

356. Caregiving with Allison Applebaum

[00:00:00] **Allison Applebaum:** When my dad was in that coma that I referenced, I learned a very important lesson, and that was without me by his side to serve as his eyes and ears and voice. That there was absolutely no way that any members of his passing medical teams could have any idea who Stan Applebaum was.

And what matter to him, what his goals of care were, and what his goals of life were. And that was my job.

That was Alison Applebaum on psychologists off the clock. We are four experts in psychology here to bring you cutting edge and science based ideas from psychology to help you flourish in your relationships, work, and health.

[00:00:57] **Debbie Sorensen:** I'm Dr. Debbie Sorensen, a clinical psychologist practicing in Mile High, Denver, Colorado, and author of Act for Burnout, Act Daily Journal, and the Act Daily Card Deck.

[00:01:07] **Emily Edlynn:** From America's Heartland, I'm Dr. Emily Edlynn a clinical psychologist based in Chicago, Illinois, and author of Autonomy Supportive Parenting.

[00:01:15] **Michael Herold:** Calling in from Vienna, Austria. I'm Michael Herold, ACT coach, confidence trainer, and author of an upcoming book on being a better conversationalist and making friends.

[00:01:24] **Jill Stoddard:** And from coastal New England, I'm Dr. Jill Stoddard, author of Be Mighty, The Big Book of Act Metaphors, and Impostor No More.

[00:01:31] **Emily Edlynn:** We hope you take what you learned here to build a rich and meaningful life.

[00:01:35] **Michael Herold:** Thank you for listening to Psychologists Off The Clock. I'm here with Michael to introduce my episode for today with Alison Applebaum, where we talk about caregiving, something that if we live long enough or have loved ones who live long enough, will very likely impact all of us at some point in our lives. So Michael, what were your reactions to this episode?

Well, first, uh, a little anecdote here, while I was listening to the interview, I, for reasons that will become apparent to our listeners, a few minutes into the episode, I was starting dancing, because this is the best book title ever, um, and it had me dance, Turn on Apple music, put on headphones, and dance through my apartment for a couple of minutes before I came back to the interview.

I won't spoiler more about why that is or what the song is, but you will, find out.

[00:02:36] **Jill Stoddard:** And, and I will admit as an author myself who struggles with book titles, I was at once both very envious that she had the most perfect, brilliant book title ever, like you said, as listeners will find out why soon, and also like so happy for her thinking about, you know, the moment she decided she was going to write this book and give it this name.

Just amazing. Yeah.

[00:02:58] **Michael Herold:** Brilliant. Yeah, and other than that, yeah, this interview made me think of my own grandparents who passed away. Just briefly be one after the other. I think there was like. months between my grandpa and my grandma, and they lived into their late 80s, and they were taken care of by my family. And I could see visiting them every couple of months.

I could see how much work it was for everyone. And I could also see with how much love they It was done. Like, my aunt made it very clear to my grandma that, uh, stay for as long as you want because we don't care how much work you're causing, as long as you stay with us, we're, we're happy. And, uh, also the laughter that came from caregiving.

I have a very humorous family and they find, uh, humor in a lot of things, especially, you know,

[00:03:53] **Jill Stoddard:** does not surprise me in the least.

[00:03:55] **Michael Herold:** Especially since, uh, the, one thing I'll spoil a little bit. You talk about elder talk, uh, how like elders aren't approaching like baby talk. And I was laughing about this because with my granddad, you would not give him baby talk.

Like if he's in the hospital and the nurse says, can we take our medication, medication now? My grand, he, he would imagine my grandfather in the hospital, Like, swearing like a professional sailor getting ready for the cursing

Olympics. He would look at the nurse and go like, you can have the beep, beep, beep medication all to yourself because I don't care.

And it was those funny moments that happened in the, in the caregiving as well. So I saw the work behind it. I saw the love behind it.

[00:04:40] **Jill Stoddard:** and it sounds like, you know, some of the things that she talks about are how, it is work and there is stress and burden and that there can be meaning and purpose and you discover new things about yourself, you know, strengths that you didn't know you had, and that it's a way to enhance your relationship even with your care partner and just you know She talks about so many things that I hadn't really thought about before.

I've been very lucky thus far to not have to have had been Uh, you know, I haven't had any loved ones who have required my care, but i've certainly seen many of my Friends and family members go through that with their loved ones and you know, it is not for the faint of heart and there can be many fulfilling elements that come out of it.

And I loved this conversation that she really talked about this in such a well rounded way. There's a lot of different kind of perspectives about this experience.

[00:05:38] **Michael Herold:** yes, I wholeheartedly agree. So, uh, shall we send our listeners towards the episode and get them dancing?

[00:05:45] **Jill Stoddard:** Let's do it. We hope you enjoy this episode with Allison Applebaum.

[00:05:53] **Jill Stoddard:** Hey everybody, it's Jill here, and I am here with Dr. Allison Applebaum today, and we are going to talk about caregiving. Allison Appelbaum is an Associate Attending Psychologist in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center and an Associate Professor of Psychology and Psychiatry at Weill Cornell Medicine.

She is the Founding Director of the Caregivers Clinic at MSK, the first program of its kind in the United States to provide comprehensive psychosocial care to family members and friends of patients who are in the caregiving role. Dr.

Applebaum is also the author of the recently published narrative nonfiction book, *Stand By Me*, a guide to navigating modern meaningful caregiving.

And that is what we are here to talk about today. So Alison, welcome to *Psychologists Off The Clock*. I'm so happy to have you with me.

[00:06:44] **Allison Applebaum:** Thank you for having me. I'm so excited to be here.

[00:06:46] **Jill Stoddard:** And before we started recording, Allison and I were talking about how we both did our graduate programs at Boston University and overlapped by a year, but this is actually the first time we're truly crossing paths. So we have the, the old BU connection.

Well, I want to start by saying I absolutely loved this book and I love that you call it, how did you describe it?

The recently published narrative nonfiction book. It is a nonfiction how to guide for caregivers, but it has so much heartfelt story in it that just makes it a beautiful, lovely, enjoyable read. Um, and I just found myself wishing that I had had it in years past when I had friends and family who had been going through the caregiver role and just knowing that it will most definitely, uh, be a book that I am recommending to anyone who finds themselves in a caregiving role going forward.

