be but but often, you guys are on different pages. Yeah, setting the agenda allows you to put out on the table immediately and directly what it is you want to talk about and why. And it's something that you can practice in advance of that conversation. So for example, with my dad, I did this often, even though he and I have talked about death our entire life, like we had lots of philosophical existential conversations since I was five years old. But nonetheless, in my early 30s, I still found this very difficult. But I would say Dad, I would really like to talk to you about what type of care you would like to receive in the future. If we could no longer control your symptoms of LBD. It's important that I know what's important to you. Because if I don't, I'm not going to know what to do if you can't communicate. Is this possible for us to discuss? Now, my dad could say, Sure, let's do it now. Or I'm not ready or many other iterations in between. But the point is, once you set that agenda, you've already done the hard work. You've done the heavy lifting, you've already put out on the table, what is important to discuss, and then likely you'll be able to have that conversation more easily. And again, the key word being repeated. You know, my dad's major illness journey began in 2013. And his goals of care in 2013 were dramatically different than his goals of care in 2019. And had I not been having those repeated conversations, and, you know, specific moments and turning points in his illness journey. I wouldn't have been able to confidently bring his voice into the room when he wasn't able to communicate on his own behalf.

Rosanne 19:50

And it's, it's so important, and it's so important, if there's other people involved in the care to have them on board as well because then that Always what always comes up that is, well, mum never said that. Remember, she said she wanted, she wanted to live forever remember that it's like, okay, and that was in, you know, 1995 we're not there anymore. And but that's that, I would think would be a helpful thing to then include others in.

Dr Allison Applebaum 20:21

So you bring up such an important point, which is that decision making doesn't happen in a vacuum. Yeah. And while there might be one individual identified as a health care proxy, that person who signed that form, and most often it is, those of us, those of us who are identified as a primary family caregiver, there are many other individuals who are in the care network, who may give more or less effort over time, but in moments of decision making have a voice. And so what's very, very important is that not only are you having repeated conversations with your care partner, but you are ensuring that all the other key members of that care network, whether they're blood, family, chosen family, friends, whoever they may be, they too, are involved in those conversations or are told about what transpired in those conversations, so that there's no disagreements down the line. And I always think, if your care partner is alert and oriented and able, better for them to be communicating their goals to everyone versus it coming from you, the family caregiver, because as we've been talking about a theme here is all of the invisible responsibilities you have and family mediator, that's a big one. And the more that we can depend on care partners to share their goals of care with others. Well, that helps us in our own responsibilities.

Rosanne 21:37

Again, it's so much it's so much and through the entire book, you've weaved this through with examples and charts and questions to ask and everything. I can't speak highly enough about this. But the caregiver then also needs that support, and they need to be supported. And it's hard for caregivers to reach out for support, whether it's financial or emotional, or they just don't, it's just not my jam. But it's important for that and your through your clinic and through your work. You've you've developed something called meaning centered psychotherapy for caregivers. Can you tell me a little bit about that?

Dr Allison Applebaum 22:15

Absolutely. I'll start by saying that yes, we as caregivers were terrible at asking for help. Where we're really good at giving help we're not really great at asking for it is something I think we can all really work on and and caregiving does that for us. And we all need support in different ways at different points in in our caregiving journeys. Meaning centered psychotherapy for caregivers is a psychotherapeutic approach that was developed to help caregivers to connect or reconnect to sources of meaning in their life, despite the challenges they're facing. And I had adapted this approach from a basic approach called meaning centered psychotherapy that was developed by my mentor the past 14 years, Dr. William Breitbart, who is a term who's the Chairman of the Department of Psychiatry at Memorial Sloan Kettering Cancer Center. And he developed this approach, which I'm just going to call MCP for short for meaning centered psychotherapy. Realizing that there was no pill that he could give patients and end of life that would address their existential distress that would address the fact that they were facing the ultimate limitation and they were facing so many lawsuits. And so we developed this very powerful brief approach in seven sessions that I've adopted for family caregivers. The basic

