

Chapters

Want to find or hear a specific segment of the episode with Denise Brown use chapters.

Chapters:

- 00:00 - Welcome Back to Empower Her Wellness
- 00:07 - [Support the Podcast](#)
- 00:34 - Introducing Denise Brown: A Caregiving Expert
- 02:59 - Denise's Journey in Caregiving
- 03:30 - Navigating Grief and Loss
- 04:20 - The Importance of Listening and Support
- 02:40 - Quality of Life and Self-Care for Caregivers
- 31:24 - Challenges Faced by Caregivers
- 40:44 - Advocacy and Future of Caregiving
- 48:26 - Wrap-Up and Final Thoughts

Transcript

Transcripts are AI-generated, and while I've done my best to catch mistakes, there will be some!

Shelly

00:00:00.520 - 00:02:30.808

Hey, friends, and welcome back to another episode of Empower Her Wellness. I'm Shelly, your host, and I'm so glad you're joining me again this week.

Hey, before we get started, I want to remind you, you can support this podcast. I am the one woman show producer, writer, interviewer, all the things, and I am also a caregiver that I don't get paid for.

So if you'd like to support my endeavor, there's a support the podcast link down below in the show notes. You can share this episode, you can like this episode, you can comment on this episode. Any or all of those things would be wonderful.

I am so happy to have with me today Denise Brown. Denise Brown is a giant in the world of caregiving. In the show notes on the website, there's going to be a link to her bio.

If you're a caregiver, know a caregiver, or if you are a business who's some of your employees are caregivers, please click on that link and take a look at her bio and all the wonderful free resources she has for you. Denise and I talk about so many things in this podcast. We really just have this conversation back and forth about what it's like to be caregivers.

She also goes into the details of how she became a caregiver starting back in 1990 and then really more intense in 2004 with a lot of things that just happened in her family are the daily struggles of caregivers, navigating multiple systems, and just the lack of support and resources.

Denise also keeps us up to date on a growing movement to address family caregiving issues with improvements such as the new Medicare services in 2024 for caregiver support.

It also talks about the progress, albeit slow, in addressing challenges faced by unpaid caregivers, the lack of compensation, and the proposal of a universal basic income as a potential solution, which would be wonderful. Okay, friends, on to my conversation with Denise. Well, hey, friends. Welcome back to the podcast.

I have with me Denise Brown, and I am super excited that you're here. Denise, we were talking before that. I feel you're one of the big stars in caregiving that I follow, and I love your work. I love what you do.

I love your trainings. I love your group. So I'm so honored and thrilled that you've decided to join me here on the podcast. Thank you so much.

Denise Brown

00:02:30.944 - 00:02:39.220

Oh, you're welcome. I'm just as thrilled. Thank you so much. I so appreciate the invitation, and I'm grateful for the time that we'll have for our conversation.

Shelly

00:02:40.000 - 00:02:58.360

So you've been in caregiving for a long time in different capacities, like caring for your parents and then also caring for caregivers. I mean, you do a lot of training. You have support for caregivers.

So if you could just tell me a little bit about your journey in caregiving to set up our conversation.

Denise Brown

00:02:59.740 - 00:03:24.330

I actually started my work in supporting family caregivers in 1990, and then my personal caregiving experience started in 2004 with my dad's bladder cancer diagnosis. And then I added my mom as a Carrie in 2015, and she had Parkinson's. My dad died in July of 2023, and my mom died in August of 2022.

Shelly

00:03:30.510 - 00:03:33.490

That's a lot of loss in a short amount of time.

Denise Brown

00:03:33.830 - 00:04:06.450

My brother actually had died unexpectedly in August of 2021. Here we were thinking who was going to go first, mom or dad? And then it actually was a sibling, and his wife just died a few weeks ago.

So my sister in law, who, honestly, she never forgave herself for his death, really was tormented and could imagine. Yeah, she's at peace now. So that's the hopeful thought.

Shelly

00:04:06.880 - 00:04:57.850

So before we go any further, one of the interesting things that I think I saw it in your training that I'm, that I'm doing through you was that when people die suddenly, like your brother, one of the first things they want to say is, well, how did he die? What happened?

You know, and you have a different framework for how we approach people, which I thought was really good, because my first instinct, Denise, when you said, I mean, I heard in your trainings that your brother had died, but my first instinct now that we're talking to face to face, was, how do you die? You know? And I was like, oh, no, you know, that's not really a question Denise would like me. Like me to ask.

So it's not something we think about, you know, these little details that we, you know, seem to be interested in. So I thought that was really an interesting perspective and part of the training that I had with you.

Denise Brown

00:04:58.990 - 00:05:03.526

Yeah. And you're in both the caregiving facilitator and our grief facilitator training.

Shelly

00:05:03.598 - 00:05:04.302

Right. Right.

Denise Brown

00:05:04.366 - 00:06:46.732

And I I. I had this really interesting and awful experience with my brother's death, which was, I felt bombarded by the questions of why did he die?

The how really was. Well, why did he die? People would ask it as, how did he die?