I mean, so many helpful resources tables. I mean, we'll get into all of that.

[00:07:46] **Allison Applebaum:** Thank you so

much.

I appreciate hearing that. The, the narrative was a really important part for me to have in there.

[00:07:52] **Jill Stoddard:** And I think it really, it matters because it gives I had like personality, heart, soul. to the book. You know, it certainly does not feel textbooky at all and yet is like such a helpful resource. So I thought where we could start is just to define caregiver. So you, you use the term caregiver. You also use the term care partner.

So let's just start with like a brief definition of what you mean by that.

[00:08:21] **Allison Applebaum:** Sure. And I want to just start by saying there is no one accepted version of the definition. And in fact, one of the goals the National Alliance for Caregiving has for 2025 is to come to consensus on how we define a family caregiver. So this is not a dictionary definition. This is the Alison Applebaum definition.

of caregiving. A family caregiver is a parent, partner, child, sibling, friend, anyone who is giving care of any kind, physical, emotional, financial care to an individual living with a chronic or life limiting illness. And this care is provided free of charge.

[00:09:03] **Jill Stoddard:** Amazing. That's perfect. Well said. Okay. So you are a psychologist who, as we said in your bio, you founded the first ever caregivers clinic at Sloan Kettering in New York, but this, you know, and as we also said about your narrative book, this has also been an intensely personal journey for you too. So can you tell us a little bit about your dad and your dual role as both his caregiver and a clinician?

Thank you. Who helps other caregivers.

[00:09:31] **Allison Applebaum:** absolutely. Um, I'm going to start with the professional because it was almost sort of leading up to the personal. So I left BU, came back to New York City and, uh, was a postdoctoral fellow at Memorial Stone Kettering Cancer Center. And I was working primarily with patients at end of life. And what was so striking to me about those therapy sessions was instead of focusing on their own mortality.

Their narratives focused on the parents and partners and children and siblings and friends left in the waiting rooms, left at home, the individuals who they identified as the linchpin of their care, and those who'd be most deeply impacted by their eventual deaths. It was also becoming increasingly clear to me back then that cancer care and health care more broadly was increasingly relying on family caregivers to shoulder tremendous responsibilities without training or education or support.

And I realized back then, shockingly, that there were no services or targeted programs available for cancer, cancer caregivers in any cancer center in this country. Um, and so I founded the caregivers clinic in 2011. Who's mission is to assure that no caregiver experiencing significant distress as a result of their critical role goes unidentified and deprived of necessary psychosocial services. The same year that I founded the clinic, my own caregiving journey began. My dad, Stanley Applebaum, um, had lived up until his late 80s with basically no

medical problems whatsoever. In fact, since we've talked about BU, I will share that I, for the five years I was in graduate school, I had an airplane ticket ready to go to get on an emergency plane ride home from Boston to New York in the case that something happened.

Because my dad was older, I always imagined something happening. We got through graduate school with no medical problems. He he he was holding on there. But, towards the end of his eighties into early nineties, a series of events occurred, one of which was a very dramatic car accident. Um, he went into heart failure.

While driving down the New Jersey turnpike, miraculously, he actually walked away from that car accident, but it was a real shift in terms of, um, his independence, of course, but also his health and us realizing that his health concerns were pretty serious. A year and a half later, I had brought him to the hospital for the treatment of a urinary tract infection.

And he had delirium, which is common in older adults. Um, I want to acknowledge for all of you who have ever experienced delirium, it is very scary to witness. It's a confused or altered mental state. And he was treated with an antipsychotic medication and neither my mom at the time who was his healthcare proxy, or I were consented.

And this medicine put him into a He was in a coma for two weeks. Um, the only silver lining of the coma is that it gave his doctors a hint that he might have Lewy body disease and a subsequent pet scan confirmed that diagnosis. So Lewy body disease is a progressive neurodegenerative disease. It leads to fluctuations in autonomic functioning and consciousness, which in my dad meant that he would have sudden drops in blood pressure and temperature to near hypothermia levels.

And he would hallucinate. He would hallucinate for a few minutes, for a few hours, occasionally up to a day and one point up to a week. We never knew how long the hallucinations would last. But what was so striking about his illness is that when he wasn't hallucinating, he retained his short term and long term memory, his zest for life, his curiosity, his ability to set goals.

And so it was really a perpetual groundhog day in navigating this illness. Um, and as I share in the book, my caregiving journey, unfortunately, was also punctuated by the very sudden death of my mother one year into my taking care of my dad. And so it was really just a crash course in illness. And loss and trauma and navigating our health care system.

Um, and I'm grateful that I've survived it and I'm here to talk about it today.

[00:13:45] **Jill Stoddard:** Yes, absolutely, and grateful that you've written this book, so hopefully for other people who find themselves on a similar path, it doesn't have to be such a crash course, or it doesn't have to be a crash course reinventing the wheel. People can benefit. From your professional and personal experience. And one of the things you say, so the very first line of chapter one is quote, caregivers are an essential extension of the healthcare team.

End quote. And I have to be honest when I read that it never occurred to me to really think of caregivers in this way. And then of course, once I did read it, I was like, Oh, right. Yeah, of course. Um, and one of the things that you say is maybe the most important role that, that caregiver, who's an extension of the caregiving team is how important it is to convey a patient's personhood.

And I thought we could even take a beat because the title of the book is Stand By Me. And that has to do with your father's personhood. So do you want to tell people who Stanley

[00:14:43] **Allison Applebaum:** absolutely. and S so my father, um, Was a very, um, well known orchestrator, arranger, composer, and conductor. And he did all of the arrangements for the big artists in the fifties and sixties, including Benny King and Neil Sadaka, Connie Francis, Brian Highland, et cetera.

Um, and he was responsible not only for the entire arrangement for Benny King's Stand By Me, but the string section that I know everyone who's listening has heard that's in the middle of Stand By Me was my dad's composition. It's something he wrote on a whim one night, playing around with how rich and full he could make just six or eight stringed instruments sound.