idea behind meaning center psychotherapy for caregivers, is that suffering, and meaning to coexist. And I often use a metaphor I've actually been using this for a very long time, the metaphor is, is of a crisper lay, which happens to be my favorite dessert. And for those of you who are not primarily aficionados, when a friend really is done properly, and I think it rarely is, but when it's done properly, it's crispy on the outside, and it's creamy on the inside, and it's cold on the inside, and it's hot on the outside, and you take that first bite, and there's so much going on. And this is how I think about the emotional experience of caregiving. At any one time, we can feel sadness, and fear and hopelessness and isolation and resentment and love and strength and resilience. We can experience suffering and meaning in a beautiful Kraemer lay and the suffering does not negate the meaning and the meaning does not negate the suffering. And that latter point is important because I want to make it very clear for all of you you can't see my face but I am not talking about the power of positive thinking. I am not talking about turning lemons to lemonade that is not who I am as a person as a psychotherapist. I am saying that we are handled situations that are difficult. I would assume that most of us have not chosen the care given roles we stepped into, we didn't choose suffering, we didn't choose limitations, we don't choose loss. But despite those things, we can connect to meaning and purpose that is always available to us. And in many centers, psychotherapy, we talk about four categories or sources of meaning that become become resources for us, both during active caregiving and then beyond into bereavement. And I can give you the Cliff Notes version, right now of these four, if you like, absolutely. So we talk about the first source of meaning, which is called the historical source of meaning. And this is this idea that we live life in a context, we have a past, we did not choose, we don't usually choose our parents, we don't choose the environment into which we're born and raised that was given to us. And for many of us, that environment has beautiful things and love and nurturing and support. And for many of us, it involves hardship and trauma and loss. But the point is, we don't choose it, it's given us what we do have choice over is how we live our life. How we live our life right now is called a living legacy. And we all will give a legacy to others in the future, either because we literally give belongings to someone, you know, we give, if we're lucky enough to give an endowment of money to someone after you know for after we're no longer here or, or we give a legacy to others just by being witnessed in who we are. And so we as caregivers can derive meaning through reflecting on the fact that caregiving is not happening in a vacuum. It's happening in this context as part of a larger story of our life. And I give an example in the book my maternal grandmother, Ida Notov had devoted the last 20 years of her life to volunteerism in Pittsburgh, and would spend six days of in various hospices and psychiatric hospitals in the Greater Pittsburgh area. And I would hear about this weekly in my phone calls with her. And I didn't put it together until after her passing. But, boy, the work I do is in so many ways, caring for her legacy. And seeing a picture of her at bedside with a patient is something that really helped me in the midst of my own caregiving journey and thinking about the fact that I was carrying her energy forward. The second source of meaning is what we call the attitudinal source of meaning. And this is a funny word. And really, we're talking about choice. And this

idea that we don't choose suffering, we don't choose all the limitations, we don't choose not being able to plan for the next year, month day hour, we don't choose loss, or we can choose how to respond. And that can include choosing to ask for help. That can include delegating, that can include choosing to set boundaries, to take care of her emotional energy. And for many of us if we can connect and reflect on how we are choosing to face challenge that itself can be incredibly empowering. I hope that for those of you listening, whose caregiving journeys whose active caregiving journeys have ended, if you can reflect back on the ways that you chose to face limitations and challenges and losses that you too might feel proud of yourself. Yeah, the third source of meaning we call the creative, and it's not just about having artistic talents. So that could fall into this category. It's really this idea that we are each the authors of our life. We are each given as we know it one life, and it's our responsibility to create our life. And I think that my just saying that might make current caregivers bristle like Yeah, but like, my life is totally put on hold right now, were you talking about? I hear you. But what are the small ways that you can take responsibility for your life? How can you reconnect to important parts of yourself? How can you engage in meaningful activities in a different way to make sure that you're still doing them? How can you continue to work towards future goals, even if you can't enact them right now? And those are important questions to be asking yourself, and I outlined all of these in the book, by the way, yes. The fourth category, which which is oftentimes my favorite is we call the experiential. And this is this idea that we can connect to meaning through our five senses through what we see, and touch and taste and smell and hear through a feeling of love, through visions of beauty, and through laughter, even the laughter You and I are having is meaningful, we are able to connect with one another. We can connect with a feeling of being, you know, in line with something greater than ourselves. And this can be as simple as you're stuck in the emergency room for hours and you're crawling out of your skin but you put your earphones in and you blast your favorite music and you close your eyes, you take a breath and you are transported to that concert just for five minutes. Or you leave that er so you can feel the sunshine on your skin. Or you go to the hospital cafeteria to get your favorite tea and you sit that tea slowly and connect to the flavor of it. Or if you have a warm relationship with your care partner realizing how awesome it is to hold their hand, or to hug them or to lie next to them. And so these are categories or sources of meaning they're always available to us. Again, they don't negate suffering, they don't take away the drama, the trauma we all face. But they, they can accompany all that. They can help us to develop strength and resilience while we face all the things we do not choose.