It was like, you have to defend this terrible thing that happened by telling me why he died. And I was so taken aback by that. And what I finally just would tell people, well, I would just say he had a massive heart attack and died at home.

And in my head, I would think, well, he lived until he died, and he lived as long as his life lasted, and then he died. It was a struggle to figure out how to answer that. And I felt like that question was about taking care of someone else.

Interestingly enough, if they knew why he died, then they could prevent that death for themselves or someone else in their family, or they could make sense of it. Oh, it makes sense. He was blah, blah, blah, blah. Of course he would have died. It's the random act of dying that people have a really hard time with.

And I get it. We struggled with it as well, but we also understood that there were things in his life that were very painful for him.

He was in physical pain because of arthritis in his back, and he was also in emotional pain, as it relates to some things with my sister in law. Who wants to go into that in a casual conversation where someone is saying, oh, my gosh, how did he die?

Shelly

00:06:46.876 - 00:06:56.388

Yeah, because that's like this whole long thing that you then have to either get into or relive or, you know, it's like, maybe it's none of their business. What can you tell?

Denise Brown

00:06:56.564 - 00:07:01.784

Right? Right. Yes. Yeah.

Shelly

00:07:01.912 - 00:07:05.776

So I loved how you reframed that. That was really, really brilliant.

Denise Brown

00:07:05.928 - 00:08:03.688

What's interesting is, after he died, I really thought through what could have helped him feel better in his life. And what I connected with was someone who would listen to him, who didn't know him, this objective listener.

And when I started thinking through, what does a good listening session feel like? It's a session where we don't have questions around situations that are random, that we can't really explain.

And one of the examples that I think of is, for instance, let's say you fall down the stairs and you break your arm. If someone says to you, well, is there a hand for you? That is the same type of question, well, why did you fall?

This random act of falling and breaking your arm makes sense to me. You know what? Sometimes it doesn't make sense.

And so for someone to have to defend why they didn't hang on to the handrail and they fell and broke their arm just really derails their feeling of feeling supported. They don't feel supported when they have to defend something that happened.

Shelly

00:08:03.784 - 00:08:09.920

Well, yeah, because my first thought would be like, well, are you blaming me because I didn't grab the heart guardrail? You know?

Denise Brown

00:08:09.960 - 00:08:10.392

Yes.

Shelly

00:08:10.496 - 00:09:05.360

And that's an interesting point you bring up. And I know we've got a little off track here, but that's fine.

Interesting point you bring up, because as a caregiver for Steve with transverse myelitis, it was idiopathic, came on very suddenly. We don't know the cause of it. And most of the time, you really can't pinpoint a cause.

They'll think either if you've had a recent virus or bacterial infection or recent vaccine, or often it's a precursor to miss. So they don't really know.

But as a caregiver, a lot of times I thought, and I don't think this anymore, but if I only knew what had caused it, maybe I could have. But really, there's nothing that I could have done.

It's just me, sort of like, then you're just like, when you're thinking, well, how could I prevent my brother's death? You're just, like, wallowing in that past of, and you can't do anything about it now anyway.

You just have to, like, move forward with your life in the best way that you can.

Denise Brown

00:09:05.860 - 00:09:17.436

And you're setting yourself up to always meet these expectations of being able to predict and prevent and see the future clearly. And I've never met anyone who can really do that.

Shelly

00:09:17.548 - 00:09:18.440

Exactly.

Denise Brown

00:09:19.220 - 00:09:55.700

And we do look for explanation about random things that happen that are just awful. Your husband's disease and diagnosis is awful, and I would like you to explain that to me so I know I am not. It's not going to happen to me. Right.

But you can't explain it. It's a terrible tragedy. It's a terrible tragedy.

And instead, what I'd love for people to connect with is the fact that we're living this terrible tragedy. And when you listen to us and offer words of compassionate support, you are helping us live through this terrible tragedy.

Shelly

00:09:56.800 - 00:10:06.112

Those are good points. I like that. I like that. We'll get into more of that later, but let's go back a little bit to when you first became a caregiver for your.

Was it your mom first or your dad first?

Denise Brown

00:10:06.176 - 00:10:07.168

It was my dad first.

Shelly

00:10:07.224 - 00:10:27.020

Your dad first. So is this sort. Was it sort of like, did you sit down and.

Because I tell people, you know, I didn't sit down with a piece of paper and be like, the pros and cons of caregiving, you know, I just sort of, like, did it. So what was your entrance into caregiving? How did that. How did that. What was that path you took into caregiving when your mom became sick?

Denise Brown

00:10:27.600 - 00:11:57.830

My parents were on vacation. My dad had blood in his urine, and he actually is a very wonderful advocate for himself. So he knew something was wrong.

So they returned home from their vacation. He went to the doctor, he had tests, and then they realized that he actually had a tumor in his bladder.

And so that's how he was diagnosed with bladder cancer, and that's how it started. And the path for the first ten years was repeated scans and tests and biopsies, and then treatment and then repeat. So he lived in that game of.

He would go in to have a scan or a biopsy or a check every three months, and then something would show, they'd remove it, he'd have another treatment, and he managed that pretty well. I attended doctor's appointments with him.