And little did he know that that string line would become beloved by generations to come. And so, you know, throughout my, my childhood and growing up with my dad and, um, knowing that, you know, the meaning of music and I came, both my parents were musicians. My mother was a concert pianist. Music was all around us, but stand by me.

was always a really special song, something that always engendered within me incredible pride for my dad. And when I thought about this book, there was only one title that came to mind, and that was Stand By Me.

[00:15:59] **Jill Stoddard:** Oh, it's so perfect. I really struggle with book titles and so I'm always just like so happy when someone comes up with a very

perfect title. I mean it just could not be more fitting and I was like feeling so happy for you. I was imagining the moment that you were like, this is the book I'm going to write and this is

what it's going to be

[00:16:17] **Allison Applebaum:** my, I stared at blank paper for that proposal for a long time, but the one thing that was not blank was the title page.

[00:16:24] **Jill Stoddard:** yeah. So let's talk about this personhood piece, especially, I think, um, you know, with a dad who was older, you know, we know that there is ageism and this fear that people are going to go, eh, he's lived a good life, he's fine, you know, and like, not really, you know, Take as good a care of this human being as one should.

So talk a little bit about why this is important and maybe even you talk in the book about the time stamped video. So maybe some sort of like specific ways that if listeners are caregivers, they, so what's the importance of the personhood and how might we express that to the health care team?

[00:17:04] **Allison Applebaum:** Thank you so much for taking time on this topic. I want to just acknowledge why this is the first chapter of the book. I've read many, many, many, many, many books on caregiving. There are many self help books on caregiving out there, but I have never in my entire career and personal experience as a family caregiver seen this element of our role and responsibility articulated anywhere.

And yet, to me, this is, this was and is so central to what we do as family caregivers. And so to me, it had to be the opening. When my dad was in that coma that I referenced, I learned a very important lesson, and that was without me by his side to serve as his eyes and ears and voice. That there was absolutely no way that any members of his passing medical teams could have any idea who Stan Applebaum was.

And what matter to him, what his goals of care were, and what his goals of life were. And that was my job. And I found myself repeatedly sharing those goals. And I, I will say defensively sharing those goals. Um, one of the things you bring up that I, that I talk about in the book is the fact that our journey as partners in care was, was, uh, was impacted very deeply by ageism.

Um, which, which is very, very common, of course. Um, and both ageism and a bias against patients who suffer from neurocognitive challenges as a result of

their disease or treatment. So you know, too often by dad's date of birth, March 1st, 1922, folks would see that date of birth and many assumptions were made about what his goals of care should be without actually learning about who Stan Applebaum was.

And unfortunately, because of the nature of his hallucinations, they often would come on when he was either suffering from an infection, such as a UTI, or if he was dehydrated, meaning when I brought him to the hospital for treatment, he would be hallucinating. And so healthcare professionals didn't get to meet Stan Applebaum.

As a fully oriented person, they would see an older 93 year old man with hallucinations and make assumptions about what goals of care should be, which was so painful for me. I want to just say that again. It was so painful for me to be challenged repeatedly by members of the healthcare team. When my dad was oriented, as I shared earlier, he was his self.

He had goals. He wanted to live to 103. He was still writing music from his bed at age 94. He learned to go log the language of his home health aides. This was not a man who wanted to stop. And I had to be his voice and I needed to share that. And one of the tools that I found so very helpful Was the timestamp video.

So to be able to say, look, this is my dad today, but six days ago, he was walking down the boardwalk in New Jersey, or three days ago, we were having this conversation about this article from the New York times that I found to be one of the most powerful tools that I could use to help his healthcare professionals get to know him.

So I encourage for all of you who are listening. And look, everyone who's listening is going to step into the caregiving role at least once if not multiple times throughout your life to consider, especially if you're taking care of someone who has an illness or a treatment that affects their cognition, to make sure you're capturing their, who they are, the essence of who they are, because that can really help you in sharing their message with members of the healthcare team.

[00:20:48] **Jill Stoddard:** Yeah, and humanizing this person so that they're not just a disease or symptom and that they're not so easily dismissed. It's hard to dismiss someone when you know their humanhood.

[00:21:00] **Allison Applebaum:** And this, this is, um, again, because when we dehumanize somebody, it is a lot easier just to say they're not worthy of care.

And I know full well that had I not been his voice in 2013, he wouldn't have survived the coma. There were many members who came by who said he's had a good life. And the reality is, yeah, my dad had a great life, but he wasn't ready for that life to end.

And thankfully, I knew my dad well enough to know that if he had a chance at continued life, that he would want it. Um, we all are challenged at times to convey personhood and goals of care, but it is particularly important in the setting if you're taking care of someone who is older that because ageism is very real.

Yeah.

[00:21:46] **Jill Stoddard:** in the book, and I didn't actually write these things down so I may not remember exactly, so you might have to help me out, but, and I think it was in the chapter or the section about ageism that even the way that someone talks to an older adult in that like baby sing song voice or.

You, you give, yeah, elder speak. So you give several different examples of how this might show up. And then importantly, something you might say as the advocate, as the caregiver, to try to sort of point out that this is, is happening, but in a, an accessible, I'm not sure that quite the word, but like a benign way.

And, and kind of what to say, can you think of a couple of those examples

[00:22:23] **Allison Applebaum:** Absolutely. Oh my gosh. Elder speak is so maddening to me. So this is a patronizing baby like tone of voice that is often used with older adults. Um, A lot of statements like, can we, can we take our medicine now? Um, can we eat our lunch now? you know, sort of asking a question, but not asking a question.

and what's so ironic about it is those higher tones of voice are impossible for older adults to hear. So it's actually not that effective whatsoever. Um, using phrases like sweetie or honey, you know, to, to a 92 year old man. I mean, my dad was my, my sweetie and honey, but Totally inappropriate for the nurse or the doctor to be calling him that, right?

You wouldn't, you wouldn't speak to a 40 something year old woman like that, probably. So why are you doing it with, with a 90 some year old? Um, so yeah, so I, I make a point throughout the book to give as many concrete tips and tools that you can use, um, in all areas and to combat ageism as one of them.

And I would ask the doctors, I say, can you please speak to him in a lower tone of voice? As opposed to standing over him, can you sit next to his bed so that you're on eye level so he can see you and actually engage in the conversation? And can you refer to him by his name? Too often, elder speak would also manifest as them ignoring the fact that my dad was sitting right there and they would just talk to me.