Rosanne 30:23

I love all of that. And it's important because it is hard to think, well, how can I do that? These are little tiny things that you can do that are necessary for your soul.

Dr Allison Applebaum 30:35

Yeah, I use an example, in the book of myself. So I had a first career as a ballet dancer, and dance and being in a dance studio is always really important for my self care. But when I was taking care of my dad, my life was so uncertain that I couldn't even commit to taking an hour and a half dance class in the afternoon, I had no idea what was going to happen within that. And this was how I lived my life for six years almost. And so when I was stuck in the ER stuck in the hospital for days and days with him, I would use the bars on his hospital bed as a ballet bar, you know, and I would stretch and I would point my toes, and I would do a little workout. And it was small, but it was so meaningful, because it was Allison connecting with who Allison is authentically. And, you know, I couldn't do so many things that I wanted to do. But there were certainly powerful and small ways that I could connect myself and connect to me.

Rosanne 31:30

It's so important. And it's especially important when you're in the midst of caring. And the one story in your book that always, you know, kind of smacks me in the face is when your father was having hallucinations. And he was hallucinating that you were angry at him or leaving him and all of this. And then when you got there, he turned away from you. Because he believed that my heart broke a bit there Allison.

Dr Allison Applebaum 31:58

Yeah, yeah. So the way by the disease hallucinations have a unique flavor. And that, number one, they're they're rarely pleasant. So like, I wish he hallucinate has been on the beach of Hawaii, like that would have been amazing. It was always it was like three men standing at the foot of his bed about to attack that was the flavor. And the key characteristic is that the individuals he would lose to date would never speak to him. And so there was one day I came home from work, and I sat down on his bed, and he turned away from me and anger and he wouldn't talk to me. And I then spoke with a home health aide who shared with me that my dad had elucidated me all day long, not talking to him, which is literally would have been impossible, like it's so the opposite of who I am and who we were. And it was so painful, because at that time I, I needed to repair a relationship that was broken outside of the context of my own lived reality, I had no idea. You know, and that was an example of some of the added complexity that so many of us experience, especially if our care partner is living with dementia is living with an illness where there are neurocognitive changes, especially when patients become disconnected from who they are. And I want to label this as grief. Yeah. You know, I think that there are many losses that we experience, long in advance at the death of her partner. And each time my dad was hallucinating to me, it was a mini death. It was a period I couldn't connect with him. I couldn't communicate and, and with his disease, we never knew if those hallucinations would last a minute, an hour a day, one time was an entire week, we had no idea. But each of those moments, these are moments of loss for all of us as family caregivers. And I think what's so important I encourage folks who come to me in the clinic, I encourage them to let that grief out, to express it to to label it. And I'm purposely using the

word grief because I think that it's very important that we use that language and we are experiencing many losses as caregivers.

Rosanne 33:59

Yes. And it's not acknowledged and it's not spoken about. And it's again another one of those heavy things that sits and you can't figure out why am I feeling like this? It's like because you're grieving. It's hard then to say how do you release that while you're carrying because you know, that's what I think that's what closets are made for and cars. Yeah, you go into Florida showers, showers, you know, I think that's why they're made honestly, but how do you do that and continue on your journey.