I provided support after he came home from any kind of appointment where they would remove something from his bladder.

It only intensified, really, in 2014 when it spread, and it spread to a kidney and a ureter, and then he had surgery to remove his bladder, his kidney, and his ureter. And that happened in March of 2015. And at that time, he was. I was trying to remember how old he was, 82 or 83. When I think about that now.

I think, why did we do that? But my dad actually was in excellent health, other than the bladder.

Shelly

00:11:57.950 - 00:11:58.718

Yeah.

Denise Brown

00:11:58.894 - 00:12:38.528

Yeah. So he passed all the stress tests without a problem. And before the surgery, they had said to him, you'll go back to your regular life.

And one of the things that was important to him in his regular life was golfing, and he never golfed again, and life never was normal. He had a bag that had his. That caught his urine, and he hated it. He hated it. He hated it. So I started managing his ostomy care.

Did that for the first few years, and then my mom wanted to do it, and she managed it. When she was in her early eighties, she did that when he was hospitalized.

She would provide his ostomy care in the hospital because the nurses didn't know how. I meant, I.

Shelly

00:12:38.574 - 00:12:38.852

What.

Denise Brown

00:12:38.916 - 00:12:41.996

Anyway. Yeah, I know. Yeah. Like what?

Shelly

00:12:42.148 - 00:12:43.292

That is making sense.

Denise Brown

00:12:43.396 - 00:12:45.724

Yeah. It doesn't. It doesn't. Yeah.

Shelly

00:12:45.852 - 00:12:46.560

Yeah.

Denise Brown

00:12:47.540 - 00:12:53.436

And then my mom then became ill in 2015, so then it was the two of them.

Shelly

00:12:53.628 - 00:12:59.156

So were you their sole caregivers? Were you the main person, mainly responsible for your parents?

Denise Brown

00:12:59.308 - 00:14:47.362

I was the primary, and then I had support from a brother, well, both brothers, until my one brother died, and then my younger sister. We have an older sister who is the agitator in the family, and she helped for a little bit until she kind of had a. She couldn't.

And so she removed herself from, actually, the family system and from caregiving which was very difficult for my mom. Just heartbreaking. Just heartbreaking for my mom.

You know, we think about what we manage during a caregiving experience, and so much focuses on the tasks, and certainly there are tasks that we do, managing medications, hands on care, getting to the appointments, being in the appointments.

But I think this emotional toll on us is something that is what leads to our chronic burnout, because we are always trying to help someone who's in pain feel better, and that's our Carrie, and that's ourselves, too. And the solutions to feeling better from our emotional pain can really be elusive. How do I help my mom cope with my sister leaving the family system?

I was tough. Yeah. I would say to my mom, she's not well. If she were well, she would make a different decision. Let's pray for her.

That took me a couple years to figure out what to say. And actually, it was ongoing. It just intensified in caregiving, but it was something that was ever present for probably.

I mean, it started in 1999, and so finally by, like, 2004, I figured out how to help my mom through it with saying that. But, you know, at some point, the words aren't enough. I couldn't. I couldn't repair that fractured relationship.

Shelly

00:14:47.506 - 00:16:01.770

Yeah. So it seems like you had some support from family members. And then so on the outside, how did you feel?

I know that when I go with Steve to urologist appointments or neurologist appointments or whatever, they'll, they'll look at me and be like, how are you doing to. And I'm always just like, fine, because I don't have, you know, two days to go into this, like, how I really am.

And then it's just like, it's just like, I feel like it's a pleasantry they feel necessary to do, and then all the focus is on the patient, which, you know, rightly so, I think, you know, the heat. Steve's there to get his catheter changed and to do whatever else he needs to do.

And then I'm just sitting over there in the corner thinking, what about me? You know? So I, you know, sort of went in. Well, not sort of, but I did go into it with, yeah, I'll be his caregiver. And then I. You're like, now what?

Because I know with your dad, like, so when he went in and got treatments and stuff and did all that, and then they send him home and you're like, now what? You've had this care.

You've had these people taking care of you for however long, doing these things for you and all of a sudden, like, well, here you go, Denise. He's yours now. You know, did you ever feel like, what, what the heck? I mean? Oh, yeah.

Denise Brown

00:16:02.190 - 00:16:11.886

My gosh. I. You know what I always worried about? That my dad's cause of death would be Denise Brown.

You know, on his death certificate, it was Denise Brown who was in combat.

Shelly

00:16:11.918 - 00:16:12.646

That's not funny.

Denise Brown

00:16:12.678 - 00:16:40.430

But it's funny. Yes. She was the cause of his death, right? Oh, yeah. Constant. Constant.

And what was really difficult, once he had surgery to remove the bladder and they had, they created a stoma, and so then he had basically a hole that came out of his abdomen and then the urine would go into a bag that attached to his body. Honestly, I would have never been this blunt. But my dad is no longer with us, so I feel like I can be more blunt.

Shelly

00:16:40.510 - 00:16:41.170

Yeah.

Denise Brown

00:16:41.630 - 00:18:30.892

He was in his early eighties and had very fragile skin. So the urine touching his skin blew it up into these just horrible red flamed wounds. And I did everything I could, honestly.