[00:23:47] **Jill Stoddard:** Mm hmm.

[00:23:48] **Allison Applebaum:** And yes, there were many times my dad was disoriented or because the chaos in the emergency room and he couldn't hear very well that I would have to take over the communication. But in most other circumstances, I wanted my dad to have as much control as possible. I wanted him to navigate the communication.

So I would stand to the side or even to the back of his bed so that he could feel in control. And then I would step in when needed. Um, and I found that really helpful in combating this elder speak approach that was quite frankly, all up and down the rungs of the hospital hierarchy.

[00:24:25] **Jill Stoddard:** Right. Right. And it's such a nice way to try to preserve dignity. You know, I think that's a lot of what you see with this is just this kind of like erosion of dignity when you're treating a person who's lived a whole life as if they're a toddler.

[00:24:38] **Allison Applebaum:** Exactly.

[00:24:39] **Jill Stoddard:** Right? Yeah. So we know that caregiving can be a short or long process and can be very overwhelming.

So if a person is, say, like, just starting to see decline in a loved one or has maybe just received a diagnosis that is known to result in decline, where do you suggest that they go? loved ones start. We know they can start with your book, right? Um, but like, is there something that you wish you had known right at the start in terms of like just how to even begin this journey?

[00:25:12] **Allison Applebaum:** Yeah. You know, so I did have the gift of my dad was my best friend, and we had a very open and honest relationship. So what was unique about us is that we had been talking about existential issues since I was like five years old. We were talking about death, we were talking about what happens after death.

We were talking about all sorts of big questions. So we had already had some of those conversations. But the conversations that we didn't have and those that I wish I had had both with my mother and father, and of course I was deprived of that because of her sudden death, are the conversations about finances.

The conversations about health care, health insurance, long term care plans, Medicare, Medicaid, how would care be provided if you needed it for a longer period of time than just a few months? And those are conversations I wish I had had with both my parents when they were both capable of having those conversations.

And so those are really important conversations to have really early on.

[00:26:07] **Jill Stoddard:** Like maybe even before someone has a

diagnosis or because you'll need care eventually.

[00:26:13] **Allison Applebaum:** let's not wait for the diagnosis or the progression of disease, like, you know, leave the podcast whenever you listen to it and go forth and ask the questions because the time is yesterday.

Um, you know, and actually that's part of what I'm on a mission to do, which is really to encourage more open communication about goals of care, goals of life. What are one's values? What is important to you? Um, I would also say that if you're initially starting off your journey, Okay. That is a very overwhelming moment and I encourage you to actually rely on members of the healthcare team in that moment to help guide you in terms of other types of conversations you should be having.

Um, it's overwhelming when you step into the caregiving role at first to then think about, well, I need to take charge of all this. Um, but I would just say at the very least, have a sense of how will you navigate as a family unit, the care in the future, you know, and what, and another question being, how Not just how will you navigate the financial side of care, who do you want to be involved in your care, right?

So while many of us are identified as a primary caregiver, the person most involved, caregiving rarely happens in a vacuum. There are other family members often available for other elements of care. And I think it can be really powerful early on to talk about that, to label that and say, well, you know, maybe my sibling is unable to do the day to day hands on caregiving, but maybe

they can help with, you know, the financial side or helping with the setting up meals or, or other ancillary aspects that are equally important and help.

[00:27:43] **Jill Stoddard:** Right. Yeah. It's so interesting. When my dad set up his, uh, will trust all of that paperwork. Um, he made my brother in charge of the financial decisions and made me in charge of the healthcare decisions. And we had a conversation about it where I was like, to what extent do you think this, you were influenced by gender?

When you made this decision, right? There's sort of an assumption because I'm the girl, I'm the daughter, I'm going to do the nurturing, the caregiving. And you know, somehow my brother, who's a man obviously must know how to deal with fiscal things more than me. Um, and I thought that was really interesting and that like that could be an important conversation.

And it sounds like what you're saying is also to talk to siblings or other people in the extended family about who's willing to do what? And I think you talk about this in the book is, you know, who does have what strengths? Maybe I'm better with finances and he's better with caring, right?

To

like figure out who has more or less time, who is good at being organized and talking to medical providers and really kind of coming up with a plan. But one question I had is, Because I imagine this must come up all the time, and certainly I've even heard it come up in my own spheres, is, is there anything you suggest when there is disagreement?

So a couple things I thought of. One is, what if the extended family disagrees about the person who needs care, about their abilities? So one thing I've seen come up frequently is, the care recipient, let's say has a diagnosis of dementia, but still thinks they should be able to drive their car. And it's very clear. They shouldn't be able to drive the car and the doctor doesn't think they should drive the car, but then everyone in the family. disagrees. One person is like, Oh, but they're going to be so upset.

If I take their keys away, we should just let them keep driving. And the other people are saying, no, somebody is going to get killed. How do you sort of navigate? And of course, another example would just be disagreement about who does what and lots of resentment because I'm doing everything and you're doing nothing.

Do you have ways that you recommend families cope with these kinds of

[00:29:49] **Allison Applebaum:** Absolutely. Yeah. Well, I think when it comes to patient capacity, patient functioning and patient safety, the best thing that you can do is outsource the conversation to the healthcare professionals. Have the physician, have the nurse say to my father, Stan, Stan, you can no longer drive. Have it come from the healthcare team so that you as a family caregiver are not the bad guy.

That to me has been most successful for my patients. And I'm speaking not just for my personal experience, but from the thousands of caregivers I've worked with in the past 15 years. So I, I say, delegate that to the healthcare team.

[00:30:27] **Jill Stoddard:** the Provider may also need need to say Stan, you can no longer drive and may also need to say Allison, Stan can no longer drive, right? Because I think sometimes there, there, there's the caregiver that wants to, it's fine, we'll let them do it a little longer, you know? And, and to maybe even highlight the safety issues involved, the legal issues, yeah.