Dr Allison Applebaum 34:31

Yeah, I mean, I think that goes back to how we open this conversation around the liminal space. How do we live in this liminal in between space? We cannot do it healthfully if we keep our emotions in? Correct. So the answer is to use the car, the closet, the shower, the pillow, whatever it is, to get those emotions out. I think we need to give voice to our emotions. And by that I'm not saying for example, go yell at your care partner. But I am saying when you feel a lump in your throat, as opposed to using energy to get that lump to go away. Why don't you take a deep breath and indulge that lung, allow the tears to come and allow yourself to cry. I say that because the more energy we invest in avoiding our emotions, the stronger those emotions will be in the future, and it's not going to help you down the line. And so it is so important to grieve. I remember that evening it happened, I remember meeting up with a friend, I was like, I need to talk to you, I need to share what just happened. And I ended up crying at a good public fry, I became an expert public prior to so pretty good at it. You know, because the grief was so palpable. Yeah. Because my dad was that my dad? And so my answer is that we all need to let that out. And, you know, in addition to crying, or speaking or yelling, privately, or into a pillow, or in a shower, or in a car, it's also a lot of people love to journal, getting out that way. And then another thing to say is that our emotions are very physical, every emotional experience we have, every emotion we experience has a physical component. And so anything you can do to get energy out of your body, run on a treadmill, run down the street, exercise, dance, yoga, stretching, whatever it is you can do, to get some energy out as well is going to help you emotionally.

Rosanne 36:17

And to find the people that are safe to share this, and not someone who's going to say, at least dot dot dot,

Dr Allison Applebaum 36:26

Safe being the key word, yeah, you know, finding your tribe, finding the people with whom you can be authentically yourself, and who are not going to engage in avoidance, who are not

going to diminish your suffering, and who are willing and courageous enough to sit in silence, to sit with you and your suffering. I hope that everyone can find even if it's just that one person. And if you don't have that person, maybe it's finding a therapist who can who can fill that role for you. So that you can be authentically yourself and let those emotions out and not hear that at least or but if and if only No,

Rosanne 37:07

No, no, none of that. I always say no good sentence starts with at least just stop. Just don't don't throw you just don't finish it. And it's it's so important. And you know, I hear that all the time in our in our daughter had circles of it's so nice to be with people that get it because if you don't get it, if you're not with that person that gets it, they don't, they don't understand.

Dr Allison Applebaum 37:28

And it can make you feel a lot worse, it can feel more isolating and invalidating. I know for many of us, myself included, we have the experience of our social circle narrowing. Yeah, you know, my social circle circle narrowed. But it became richer, because the folks who stayed in it were those folks who could presents to me, were those folks, I could reliably be myself and not not expect a train response. And I had to actively actually cut some people out because they drained my energy and were unhelpful, and it started sentences with at least in that my greatest moments of trauma and stress was was damaging.

Rosanne 38:06

And it makes you then go, I can't talk to anybody. Nobody's going to get this. So I'm not going to say a word. And I'm going to sit with this. And it's going to get bigger and bigger and bigger and eat my insides and just leave you with nothing.

Dr Allison Applebaum 38:20

I hear this. I hear this a lot in my clinical practice, where folks will say that I'm the only person they're sharing this with. And while I'm grateful I can be present to them. I always try to problem solver. Well, who else outside of these 45 minute sessions once in a blue moon, can you be speaking to because isolated on your own is also not the answer? There has to be a happy medium in there. And I think that's the beauty of, of the types of circles that you have of caregiver support groups have all sorts of so many communities are available for us right now as family caregivers. And the beautiful thing is that everybody who's joining these communities, they get it. Yes, they get us.

Rosanne 38:59

Yep. And it's it's traumatizing. There are things that you witnessed that you're like, whoo. And it's the same as the grief. Nobody talks about that. And it's just, you know.

Dr Allison Applebaum 39:08

Oh, I'm so grateful you brought up trauma. This is something I've been speaking about so frequently. And it's come up increasingly in this in this post pandemic era, but a trauma, PTSD, post traumatic stress disorder, and post traumatic stress symptoms, which I think are most often associated with veterans returning from war. These are very common in family caregivers. In fact, I'm running a clinical trial right now with both patients and caregivers, who are survivors of stem cell transplantation, addressing trauma symptoms, and we're finding that a much larger proportion of those caregivers are traumatized and patients themselves. We as caregivers experience so many events and moments that are potentially traumatizing. You know, I'll speak for myself. It's traumatizing a witness delirium. It's traumatizing a witness a hallucination. It is traumatizing to ride Enter the ambulance and be told the sirens will only be used if his health deteriorates and then you hear those sirens go off. All of these moments are traumatizing. And it's traumatizing to witness a death, even if that death is occurring in the way that you and your care partner discussed. Even if it's peaceful, whatever that means to you and your care partner, because that's very specific. Batu is traumatizing. And I think that we as caregivers, walk away from these experiences carrying a heavy burden of trauma that must be addressed that needs support that needs tender care and love.