I counted how many nurses I asked for help from, and it was something like twelve or 13 nurses that I would say, what can we do? What do we need to try?

It was constant and there was one appointment that we were going to with his oncologist, urologist, and I thought I had cleared up this terrible red flaming rash and they removed his bag and there it was. And it was like 911.

It was almost like they were going to bring in the crash cart for him and they started asking him questions like, how is your nourishment? You know, are you eating? Who's taking care of you? Here I am in the room and the room is just getting smaller and smaller. Oh, my gosh.

I was in a red flaming rash and it felt like, your daughter is incompetent. So what are we going to do about this? And you know what actually happened?

They kept telling us this particular practice, the nurse at this practice would tell us, you have to keep the bag on for five days. And we were like, oh, my God, five days. We can't. We tried. We tried.

Finally, as general practitioner referred us to a different nurse who handled ostomy in a different hospital system. And she said, oh, my gosh, don't have it on for five days, two days. Once we started changing it more frequently, it cleared up. It was fine.

It was so frustrating. They were giving us wrong guidance because my dad was older with really fragile skin and it really was creating a lot of problems.

But I wasn't the problem, but I felt like the problem. Oh, it was terrible.

Shelly

00:18:31.036 - 00:19:16.148

I've been in those situations with Steve before, so. And I think that's an important point that you bring up that if something's nothing, one of the things that I say.

So, like, Steve is on a catheter and he talks about this all the time. He has a blog, so he's always talking about his bowel and bladder problems with transports my life.

So I feel very comfortable telling him, telling people these things, but, oh, I lost my train of thought, Denise. I hate it when that happens. What was I going to say? Oh, my gosh, I hate my words come out faster than my. That I can think or the opposite.

The opposite way around. Anyway, it'll give me a minute. Good thing for editing. It'll come back to me.

Denise Brown

00:19:16.204 - 00:19:22.572

I think it might have been related to something around. It'll come back to you. Something around advocacy. So when we see something that's not.

Shelly

00:19:22.596 - 00:21:32.242

Yeah, yeah, yeah, yeah. So thank you. Thank you. So, yes, so Steve is on a catheter, and as people who are prone with on catheters are prone to utis. So Steve's UTI for his.

Because the transfer of my lyce would not present like it would in you and Ri. He doesn't have the same symptoms that you and I have. But one night on the couch, he just was sitting there and he just passed out.

So I thought, well, that's not right. If you just, like, sit on, you know, you expect someone to pass out. Like they stand up or they're walking around or something.

And so emergency people came and took him to the hospital. Well, his diagnosis was a raging Uti, you know, and so they started him on some stuff.

And then we went to his urologist and I had a conversation with him and I said, you know, we need to get him tested to make sure because he was in the ER. And he's like, yeah, if you go to er with the catheter, they're always going to, you know, do a Uti on you and a test on you.

And if you're in a catheter, you're always going to have bacteria. And I'm like, I know that, that. But I know my person. I know my person, and my person does not present with a Uti like you do.

So you're the expert on urology, but you're not the expert on a person with transpersonalitis on a catheter. So my point for that, Denise, is you're the expert on your dad with his skin at his age. You're the expert on that.

And so we really have to advocate for our people. And so finally, the urologist said, well, I'll pull a sample. And sure enough, he still had a huge amount of bacteria in his urine.

So, yeah, so I think it's really important if you know that this is not right with, like, with your dad. Like, you knew how his skin was, you know?

And so we've got to step up as caregivers and say, as painful as it is, because they're the experts, step up and say, I know my person. This is not right. So that's my. That's my rant, people.

Denise Brown

00:21:32.426 - 00:21:47.338

Yes. And, you know, I said it to twelve or 13 different nurses, and it's important for us to not stop saying it. And that's what I did.

I just kept telling everybody this, you know, we're trying to clear this up. What can we do? What can we do? What can we do?

Shelly

00:21:47.434 - 00:21:48.070

Yeah.

Denise Brown

00:21:50.260 - 00:23:36.440

And it can be difficult to connect to the one person that can help you figure out what to do. And that's frustrating. It's frustrating.

We should be able to connect to the right professional for the right situation, for the right solution right away. And it's really aggravating and painful.

That's part of the emotional pain we carry during our caregiving experience, that it's so hard to connect to solutions. It's demoralizing on some level, and it can take a hit to our confidence. And it's most important that we remember that we have a PhD in our care.

And that was actually someone who had left a comment. I used to do annual family caregiver surveys, and I would ask for feedback on what would you like other family caregivers to know?

And someone wrote that, and I thought, that is beautiful. Yeah. We have a PhD in our career. We know best.

We know what works and what doesn't, because they'll suggest something that's not logical or reasonable or affordable, realistic or possible. And we have to be able to advocate for ourselves. And here's the other thing, too, that also happens.

Well, they'll tell us to do something that is good for our Carrie, but it might make our life really hard. So we have to figure out what's the compromise.

So our Carrie receives the treatment and care that he or she needs, and it's done in a way that it doesn't blow up our life. And that can be a difficult compromise to find.