[00:30:47] **Allison Applebaum:** it. What's really important in that example, and it's similar to many other things is for so many individuals, my dad, for sure. My dad loved to drive. It was his independence. It was his freedom. And so not being able to drive, it's a major loss. What is really important as a caregiver, if you're in a situation like this is to label that to say, Dad, I know this is really hard that you can't drive anymore. What can we do to ensure that you can remain connected in some way to a sense of independence? I know it's not going to be the same, but I really care deeply about you being able to feel that. Let me help you feel that.

Um, you know, whether it's going to the grocery store on their own or maybe you go together, but you keep a distance so they can shop. They can shop on their own can be helpful. I

think

[00:31:37] **Jill Stoddard:** Like you're just the backup.

[00:31:38] **Allison Applebaum:** Exactly. Exactly. You know, in terms of navigating the disagreements with family members, that's, that's very complicated.

That is not to be delegated to the medical team. Um, you know, I think what's important to remember for yourself is that you as a, you as a caregiver play this role, unfortunately, in case manager often, like you're forced to navigate these dynamics, but ultimately the only person you can control is yourself. I talk about very specific communication techniques within the book, one of which is the x, y, Z technique, which can be helpful when there are disagreements between family members about anything. So for example, um, so it's, I feel X when you do Y because z. It makes me feel sad when you don't visit dad once a week because I've been there every day and I've given up all of my free time.

And what's great is to follow that XYZ technique with a concrete ask. Could you visit a little bit more frequently? And the reality is the best we can do is communicate our needs. We cannot force anyone to do something that they don't want to do. I think one of the most powerful things we can do as caregivers in situations where there are disagreements within families.

So after you just take a step back and disengage and to really protect ourselves energetically because trying to get family members to do something they're not going to want to do is really not a good use of your energy and you as a caregiver don't have a limitless supply of energy.

[00:33:10] **Jill Stoddard:** You talk in the book about caregiver burden. And so I want to talk about what that is and what we can maybe do to prevent or address it, but also is that the same or different as caregiver burn out?

[00:33:24] **Allison Applebaum:** Love this question. Um, so caregiver burden, caregiver burnout, I'm going to use both these phrases right now. These are not ICD 10 codes. These are not psychiatric diagnoses. These are not billable codes. These are catch all phrases that refer to the multidimensional distress experience by family caregivers, including the physical, emotional, spiritual, existential, financial distress. And caregiver burden really is, you know, in, in very much many ways, you know, it deep pathologizes the experience that caregivers have when they are feeling all the negative emotions are having. So I think there's great benefit to these phrases. Um, but I'm at the same time, they're not always that useful, but they're really what they're saying is, is that weight on your shoulders?

You have as a family caregiver, that's your caregiver burden. And. It, we know it ebbs and flows across the caregiving journey and that, um, it can increase even if you are having an improvement in depression, your burden may still be high. Um, so it really, it really refers to all the multifaceted ways in which your life is dramatically impacted by caregiving.

[00:34:43] **Jill Stoddard:** And so then can a high caregiver burden. Be the, like, the thing that leads to caregiver burnout. Where it's like, it's just

[00:34:51] **Allison Applebaum:** Absolutely. Absolutely. yeah,

Absolutely. Like, like there is no caregiver in this world who is not experiencing distress, not experiencing burden in some capacity. We all do. It's a matter of to what extent we're able to cope with that. And to what extent we have resources, both internal, internal resources, emotional resources, and external resources, to what extent we are providing care and isolation versus within a network of care, to what extent we have the financial capacity to pay for care or not, to what extent we've had to give up our paid employment.

Or not for caregiving. I mean, I think that's an elephant in the room. We do not as of today. I won't get too political, but we don't have a universal robust paid family medical leave plan in this country. And too many of us are forced to choose between paid employment and family caregiving. That leads to burden.

So, um, inevitably without addressing these areas, the physical, emotional, spiritual, existential, financial, without some support, you're, you're going to burn out for sure. This is one of the reasons why I started the program that I did.

[00:36:01] **Jill Stoddard:** right. And so other than support, I mean, we can't prevent the burden, the burden is just the description of all of the ways in which this is caregiving is affecting all these multi domains to prevent burn out, or maybe to like, try to cushion the blow of the burden.

Are there, is support kind of the main thing? Are there like, what are

[00:36:22] **Allison Applebaum:** I think it's multifaceted. It's,

um,

support is big, but support is a umbrella term. So I think it's information and training number one. So we are increasingly asking family caregivers to perform tasks once assumed only by trained healthcare professionals. And too often we're doing that without giving them actual training to do so.

I mean, I use myself as an example. I was changing my dad's catheter bag, cleaning the opening to a super pubic catheter, giving him injectable medications. And no one ever gave me training. I eventually asked the visiting nurses to show me, but that contributes to burden. So instruction and training.

So the caregivers feel confident and competent to take care of their care partners.

That will be helpful. Um, support both in terms of emotional support, but also a support network so that there's a delegation of all the different caregiving responsibilities. A big piece, elephant in the room, the fact that caregivers too often feel invisible in the hospital to invisible in the treatment room to invisible with that healthcare professional that too contributes to burden and burnout.

And the more the caregivers are identified and acknowledged and honored for their role and responsibilities, that too is going to help combat burden.

[00:37:42] **Jill Stoddard:** Yeah. And I love, you have these great questions at the end of the chapter that's on this, for how to balance the emotional, the physical, the financial, the competing time demands, you know, and how to try to balance it so it's not unfairly landing on, um, one person. And I think the end of most of the chapters, you have these like really great resources, you know, questions and then there's a great table. Uh, it's in chapter four about how to assess your loved one's needs with domains like, you know, activities of daily living and their cognitions and caregiver to do's and things like that.

So there, there are so many resources like that, that I think can help make all of this feel. So much less overwhelming, but I want to talk about, you know, we, we know that a lack of perceived control, difficulty tolerating uncertainty, and a high sense of responsibility that when those three things come together, they really fuel anxiety and distress.

And of course, all of those can be really intensely present for caregivers. And you talk about some of the unhelpful ways that caregivers might try to get a, you know, a greater sense of control or certainty. So I thought maybe you could talk about kind of like maybe what to try not to do and then what you recommend instead when people are feeling distressed or feeling burdened or burnt out.