Rosanne 40:33

I fully agree with you, and it gets caught up in the well, aren't you happy? You got your life back. And it's like, happy isn't that like, yeah, there are people that are relieved and it's it's a relief to some and that's fine. But it's like, it's it's like being battered? And coming through this, this washing machine of caregiving.

Dr Allison Applebaum 40:56

Ah, you know, it's another creme brulee moment. Right?

Rosanne 40:59

Yes.

Dr Allison Applebaum 41:00

Because, yes, you have, I was then able to schedule a dance class for an hour and a half. And I could even schedule the week in advance, I had that flexibility for the first time in almost a decade, that my dad was here. And I was grieving. And I was, you know, traumatized from so many repeated traumas that had happened in my own journey and going through another loss that happened in the midst of it that, that being able to just be joyous, that I had free time and, and a control over my schedule. Really, you know, that wasn't that wasn't realistic. And I think what's so important is educating the folks around us and it's so noxious because you as a brief family caregiver, the last thing you want to do is have to train or teach the people around you how to talk to you. The reality is that unfortunately, another invisible, you know, responsibility

you have is this piece, which is that we often need to teach others about where we are, and that just because the burden of caregiving has, has lifted just because your responsibilities as a physician, a nurse, and case manager and social worker, and all the other things that those aren't there, that you as a human, have just gone through one of the most life altering changes, and there's not only the death of the patient, but there is the loss of the caregiving role. And that leaves a gaping hole for those of us whose lives have orbited around someone for years and years. So it's another another creme brulee, for sure. It sure is.

Rosanne 42:28

And again, it comes back to support, it's always it's always about support. And as much as we're supporting our care partners, we also need that support, to continue and to be ourselves and to try. You know, it's hard to remain connected to yourself while you're caring. Because you're expending all of this energy and everything is out outward for you. What's the best way for caregivers to try to remain connected to their selves?

Dr Allison Applebaum 42:56

So often caregivers will say, I don't even recognize myself anymore, or I've become so disconnected from who I was, I don't even I don't even know what to say to you right now. And the reality is that caregiving comes with so many losses, loss of our ability to work full time or to fully indulge that professional identity we have or you know, travel or do engage in leisure activities that we once did, or whatever those things are, that they're there. Those are real losses. You know, first of all, I always encourage caregivers to consider who they are authentically at their core. Because caregiving doesn't necessarily take those things away. Who you are as a loving and caring person, who you are as a lover of nature, who you are, as someone who sets goals for the future, those things are still in you. Now, maybe you can't enact those goals, but you can still set those goals. And so one thing is to really consider who you are ask the question, Who am I? And who am I authentically, in what ways has caregiving not touch those things? Right. So for me again, I was always a performing artist, I couldn't go take class or perform, but I could connect to that part of myself who enjoyed enjoyed that, and not just enjoyed it, who derive meaning and purpose and strength from it. The other side of this is that while so much is taken away from us, we gained so much from character. And by that I mean that we developed new strengths as a result of caregiving. As I shared earlier, so many have told me that they found their voice, because of caregiving that they knew they learn new things about themselves. Perhaps there's been an improved relationship with their care partner or they healed a relationship or they didn't, but they developed other they cultivated other relationships outside of a care network. And all these things can Oh, one to feel like there is a cohesive sense of self and identity, despite all the things that are taken away.

Rosanne 44:51

I always say being a caregiver. It's like you get superpowers.

Dr Allison Applebaum 44:55

Oh yeah. Oh, yeah, we all have a invisible cloak on. For sure agreed 100%.