And it's important that we connect to healthcare professionals who get that, who don't set this really unrealistic expectation on us to drop our life. We have to keep going, we have to keep going.

Shelly

00:23:37.900 - 00:24:19.510

So true. Those are really, really great points.

So when you were, you know, going off of that, when sometimes you're giving these things that, or other caregivers giving these things that are really unrealistic for them to do, I know people who are, like, gone home. They're changing IV's and they're changing ports. They're just like, oh, my gosh, I don't know what I'm doing.

How can, and just relating to just the task of caregiving in general, the physical and the emotional, mental that you talked about earlier, how do, how did you take care of yourself and how yourself during that time and how, what advice do you give to caregivers to help them take care of themselves?

Denise Brown

00:24:20.210 - 00:25:21.550

I should also say that my dad was a narcissist and unfortunately, that's my older sister's challenge.

So what would happen is my dad would think that everything should fall in place for his comfort and convenience and that I should be available at his comfort and convenience. And sometimes that was difficult.

And I had a conversation with my niece that really changed my perspective because he wanted me to do something that seems probably like a non issue. But at the time, I was like, I can't do any more for him. I need to take a break.

And I was talking to my niece and she said, your quality of life matters, too. And I was like, I knew that. But someone else telling me that, yeah, just opened up my eyes. I didn't always have to say yes.

I didn't always have to drop everything. I didn't have to always blow up my schedule. I could really think through what can I do?

What's possible, what's realistic, what can others do, what's realistic for them as well.

Shelly

00:25:22.330 - 00:26:47.790

I love that. Reframing. I love that.

So when someone, instead of saying, you know, you need to take care of yourself, I know that to say something that's a little more, not quite as passive, but, like, more, you know, powerful, your quality of life matters, too. And I think that just when you said that, Denise, I sort of got this thing in my head, like it does.

And what, for an instant, I was like, what did I like to do before that I could still do now?

That's realistic for me and not time consuming in little ways that would lead to this quality of life because, you know, you don't take care of yourself, can't take care of your person. I mean, that's just, you know, everybody, everybody knows that. So I love, I love that.

So I would say to somebody, anyone listening who knows a caregiver is, don't tell them, you need to take care of yourselves because we know that you need to make a statement that is positive and

makes them feel good and have them go, you're damn right my quality of life matters. You know, it's just a whole different. Like, I know I need to take care of myself now. What? Instead of, oh, yeah, my quality of life matters.

That would get you on a different path, I think. I love that. Kudos to your niece.

Denise Brown

00:26:48.180 - 00:27:43.568

Yeah, she was. She was really helpful. Something else I learned, too, was to tell my parents what gave me quality of life.

I would like to go to the pool, and they would ask me on a regular basis, did you go to the pool? Oh, it looks like you went to the pool today. How was the pool? It was. Yeah, it was. It made them feel better, especially my mom.

That I was doing something that brought joy to my life, was very important to her. So I think we have to tell people what brings quality of life to us. Right? We can't just say, oh, I enjoy doing this, and then keep it to ourselves.

Let's tell people, I enjoy going to the pool because it refreshes me. It energizes me. And then when people can see that it's a joyful experience for you, they'll support you in that.

We are excellent at mind reading as family caregivers, which I think it's a.

Shelly

00:27:43.584 - 00:27:45.140

Curse and a blessing, Denise.

Denise Brown

00:27:45.780 - 00:28:12.924

A blessing. And no one else does it the way we do it. We read minds. We read hearts as well. And then we step up based on what we read and what we hear.

Others can't do that. They can't read our mind as much as we think. Why can't you? I can. We have to say it out loud. We have to say it out loud.

And it's not just saying out loud what help we'd like, but it's saying out loud what we love, what we love to do.

Shelly

00:28:13.052 - 00:30:02.920

Yeah. And I love that. And I just thought of, you know, my own quality of life, and I. This little tip to caregivers out there.

Before Steve got sick, I'm not working in my jobs anymore. I was actually. I've been a not for profit for decades, and I was a fund development, a fundraiser for numerous not for profits for.

Since, like, 2008 or something like that for a long time. And so, you know, I did presentations. I talked to people. I networked. I did public speaking. I did, you know, media interviews. I did all those things.

And all of a sudden, they stopped, just like, boom. So that was a large part of my identity that was gone.

And so I'm sitting here thinking, well, I don't want to go back to work because I don't want to leave Steve. We can't get in home health care for him because that's another thing with Medicare.

Can't get in home health care because he's in outside therapy, you know, just ridiculous rules. So we decide, you know, we're fortunate enough that I can just stay home, take care of him.

But then I thought my quality of life really was being out in the public and advocating for these agencies that I worked for. So I told Steve, said, I said, I'm going to start a podcast.

So that was how I was able to transfer my former quality of life and my skills and my strengths into something that's doable for me. And I tell all my people I'm a caregiver. I may have to cancel at the last minute. That's just how it is, you know?

So I think that's a good thing, if you're a caregiver, to think about that in terms of what can be my quality of life. What did I do before? Perhaps I can't do it exactly, but I can take it and tweak it into something that works for me. That is a podcast for Shelly.