[00:39:02] **Allison Applebaum:** So there is one commonality for every caregiver, regardless of their loved one's illness, disease treatment prognosis. And that is the challenge of sitting with uncertainty of not knowing what the next year or the next month or the next week or the next day. Or when my dad was hallucinating, the next hour was going to bring.

Right. We sit with that uncertainty. That is a challenge for every caregiver. And as a result, most of us find ourselves worrying and ruminating. Worrying is, you

know, repetitively thinking about things, what's going to happen in the future, rumination, thinking about what happened in the past. Certainly there are many unhelpful coping strategies to navigate uncertainty and navigate this anxiety and worry.

And those really have to do with avoidance. So, you know, avoidance can take many shapes, um, often in, in caregivers I've worked with, it takes a shape of engaging in, you know, distraction on one's phone, that two minutes in social media turns into an hour, um, excessive exercise. We do see increased substance use in caregivers.

So increased alcohol use, increased marijuana use, um, you know, anything that helps one to avoid for the moment, the emotions they're feeling. But we know if we say, do not think about that bright pink elephant, whether it's a bright pink elephant or death or anything in between, that that thought's going to come back and it's going to come back stronger.

And so the best thing we can do is we can use the uncertainty of caregiving as an opportunity to learn to strengthen our capacity to sit with uncertainty, to strengthen our capacity to be in the moment. And to feel that emotion and one of the most important things we can be doing at that moment is to think about, well, what am I worried about right now?

And is this worry rational? You know, it's interesting. We were talking earlier about our graduate school training. So we both trained at Boston University and I often use this example of, um, you know, if graduate students coming into our counseling center, we're talking about the headache they were having and they would say, you know, I must have a brain tumor.

Well, with that student in the counseling center, I might say, well, that's catastrophic thinking. But in the setting of illness and caregiving, if someone says, I have this symptom, it must be X, Y, Z, or in the case of caregiving, my husband's out of breath, the cancer must be spreading. Well, there are many grains of truth to those thoughts.

They might not be catastrophic. What's very important is to really examine closely how honest and helpful those thoughts are. I'll give an example that's very, very common. I think we all have this in some point in our life. And it's the thought, I will not be able to survive his death or her death, their death. I had this thought. I have yet to meet a caregiver who has not survived the death of their care partner. Certainly that death was devastatingly painful, but their capacity to survive it was present. And so helping that caregiver to examine that

fear, the fear being that I won't be able to cope with the pain, that's a different thought.

And that then allows one to problem solve around how can we help you to cope more comprehensively with the pain? How can we establish greater support for you? And so when we think about the worries that caregivers have and sitting with uncertainty, one of the most proactive things we can do is really just actually honestly examine the thoughts. And think about how helpful, how honest, how real they are, how valid they are. And if they're not, can we challenge them?

And if they are like, it will be very painful when my dad dies to then take a deep breath. I always suggest a deep diaphragmatic breath in through your nose, held for a few seconds, out through your mouth, get that, that oxygen to your brain, lower your stress hormone cortisol, and learn to sit with a pink elephant.

And then I also will often talk about throughout the book is that the worries that we have as caregivers are often the same worries that our care partners have. Caregivers and patients, we often walk around in what we call a network of silence. We are avoiding talking about the elephant in the room because we don't want to hurt the other person.

But the other person is avoiding talking about the elephant in the room because they don't want to hurt us. So we're joined and not talking about it and we're isolating one another.

And while certainly opening conversations that invite that pink elephant in can be really difficult to start, Once you open them, you are absolutely going to take an exhale and you're going to likely find your partner in care has had the same exact worry

[00:43:50] **Jill Stoddard:** Yeah. And probably also wants to, wants and doesn't want, but you know, wants the permission to be able to talk about it with each other.

[00:43:57] **Allison Applebaum:** That word permission is really big, right? So when we avoid talking about something, we send the message. It's not okay to talk about it. So you as a family caregiver can give your care partner and other members of the care network permission again just by virtue of you opening the conversation,

[00:44:16] **Jill Stoddard:** Right. And I think even sometimes talking about talking about the conversation, you know, I've noticed that we're going through this really big thing and neither one of us is really talking about it. And I know for me, it's because I don't want to upset you. And I'm wondering if maybe you're worried about the same thing, but I'm making a lot of assumptions.

Is this something that you want to talk about? Because I'm open to it. If you are. You know, sort of that, like opening the conversation without just diving into the conversation is a way to give permission.

[00:44:44] **Allison Applebaum:** beautifully said. Yeah. absolutely. It's a

[00:44:47] **Jill Stoddard:** And that uncertainty piece I think is just huge. And I'll sometimes give people almost like a mantra, like something that's easy to remember that they can say that when there's that like amygdala hijack and you're, you know, it's really hard to kind of think rationally so that you don't have to come up with a way to deal with it is something that's like, I don't know, I can't know, and I don't need to know.

Right. Because we believe we must know, or we can't possibly tolerate, you know, this, this, this But we can tolerate it. We tolerate it all the time. You know, most people, when they read a book, don't read the last page first. All right,

like the whole point is that now I will say one time in therapy, I said that to the client and she said, Oh no, I read the last page first.

So that one really backfired on me and we had a lot of work to do around tolerating uncertainty. But you know, for most of us, we, we get in our car and we drive from A to Z not knowing if we're going to make it there safely. And we don't even really think about that. And you know, many of our opportunities to practice sitting with uncertainty have gone away with technology.

You know, we have just so much at our fingertips. Um, you know, but I do think looking at those ways that, you know, you don't read the last page first, the ways we do sit with uncertainty, we know you can do it. So to be able to say to yourself, like, this is uncomfortable, but I don't know the answer. I can't know the answer, right?

It's just not, that's just not how it works. It's not there. And I don't need to know,

like to be okay, to move forward with my care journey.

[00:46:16] **Allison Applebaum:** Yeah. You know, I, I know I've written about this, this idea that for most of us, well, most of us would give back our caregiving journeys. I certainly would. I wish my dad was here. I wish he wasn't ill. I wish my mother was here. Um, you know, I emerged from caregiving as a more grounded and peaceful version of myself.

Um, in part because I needed to learn to tolerate waves of uncertainty. Now I had a crash course in it because his hallucinations provided this often daily experience of a mini death. I never knew if he would return from hallucinating. There was

no

way to know,

[00:46:53] **Jill Stoddard:** Yeah.