Rosanne 45:01

And it's this thing, it's like, you come out of it, you're like, yeah, that all? Is that Is that all you've got? Because I can do that with my eyes closed. It's because you're dealing with so much all the time. And it's, it's, I think the key is to try and I hate to say it this way, it's almost like you have to support yourself during this journey to survive the journey. And you have to find those self supporting ways to keep yourself afloat. But it's hard, because you're tired, and you're grieving. And you're traumatized.

Rosanne 45:36

All of the above.

Rosanne 45:38

Yeah, you're all of the above.

Dr Allison Applebaum 45:40

You know when you were sharing about the superpowers, it made me think of so many patients of mine who shared during the height of the pandemic, and I was doing all my work over telehealth platforms as we continue to. So many folks said to me, like this pandemics, nothing. I got him through a stem cell transplantation, or he had, you know, we've been through a lot worse. And I think that caregiving shifts the prescription in our eyes, or our chi or contacts or glasses, or whatever that that that how we see the world is different. Yeah, and who we are as different. And we do emerge as most frequently much stronger, resilient versions of ourselves. As a result, I think many of us would give back caregiving, we would probably I would do anything to have my dad here and give him a hug. And in this space time, but, you know, barring that I have emerged as a much stronger and more grounded and more peaceful version of myself as a result of of all of that trauma.

Rosanne 46:37

Well, and you know, you were balancing actively caregiving, and starting the clinic, the caregivers clinic and supporting all of these people. How did you do all the that?

Dr Allison Applebaum 46:47

Small detail, small detail, right, so I began the caregivers clinic at Memorial Sloan Kettering Cancer Center in January of 2011. And in the winter of 2011, my caregiving journey really began. And so I had already kind of my professional identity sad, I was joining the faculty, I was speaking nationally about this issue, I was getting funding from the American Cancer

Society to study cancer caregivers. And then I became, you know, I stepped, I stepped, I was asked to step into into this caregiving role, which was was very complex for me, and I'll share a few pieces of how I navigated that, and one was that, and this goes to what we just discussed about identity, which is that it was so important for me to be able to preserve in whatever way possible my identity as Dr. Applebaum. And that meant that and quite frankly, up until this book, and these podcasts that, you know, my caregiving journey is something I never shared with my patients. And it was not something that I shared with my broad professional network, because I really wanted to have that part of myself was only a close circle of colleagues who are aware of, of the crises that were happening morning, noon, and night, and were supportive, but it was so important for me to really protect that part of my identity. Second, my self care was number one priority. You know, realizing that I was both during the day and after hours, so of course, those were intertwined, because I was, you know, obviously family caregiving doesn't have a schedule, right? That it was so very important for me to protect whatever time I could for myself, it was a crash course in self care. And by self care, I mean, anything I could do to protect my energy, anything I could do to preserve myself to give myself small spaces to to breathe, to dance to be Dr. Applebaum, whatever that was, that was self care to me. The other piece here is that, inevitably, my my professional work, and both in terms of the research, I can talk, but the fact that I've obviously now, it's been, you know, 13 years since I began the clinic, and I've worked with 1000s of caregivers that, that doing this work has certainly highlighted for me, important areas for for my research and my professional work and my own caregiving journey. For example, early on, I mean, this is this goes back to our conversation earlier about invisible responsibilities, I was so struck, that nobody was guiding me in terms of how to have any of these in these conversations with my dad and with members of the medical team. It was mind blowing to me that I ended up having to be the point person for multiple health care teams. And so I then earmark This is an important area for my own work. And subsequently, I've developed a communication skills training program for caregivers, to give them the tools they need to engage in advanced care planning conversations with confidence, because this is one area where I was like, This is so hard, and it was hard for me somebody who's been through a doctorate in clinical psychology and likes to believe she has good communication skills. Well, oh my gosh, this must be absolutely impossible and overwhelming. Right. You know, the other thing that happened for me and this might be cutting away from your question, but you know, my personal experience, aligned with taking care of all of these family caregivers, really We've really underscored the role that our public policy landscape plays and our experience that all of those roles that we play, and all of those invisible responsibilities are shaped by what we do, or most often don't have right now, in terms of support. You know, I, I talk often about how we do so much more in this country to support expecting parents than we do for new family caregivers, you know, we don't get a correlate of a baby shower, where we get support and financial support and supplies for a year, like a year's worth of adult diapers that would have been incredible, never got that, you know, information, and information and emotional support. And then on a broader