Denise Brown
00:30:04.260 - 00:30:05.508
Yeah. I love that.

Shelly
00:30:05.644 - 00:30:08.676
Yeah, I just thought about that. Just thought about that. So.

Denise Brown
00:30:08.748 - 00:30:16.468
And I want to mention, when you were talking about that, your face was just right. That's joy.

Shelly
00:30:16.484 - 00:30:18.772
I get very excited about this kind of stuff, Denise. Very excited.

Denise Brown
00:30:18.836 - 00:30:32.894
Yeah, that's joy. And we want to support you in these joyful experiences, these joyful moments. It's important. It's so energizing to see someone else enjoy.

We just saw you enjoy.

Shelly

00:30:33.022 - 00:31:34.370

Yeah. Yeah.

Well, I've always been like that when I get on these tangents and these rants and when I go out and do public speaking about the agencies that I was passionate about. So it was just an easy way for me to transfer my skills and fill some of my time.

Now that Steve doesn't need me, you know, 24/7 it's more like, I don't know, twelve, seven or whatever, you know? So. So back to you. Do a lot of work with. With caregivers. And I'm just curious.

I know this, this, you know, we don't have days here to talk about this, but I'm just curious about if you have off the top of your head, like, the top five concerns of caregivers when it comes to either dealing with their person or dealing with outside agencies or families or advocacy, grief. I mean, I know that you talk a lot about grief and.

And things like that, but what sort of stands out in your mind that years of work that you've done, issues with caregivers.

Denise Brown

00:31:37.270 - 00:32:44.406

Think about the pain and suffering that happens in homes that we don't know about.

The outside of a house looks normal, so to speak, but we don't know about the pain and suffering that's happening inside the home and how hard it can be to find support to help ease that pain and suffering. Part of it is the grind. I started thinking about the different systems that we navigate, manage, and advocate within. Started thinking about this.

I think it was three years ago, and I started counting, and I came up with, like, ten. And then I thought, well, that's not enough, or that's not all of them. And then it was 15, and then it was 17. And I thought, that's. That's it.

Think about it, though. One experience, one situation, one episode has you managing multiple systems at the same time. That's part of the grind.

And it can be hard to get up every day knowing that the grind is waiting for you.

Shelly

00:32:44.558 - 00:32:47.734

Steve and I both feel that some days. Yeah, yeah, yeah.

Denise Brown

00:32:47.782 - 00:32:55.106

And that's part of your pain and suffering. How do we get up to face this? We don't want to. We don't want to.

Shelly

00:32:55.178 - 00:32:56.430

That's an excellent point.

Denise Brown

00:32:56.730 - 00:34:11.702

So we think about respite, the ability to take a break. I think we also really need relief. The ability to have relief from the worries, the grind, the stress. And both of those are difficult to access.

And it's also hard to know which one for which reason. And we don't have access to a community of professionals who have committed to understanding family caregiving issues that can help us through that.

I'm trying to create that.

I want to create the stable of professionals that are available within a community that can help you with family emergency planning, figuring out when you need respite, when you need relief, and then how to create plans to receive that. We just aren't set up, and we know this, to support family caregivers.

And the reason that it was never set up to support family caregivers is because there was never reimbursement set up to support family caregivers, which is why would you talked earlier about sitting in that doctor's office, and they feel like they have to ask you how you are, or they have to acknowledge your presence in the room, but they don't focus on you. They don't give you attention because they're not reimbursed for that. They're reimbursed for focusing on the patient.

Shelly

00:34:11.806 - 00:34:13.805

Ding, ding, ding. Never thought about that.

Denise Brown

00:34:13.917 - 00:34:40.409

Yeah, it's changing slowly.

So, for instance, there are new services that are reimbursable through Medicare available in 2024, starting in 2024, that will reimburse to help a family caregiver with system navigation, care coordination, and managing their stress. That's huge. That's huge. It is starting to change. It's just that the change is happening slowly.

Shelly

00:34:40.900 - 00:36:21.060

Yeah. Yeah. Well, those. Those are good tips.

I have to look up that because Steve is on Medicare, and I've looked at it a little bit, sort of trying to navigate that, so I need to. I knew that there were some new things coming down, and it is. It is very slow. I had another question while you were talking.

I should write these down while you're talking, because I had another question, but it. It'll come back to me. Oh, I know. So, um. Give me enough time, Denise. I'll hop right back on that train. So I used to do the public speaking. I'd be.

I would just be in front of crowds of people, and I would just stop and think, what was I gonna say? I would say, train left without me. And then I would get back on the. On. On the train. You know, I.

It doesn't make sense to me because I don't know the number off the top of my head. I should know because I look at it all the time.

But just the millions of caregivers there are, and then just the billions of dollars that caregivers provide, unpaid caregivers provide. So I'm always like, you know, you can thank us.

Insurance and government, and maybe that's part of the issue, is that we are not reimbursed, that we're unpaid. So we're doing it out of the kindness of the heart or the goodness of the heart or, you know, we don't have.

We can't afford to have someone come in and take care of Steve or whatever. And these are institutions know this, you know, and so why bother with us?