[00:46:54] **Allison Applebaum:** that that was a microcosm of the bigger picture of caregiving for all of us, which is that caregiving gives us the opportunity to practice saying goodbye.

It gives us the opportunity to practice letting go. Every time my dad went to sleep, I practiced letting go. Every time I left the hospital, I practiced letting go. I always said the voice in my head, this might be the last time you're going to see him alive. Every time he was taken for a medical procedure, MRI, I practiced letting go.

And with those repeated practicings, I cultivated a greater capacity to live fully in the present moment. And I will say for that, I am grateful to caregiving.

[00:47:39] **Jill Stoddard:** Yeah. I love that. That's beautiful.

I, also really loved your discussion about meaning and purpose. And I thought that I would read a paragraph that you wrote about this because you, you say it better than I could say it. So quote, taking care of a loved one with a chronic or life limiting illness rarely feels like a choice. And even in instances when it is, it's a difficult one to make. Once you're in the role, the challenges of caregiving are significant, and the downstream effects on you can be profound. I have yet to meet a caregiver who has not struggled in some way with their responsibilities.

At the same time, caregiving is an opportunity to connect to what's meaningful to you, to a sense of purpose, both in caregiving and in life more generally. It's a chance to improve your relationship to your care partner and to others in your support network. It's a chance to learn new things about yourself and develop strengths you never imagined possible.

And it's an opportunity to redefine the goals you have for your life, end quote. And, you know, you make it a point to say like, this isn't about turning lemons into lemonade. The suffering is there. And caregiving can also be a way to discover meaning and purpose and growth. And you give lots of suggestions in the book for how to do this, but I thought maybe you could share one or two of your favorites with our audience.

Because I think that's probably hard when you're really in the thick of the to dos and the stress. How can people try to connect with that sense of meaning and purpose?

[00:49:11] **Allison Applebaum:** So, and I, I appreciate your reading that whole paragraph because I think it's so important whenever I speak about meaning and purpose that it's not misinterpreted as the power of positive thinking or me turning lemons to lemonade. That's not who I am as a person or as a therapist. Um, certainly I'm definitely not, but we do know that suffering and meaning can coexist.

And that we can experience situations in which we feel sadness and fear and disgust and guilt and powerlessness as well as love and hope and strength and connectedness and growth. And they can all coexist together. There are many routes through which we can connect and reconnect to meaning. One of them is very powerfully Thinking about who we are authentically as humans.

And when I say this, for so many of us as caregivers, we become, we feel like we've become disconnected from who we are authentically because we're no longer able to work full time. We're no longer able to travel. We're no longer able to do the things that once brought us pleasure and meaning and purpose.

And so we're like, who are we now? I mean, I spent months of my life in the hospital. I didn't know if it was nighttime or daytime. But one of the most powerful things you can do to remain connected to what's meaningful is to ask yourself the question, who am I? And to answer it from the vantage point of who were you before you stepped into the caregiving role.

And then to consider how you can remain connected to that part of yourself. That can be very meaningful. My dad modeled this for me masterfully. Um, I have videos of him conducting an orchestra stuck in a hospital bed. We would turn on the music and he would practice his art. Yes, he could not get out of bed, but he was still a musician.

I had a first career long before BU as a ballet dancer, and I found myself during those long hospital stays using his hospital bed as a ballet bar. And doing that reconnected me to a part of myself that was grounded and strong and even joyous. It didn't take away the pain. I have one of my last pictures of me and my dad, we're in the ICU and I have my leg up on the bar and I'm stretching over towards him and I was crying.

But I was also connecting to meaning in that moment. We can connect to meaning through how we choose our attitude. How we choose to face the circumstances we're faced with. Um, you know, we, most of us don't choose to become caregivers, we don't choose illness and loss, we certainly don't choose death. For But we can choose how we respond to limitations and challenges and losses.

And I think for so many of us, it can be incredibly powerful and meaningful to take a pause, step back, and reflect on how we are choosing to face the day to day of caregiving. It can be incredibly empowering. It can engender a sense of pride. You know, and meaning also, I mean, there's many routes to meaning.

I won't go through all of them, but I think very simply, meaning can also be experienced through the five senses. You know, even in the most devastating moments, the most challenging moments through what we see and touch and taste and smell and hear through feelings of love, through visions of beauty, through humor, even, even in that dark moment, you can laugh.

You can feel connected to one another and connected to something greater than ourselves. You know, I think back, someone recently asked me to give one of the most difficult, an example of one of the most difficult moments of caregiving. And how in the world could it be meaningful? So my mom died suddenly a year into my caregiving journey.

Um, my dad wasn't in the home. He was actually staying in my apartment when she died. I found her. Thank God. No one else did. the worst day of my life was finding her and then having to go to share the news with my dad

[00:53:12] **Jill Stoddard:** Yeah,

[00:53:13] **Allison Applebaum:** who was bed bound and so limited. And while that was the most shattering earth shattering day of my life. When I was sharing the news with him, I was overcome with a sense of responsibility to take care of him, to take care of this vulnerable human whose heart was breaking in front of me. And in that moment, I was reminded of the strength of our bond and our relationship and our love. And it was incredibly meaningful. And that helped me to keep going in the depths of my own grief and my own trauma. And that's a, you know, example for me of where, yeah, I would give that back that moment for sure. That was hands down the worst day of my life. Let's hope it stays that way. But it was also a moment that was very meaningful.

Because I was able to be there for him and I was able to, within myself, find the courage to say, I can take care of him now.

[00:54:07] **Jill Stoddard:** That is so, so incredibly beautiful, and I really love the way you point out that the way that all of these complicated and difficult and lovely, sometimes, emotions can all be present at the same time. Because I do think we sometimes make the mistake of thinking if something has meaning and purpose that it's going to feel really good.

And that's often not the case. Um, and, and how important it is to really You know, learn to hold all of the different emotional experiences that arise and how much power can come from being present with all of the little things. Yeah, that's, that is so lovely. So we're, we're getting close to the end of our time here.