perspective, we don't get to say, Okay, well, I'm going to be a caregiver. So I'm gonna be out from work for three months, and you're gonna pay me during that time to do that we don't get these things. And so I bring this up, too, because it was one of the lessons that had I not been in the family caregiving role myself, while I heard about it, anecdotally, having to live it on my own really drove home how so much of our burden and distress and challenges family caregivers is driven by our public policy landscape, and how urgent urgently needed reform is in this country. And the fact that, you know, elephant in the room, we are the long term care system. Right?

Rosanne 46:51

Yes we are.

Dr Allison Applebaum 50:11

We are the CR system in this country. And, and we are, I think, the most important, invisible element of the health care system in the United States today.

Rosanne 51:31

We absolutely are essential, we are essential workers.

Dr Allison Applebaum 51:35

Yeah. Yup.

Rosanne 51:35

But we're not viewed that way. And it's, it's such a responsibility that we carry on a daily basis, and we're literally holding the system up, there needs to be a change, there desperately needs to be something in place. And I don't know how we get that policy moving. But we need to get it moving.

Dr Allison Applebaum 51:52

There's definitely more conversation, I keep thinking about what the environment was like back in 2011 When I started the clinic, and yeah, you know, I felt like a lone ship and a sea. And I know there were other lone ships in the sea, I go around the country. But there is a there is a much louder national dialogue, and certainly the Administration for Community livings 2022, National Strategy puts out goals, right, we have some goals, and we have some potential federal actions, I think the next step is getting those federal actions made, you know, implemented. And really, for us to see some changes downstream that will affect the day to day life of family caregivers, help them to no longer have to choose between paid employment and caregiving, to be able to get tax breaks for their efforts to get paid for their efforts. And I'm going to say, because this is really, of course, most important to me as a clinical psychologist

and as a director of a counseling program. But that mental health care for caregivers becomes required and required as an offering in every health care center.

Rosanne 52:52

I fully agree with you fully, let's make some signs. I fully agree with you.

Dr Allison Applebaum 52:57

Done, well, I'll make some T shirts,

Rosanne 52:59

You got it. Well, and you know, with, with everything, when caregiving ends, and going forward, trying to get the voice of the caregiver out there. And, you know, I find people when they're done with caregiving there, they fall into two categories. I never want to talk about this again. Right? I just I don't want to talk about it, or the two of us were the two was exactly. So how do people find their voice after caregiving? Because there's a lot of people that are like this was I want to make it better for the next person. So how do we how do we, you know get that going?

Dr Allison Applebaum 53:32

There's no, there's no one right way. And and I want to be very clear, you know, my path and Rosanne's path is not better or worse than the path of the caregiver who chooses their attitude, choose a meeting centered psychotherapy term and says, I'm done with that I'm putting it aside.

Rosanne 53:47

Absolutely.

Dr Allison Applebaum 53:48

You know, I think that it is very vulnerable, to speak about our caregiving journeys, I know that that's something I grapple with as I enter this period of my life where I'm speaking more openly about it, it's requiring me to connect and reconnect to the sadness that's still very strong, is from reconnecting me to the traumatic events that were many and throughout, but it's also very empowering. And I think that we can speak out in many different ways. It can be as small as just sharing anecdotes with friends, it can be as simple as hearing that another person in your social circle is entering a caregiving period and you reaching out to them and sharing your your best tips. I mean, you all are experts here, you know, we are all are experts in caregiving, and we have a wealth of information to share and, and so it's great to do podcasts and write books and speak on a national level, but our impact can be much smaller. You know, I talk about this idea and meaning centered psychotherapy about giving a legacy to others. The fact that, you know, we again, we can physically give something but we can also give a legacy by being

witnessed. And for everyone who's already been a family caregiver you've been witnessed in that role. So you've already impacted so many others, you might not be aware of it, maybe you never want to talk about it again, but you were witnessed. And I'm guessing that you were also quite inspiring.