Now, I'm not a conspiracy theorist by any stretch, and I could just be talking out my you know what, but I sort of feel it that way. It's like, you're going to continue to give unpaid care, so we're just going to let you do it.

Denise Brown

00:36:23.000 - 00:36:40.586

Right? And here's what I think.

If we were, for instance, nurses and overworked and underpaid, we might do what nurses have been doing for the past couple years. They're part of a union and they have organized strikes.

Shelly

00:36:40.698 - 00:36:42.426

Yeah, yeah.

Denise Brown

00:36:42.618 - 00:38:03.958

We have no ability to do that. We're not going to go on strike because our Carrie suffers.

It's very difficult for us to put ourselves in a position of strength to advocate for what we need.

So this idea that Medicare is going to reimburse for services to help us as part of that, and they're going to reimburse professionals who help us, that was part of the problem. Professionals weren't reimbursed to support us, so they didn't.

And then the other problem is, how do we still pay our bills as family caregivers if we are not reimbursed for the care that we provide?

I have been thinking about this for several years, this idea that perhaps it's universal basic income for a family caregiver, so it's not part of a Medicaid waiver program. And that's typically how a family caregiver is reimbursed if a carrier qualifies for Medicaid, and that's a small percentage.

But if it's a universal basic income program, so that if you're a family caregiver, you are guaranteed a certain amount every month. In truth, if family caregivers aren't making money, guess what takes a hit. Taxes. Community, businesses, until security.

Shelly

00:38:04.134 - 00:38:05.646

I'm not paying anything. Social Security.

Denise Brown

00:38:05.718 - 00:39:04.330

Right. Everything will stop. And I think we're moving toward that happening where so many family caregivers are going to have to think through.

How do I continue to work? Maybe I take a leave of absence for a year or whatever it is. We're just not earning money.

And if we're not earning money, there is not revenue for our communities to continue to flourish. There is not a tax base for our country to continue to flourish. We have to think about it from that perspective, I believe.

How do we keep our country, our community flourishing? And it's by having families flourish.

And when a family caregiver within the family has to rethink how they actually are bringing in income, we need to be able to provide a solution for them. Part of the quality of life conversation, too, is you've made a decision to be with your husband because that's quality of life for you as well.

Shelly

00:39:04.490 - 00:39:06.244

Yeah, exactly. Yeah.

Denise Brown

00:39:06.412 - 00:39:35.280

And people don't get that. They think, well, it's so stressful, why don't you do something different?

Like he lives somewhere else and you work somewhere, you know, people will come up with crazy ideas. They don't get that part of our quality of life is managing our worries.

What gives us peace of mind and peace of mind is being present with our Carrie at doctor's appointments in their day, together with them in our day. That's what gives us peace of mind. And that's important, too.

Shelly

00:39:35.860 - 00:41:06.110

And I think that's a great point to put up because, to put out because some people would say to me, well, you really didn't have a choice in taking care of Steve. You could have, you know, you don't. I did have a choice. I could have been like, I'm out of here, buddy. This is too much for me.

I'm not going to get laid. I'm not going to get fired from my job. But the quality of life that, that you talk about is also the value systems that we hold.

So my value system was, you know, I care about this person I've been with for twelve years and I think I'm in a really good spot to take care of him. And I just, so I could, I really didn't have a choice because my quality of life and my value said to me, this is where I have to be.

You know, you, I, I know that you've done a lot of advocacy. Like you've written newspapers and, you know, you've written to biggest journals.

You've just done all sorts of stuff to try to get this, you know, this advocacy and this ball rolling. And I think that's so important because I think it's like there's 10,000 people turning 65 every day.

It's like the pig in the python, you know, parent at one time, we're going to be just, you know, all backed up against that. You know, care workers are overworked anyway. Nurses, you know, people in nursing homes, you know, there's just not enough of us to go around.

So that's one thing too, that's going to have to really be, to be looked at. So.

Denise Brown

00:41:08.050 - 00:41:28.242

I want to mention something else about quality of life and then I'll go back to what's going to happen when there's too many caries. And that is when people would hear me talk about caring for my parents. They would say, well, you care for your parents because you love them.

And I would say, I care for my parents because I love myself. Very similar to your value statement.

Shelly

00:41:28.346 - 00:41:28.770

Yeah.

Denise Brown

00:41:28.850 - 00:41:31.850

I couldn't sleep at night if I didn't help my parents, I couldn't.

Shelly

00:41:31.930 - 00:41:33.138

Sister, right. Yeah.

Denise Brown

00:41:33.274 - 00:41:36.314

That was how I looked at it.

Shelly

00:41:36.402 - 00:41:38.042

Yeah. Great point.

Denise Brown

00:41:38.186 - 00:42:14.040

Yeah. I also want to mention something too. We take care of ourselves because we have a future and that matters.

Oftentimes people just attached our self care to our career, which is important. We want to be our best to help. We also want to be our best for ourselves. We have a future. We have purpose and passion.

We have things that are, we have left to accomplish. We have things that we want to achieve goals we want to meet. Our self care is also about us because we have the future.