And of course, as always, I have lots of, of different things that I'd like to ask. Um, oh, you know what I also wanted to read just related to the meaning of purpose. You include the Nietzsche quote that of course, you know, everyone has heard. It's very famous, but he who has a why can bear almost anyhow and I just I thought that was that was worth repeating.

It's

such a good reminder for all of us Yeah,

[00:55:14] **Allison Applebaum:** He who has a why to live for can bear with almost any how.

If you have a why, a purpose, the reason to be, then the how, the day to day of caregiving can become more manageable. And so I encourage you, if you are in a caregiving role, to think about your whys. The example I gave, of course, my why was so clear that day, right? He was right in front of me. But when we're in

the thick of it, the drudgery of caregiving, sometimes it's so powerful just to take an I step back, take an exhale and say, well, what is my why right now?

[00:55:53] **Jill Stoddard:** Yeah. Why am I choosing to be here? You know, you made the point It's it's often not a choice, but really at the end of the day, I think it kind of always is is a choice because you could say I'm not doing this. Like you could leave this loved one high and dry, right? And so most people don't. And so it doesn't feel like a choice and it can feel, you know, there is that burden and there can be that bitterness and resentment that comes with that.

But I do think part of that, that why is also sort of reconnecting with the fact that you are choosing.

To show up for this person and and why are you choosing to

[00:56:31] **Allison Applebaum:** Yeah.

[00:56:31] **Jill Stoddard:** up for that person?

[00:56:32] **Allison Applebaum:** And, and, and how are you choosing to do so? So, you know, maybe you're, you're, you're so overwhelmed and burnt out, then you can choose to engage in caregiving differently. You know, often caregivers will come to me after choosing to be the only caregiver, to not let anyone else help because they feel like nobody else can do it as well as I can, or they don't hire a home health aide because they don't want a stranger in the home, but they realize at some point that's not going to be feasible over the long term.

And so they can choose their attitude and choose differently. I think you bring up a really good point that there, there is always choice of some kind.

[00:57:07] **Jill Stoddard:** Yeah, it often doesn't feel that way and even reconnecting with that like well No, actually there is can can hopefully be be helpful. You bring up home health aides and that was a question I think you know, we probably don't have quite enough time, but I did just want to mention You know, I think often outside help is needed and people don't even know where to start.

They don't know what resources are available They don't know what's And I just wanted to mention that your book does a really beautiful job of outlining so many of those questions and where to start and what to do. And, you know, I just think it goes such a long way to help minimize that sense of overwhelm.

You know, it really gives people a place to start. So There's so much richness in this book that, that speaks to the heart of the caregiving journey. And there's a lot in this book that speaks to the overwhelming logistics and questions that people have when it comes to just the nitty gritty of, doing this.

And so I just wanted to kind of give another plug that for anyone who's going through this, there is so much that you don't have to like reinvent the wheel and start from scratch. You know, there is this this roadmap right there, and it's a great read, and you'll learn a lot about Stan.

[00:58:21] **Allison Applebaum:** That was my goal. You know, especially with that chapter that you're referencing chapter seven on home health care. It's such an overwhelming complex system. There's so many moving parts and I just wanted to spell it out so that the time spent trying to figure out the mystery could be given back to you.

[00:58:35] **Jill Stoddard:** Yes, totally. And so much of this is about, time. So that is amazing. So in the couple of minutes we have left, is there anything else, I mean, there's lots of things we didn't get to talk about, but is there anything else you really wished that you could have said or that you think would be really helpful for our listeners to know?

[00:58:54] **Allison Applebaum:** you know, I think it's important to acknowledge that the emotional experience of caregiving doesn't end with the death of a patient. And that we continue and carry forward many of the emotions we had as caregivers and that for many of us, there's not just the loss of our loved one, but there's a loss of the caregiving role.

And that's

very real. Um, especially for those of us who are the quote unquote, long haul caregivers who were doing this for years or even decades that, you know, my life orbited around my dad for so long and it was so disorienting for me. When he died to no longer have my phone constantly ringing with the home health days and the visiting nurses and Medicaid and the, the pharmacy and, um, that that was a loss

in a way. Um, and there was a major adjustment for me.

[00:59:42] **Jill Stoddard:** Right. And another one of those places where maybe you're experiencing a wide range of emotions all at the same time, that there may be some relief while also there is grief.

[00:59:51] **Allison Applebaum:** exactly,

exactly, both of those are very, very real. They were very present for me, um, because the lack of those phone calls meant that my dad was no longer here, and that was incredibly painful. And then of course to acknowledge, and I do, I do touch on grief and bereavement that that that's a very, it's a very personal and unique journey and there's no one timeline and we don't want to say you should be feeling X, Y, Z by X, Y, Z time, but that, um, it takes a lot of healing.

Especially when you've been taking care of someone for a very long

[01:00:23] **Jill Stoddard:** Yeah. Absolutely. Well, Allison, thank you so much for joining me. Great book and a great conversation. I really appreciate it. Where can our listeners find you if they want to learn more?

[01:00:35] **Allison Applebaum:** time. Thank you so much. Um, you can find me, um, allisonapplebaum.com and I keep an updated list of all of my speaking engagements and events on there. You can find me at [drallisonapplebaum](#) on Instagram and [docapplebaum](#) on Twitter or X or whatever you want to

call it.

[01:00:51] **Jill Stoddard:** Whatever it's called these days. Yeah.

[01:00:53] **Allison Applebaum:** that.

[01:00:55] **Jill Stoddard:** of that.

in our show notes. And Allison is spelled with two L's and an I. Thank you so much for joining me.

[01:01:00] **Allison Applebaum:** Thanks so much for having me.

[01:01:02] **Jill Stoddard:** thank you for listening to Psychologists Off the Clock. If you enjoy our podcast, you can help us out by leaving a review or contributing on Patreon.

[01:01:18] **Emily Edlynn:** You can get more psychology tips by subscribing to our newsletter and connecting with us on social media.

[01:01:24] **Michael Herold:** We'd like to thank our podcast production manager, Jaidine Stoutt Williams.

[01:01:28] **Debbie Sorensen:** This podcast is for informational and entertainment purposes only and is not meant to be a substitute for mental health treatment. If you're looking for mental health treatment, please visit the resources page of our website, offtheclockpsych.com.