Rosanne 55:11

Well and it's going forward and afterwards as well. So you're going forward, which is another, you know, struggle in the after caregiving part how, how you go forward and how you try to bring your person with you.

Dr Allison Applebaum 55:25

It's complex.

Rosanne 55:26

It is

Dr Allison Applebaum 55:26

It's complex.

Rosanne 55:27

I mean, how do we, how do we do that?

Dr Allison Applebaum 55:30

Yeah, and again, there's, there's no one answer to this. And I often will say in clinic that grief is very personal, and very unique to each one of us. So how you grieve and how I agree might be completely different. And, you know, one route is not better than the other. I think there's many ways in which we can carry forward our care partners with us, you know, I do often encouraged caregivers who, whose whose losses are more recent, my recent, my loss, so it's hard to believe my dad will have died five years ago, this month on February 23, it feels like I just blinked my eyes. The pain is still quite sharp. You know, I encourage caregivers whose losses are, you know, more recent to consider ways in which they are able to continue to speak with their care partner, you know, even though they're physically no longer here, why can't you continue to talk to them. And the reality is, especially for those of us who are who've been caregivers and have been in these long relationships, you know, what, you know, what your partner would say to you, you know, what they would say, you could hear their voice in your head. And I encourage you to continue dialogue. And that that is something that so many find very healing. You know, I encourage thinking about what was so important to your care partner, are there certain valued activities that you can do or carry forward in their honor, I always wear my mother's jewelry, I have her jewelry on me every day as a way to carry her with me. You know, I listen to classical music every day and connect to my dad in that way,

because that's something that we share. You know, but I also think about, and again, going back to this idea of legacy, the fact that we are very impacted by our care partners, you know, and so my dad gave me his legacy, he modeled for me how he faced his illness, how he was facing his inevitable death. Not only that, how he faced his life for the years and years and years before he became ill. And that's an imprint on me. And I carry that forward. And we all have that. Our care partners have imprinted who they are going back to that holistic care who they are as humans, that's imprinted on who we are. And we now can carry them forward. And I want to again, say it doesn't negate the suffering, I'm probably going to cry for a little bit after this podcast is done, but it does mean that we are able to remain connected to them in smaller and in different ways.

Rosanne 57:53

I love that. Yeah, I you know, that's just really beautiful.

Dr Allison Applebaum 57:58

Thank you.

Rosanne 57:58

No, thank you. I of course, I always ask a final question, which for me, you know, you've lived this, you've documented it beautifully. You've you've shared your heart with everyone here. What would you say to a caregiver who's listening, and is just overwhelmed by where they're at?

Dr Allison Applebaum 58:17

Yeah, two things. One is that you cannot and should not do this alone. There is just no way to take on all of these responsibilities in isolation. And while it is so very hard to ask for support, it is the most important thing that you can do, especially when you feel overwhelmed, that support can be, you know, physical support, financial support, tangible support, it can be just a shoulder to lean on whatever that support is, I would encourage everyone in that mat moment to make sure that they are asking for support and that they're not alone. I know that so many of us are very isolated as family caregivers, we I did not have a large family to lean on, I did not have a lot of resources at my fingertips, but I asked for help. And that was one of the drivers of my survival. And the other is the fact that we always can take a deep breath. There are so many things that we do not have control over. But one of the things we do have control over is our breath and take any very deep diaphragmatic breath in through your nose, holding it for a few seconds, exhaling slowly through your mouth. That brings oxygen to your brain. It lowers the stress hormone cortisol, and just a one minute of deep diaphragmatic breathing can lower your stress. And it's something that I realized especially when I'm stuck in emergency rooms. When I was riding the ambulances, I would do that deep breath and realize, I don't know

what's going to happen in 10 minutes from now, but for the next 60 seconds, I'm in control of my breath, and that is always at your fingertips.

Rosanne 59:53

A big thank you to Dr. Allison Applebaum for being my guest today. You can find more information about Allison, links to her caregiver articles, interviews and her book, *Stand By Me A Guide to Navigating Modern Meaningful Caregiving* at Allisonapplebaum.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 find and review us on Apple podcasts or 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 we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song *Mamas Eyes* from her album *Lessons In Love*. I hope you found what you were looking for today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in *Daughterhood*.