We want to show up into our future, our best self possible. Whatever we can do.

Shelly

00:42:14.350 - 00:42:15.130

Yeah.

Denise Brown

00:42:15.790 - 00:43:41.324

When I think about how many individuals in our country, in our world who are going to need our care, it is staggering to me. My stomach just jumped thinking about it.

And it's not necessarily just age related, because we know that young adults struggle with their mental health. We might be in a situation where we are caring for a parent, spouse, child, and it could be different types of situations and issues. That's a lot.

That's a lot. And you might feel like, I've got to keep working.

What's going to happen when a business looks at how many employees are working that day and productivity is down because instead of being in their cube, so to speak, they're in the emergency room? Yeah, it's going to really change how we work because we have to.

But if you're a smart organization, you've already started to think about who are your customers. Your customers are family caregivers. Guess when they have available hours, it's off hours, it's weekends, it's evening.

If you're a smart company, you're already thinking through, we have employees that probably would benefit from a flexible work schedule which will also benefit our customer. What can we do to create that? Win win.

Shelly

00:43:41.452 - 00:44:57.392

Yeah. Yeah.

That's a great point because the place that let me go wanted me in the office five days a week, 8 hours a day, and my job just wasn't that type of job. So I don't know if they just wanted to get rid of me and this was the way to do it. I don't know, it doesn't matter. But, um.

But, you know, it's such a big shift to turn that whole, like, because, you know, we have to be, we have to be like you and be always a step ahead of, you know, we have to look ten years down the road, 15 years down the road, 20 years down the road, and start turning that ship now and not waiting until, you know, 20 years from now where all of a sudden, like, everything's imploded because everyone's at home taking care of somebody else and they're not getting paid to do it, you know, and then everything just implodes upon us. So. So in the time we have left, Denise, for all the caregivers who are listening here, or as Rosalind Carter, there's a saying that she does.

I hope I can get this right. There are four types of caregivers. You are a caregiver. You were a caregiver. You're going to be a caregiver or you're going to need a caregiver.

So for everyone out there listening, Denise, tell us how you work with caregivers, because you do a lot of stuff. I know what some of the things you do to help us.

Denise Brown

00:44:57.546 - 00:46:06.504

Yeah, we have events and conferences and workshops on a regular basis, and they're typically free. So, for instance, we have programs that help you during and after your caregiving experience.

We have a beginning again retreat, which is for those who are adjusting to life after caregiving ends every October and then throughout the year, we have different projects, too. We have a caregiving listener project where you can connect to a trained volunteer listener and share something that weighs heavy on your heart.

That happens in October and February every year. And then we have an online community which is carrying our way.com. you're a member of our community.

We have a 36 hours Christmas chat that happens every year where we open up one of our chat rooms for 36 hours. We actually have volunteers who man the chat room so that if you're in a holiday where you think this is a work day, it's not a holiday.

I'm really working it. And you need to connect to others who get it.

You can come into our chat room, you can come in for five minutes and just say, oh, my heavens, and then back out.

Shelly

00:46:06.552 - 00:46:07.208

Yeah, yeah.

Denise Brown

00:46:07.264 - 00:47:08.302

Catch your breath and go back at it. I'm really trying to figure out what are the moments in the day that a family caregiver could really connect to support.

So I post good morning messages five days a week that you can read that hopefully help you get out of bed, because I know that sometimes we just don't want to get out of bed. Right? I mean, yeah.

And then we have a free training program for family caregivers, which is our certified family care manager program.

And the goal is for you to have a professional designation you can put on your resume that really professionalizes the work you're doing as you care for a family member. It's a twelve class course. It's self paced.

You do it as you can, and at the end you are awarded a certificate that you can put on your LinkedIn profile that you can share on LinkedIn. It really helps you talk about that personal caregiving experience as a professional, experience that built skills for you.

Shelly

00:47:08.406 - 00:47:28.596

Yeah, yeah, yeah. Well, my friend, you are doing so much, and I, for one, really appreciate you. Everything that. Oh, thank you. I really do.

And I'm so glad that I was able to connect with you. So, before we wrap this up, Denise, do you have any parting words of wisdom, encouragement, inspiration for my listeners that you'd like to share?

Denise Brown

00:47:28.788 - 00:48:22.680

I do think that our caregiving experience is about our priorities, and our priorities are inspired by our values.

When you understand your values, you can create your priorities and then allow yourself the flexibility for your priorities to change within a day, within a part of the day, within the week. A priority for you on a Monday is going to be different for you on a Saturday. So give yourself that flexibility to figure out what works for you.

And then when you figure out what works for you, tell everyone, this is what works. This is what we're going to do.

We have to take the lead in our caregiving experiences, which is also sometimes the grind, like, oh, however, people are waiting for you to take the lead, so just go for it and take the lead in the way that works for you and let people know this is how we're doing it, and then they'll follow.

Shelly

00:48:23.460 - 00:48:28.972

Well, those are empowering words to end our conversation on. Thank you so much, Denise. I appreciate your time.

Denise Brown

00:48:29.116 - 00:48:30.460

Yeah, thank you, Shelly. This was great.