

# MG S3 Jessica Transcript

[00:00:00] **Jessica:** Oh, by and by, when the morning comes,

[00:00:07] All the saints of God are gathering home. We will tell the story.

[00:00:20] How we overcome, oh, we'll understand it better by and by.

[00:00:27] Oh, by, by, when the morning comes,

[00:00:36] all the saints are gonna gather at home, and we will tell the story, how we overcome.

[00:00:51] Oh, we'll understand it better, by and by.

[00:00:57] Oh yeah! I got it, girl! Did you hear me?

[00:01:19] **Dana:** Hey friend, welcome to I Swear on My Mother's Grave. Or, in the case of today's episode, welcome to I Swear on My Mother's Grave. Someday. Because today's mother is still with us, and her name is Constance, or C. G. as she is called by her daughter. And she loves gospel music, especially when her daughter Jessica sings it.

[00:01:41] The voice you heard singing at the top of the episode was Jessica, and she's a millennial only child of a single mother living with Alzheimer's. Jessica likes to say that she's made an active conscious choice to care for her mother in the last eight years. At first, commuting from Texas to Virginia. But since 2019, she's been living with her mother as her full time caregiver.

[00:02:03] In this episode, Jessica and I will talk about the definition of caregiving and what it means to her now. How Jessica always thinks, what would my mom have done for me if their roles were reversed? How hard dating is as a caregiver. We're going to talk about advocating for good care for our loved ones and how dignity isn't about you.

[00:02:23] It's all about the other person. Jessica likes to say to her mom, I got you. And I hope after listening today and following Jessica on Instagram @careerandcaregivingcollide, you will feel like she has you too. As she spends a lot of her life now educating others on social media about what she has learned caring for her own mother living with dementia.

[00:02:46] This is Jessica Guthrie.

[00:03:04] Before I got on this call, I wanted to, I literally was like, I want to Google what caregiving means from the internet and then just read it to you and let you react accordingly to where you are today.

[00:03:16] **Jessica:** Okay.

[00:03:17] **Dana:** A caregiver is a person who gives care to people who need help taking care of themselves. This, the examples can include children, the elderly, or patients who have chronic illnesses or are disabled.

[00:03:28] Caregivers may be health professionals, family members, friends, social workers, or members of the clergy. Thoughts, and they can be Jessica and here she is today.

[00:03:41] **Jessica:** Yeah. Oh, interesting. Oh, Miriam Webster.

[00:03:44] **Dana:** It's the literal, there's no emotion in it. There's no obligation. There's no representation or health. Talk about insurance and health care providers.

[00:03:52] And it's literally just the definition of right... what a caregiver is.

[00:03:57] **Jessica:** And I think in plain language that that truly is a large component of it. What is missing is I think caregiving is an active choice. Not everyone's cut out to be a caregiver. Not everyone is going to be a caregiver. And I think you have to choose to be one, even if you're thrown into it like.

[00:04:18] For me, I, I, Jessica, I'm an only child, daughter of a single mother, and given all the sacrifices my mother made, it was, there was no question whether I was going to be one, but I still have to get up every day and make an active choice to show up for my mom. So that's what's missing. I think the other thing, my other reaction was like, Yes, and the part of caregiving that no one talks about is how do you preserve someone's dignity while you're navigating whatever disease it is you're caring for?

[00:04:46] And it's, it's not just the emotion, it's the, how are you holding space for someone to literally depend on you and change right in front of your eyes? That is, regardless of whether it's dementia or, you know, another terminal illness, I just think that, Caregiving is a two way street, and I think we often talk about the care that we give to someone else for their problem, but there's also

like the, the care that happens of holding space for them as they change, holding space for them as you figure out who you are caring for them.

[00:05:22] And so, yeah, I hear the definition, but it's, it's missing some of the complexities and nuances that really make this come to life for people. And for me, really.

[00:05:32] **Dana:** What have you learned about holding space and dignity? I mean, you talk, obviously you, you have a lot of videos and a lot of content and everyone should follow you.

[00:05:40] And I, you know, that's, it's incredible. What would you say today is the thing that you have learned about? caring for someone?

[00:05:51] **Jessica:** That's such a great question. And I think my orientation to preserving my mother's dignity has always been Because that's what she would have done for me. And so it's everything that I've done and how I show up for her and like the, the, the ways in which I try to preserve the outward image to other people.

[00:06:12] She was, you know, in the early stages and starting to progress and forget things. And even now. As she's in a hospital bed, fully bed bound, no longer ambulatory, I, I still think, what would my mom have done for me? And my mom would have made sure that the story that was being told was like positive and honest and clear.

[00:06:32] My mom would have made sure that I was always dressed well and my hair was done. My mom would have always made sure that I looked, quote unquote, presentable. My mom would have always made sure that I had all of the resources to thrive. And so that has honestly been...

[00:06:47] **Dana:** Fed. Cause you do a lot of like food, food prep.

[00:06:49] Like she would have done all that.

[00:06:51] **Jessica:** Yes.

[00:06:51] **Dana:** Make sure you're nourished.

[00:06:52] **Jessica:** Comfortable. Right. Like I am, there's joy rather than connection, whether that's in singing or activities that we do, right. That was

how she, how she poured into me growing up. And I find myself literally mimicking that for her over the last eight years.

[00:07:10] And I, I say that that's important because I think that's, that's how I think about preserving her dignity, is, is ensuring that she does not feel like something is wrong with her, she is lacking in anything, she doesn't have anything, and it's actually like, no, there is so much here, and I'm going to provide and create whatever I need to so that You feel that and know that, whether she can articulate it or not.

[00:07:41] I also think I've learned that, especially navigating Alzheimer's disease, is that there's so much life left, even as we are in the late stage. And I think what I often feel is, when you say Alzheimer's disease, people are like, Oh, well, does she even know your name? Does she even know who you are? Or she must, my, her siblings think that she's literally on her deathbed.

[00:08:05] And granted, we were on hospice, but she's still there. Like she is still alive and well.

[00:08:10] **Dana:** You mean like mentally, even, even that you're saying she knows.

[00:08:15] **Jessica:** She knows. She knows when you don't come and visit or she knows when you are there. She knows when your energy is off. She knows when you're like sad. And while she can't say it, she'll reach her hand over and hold you.

[00:08:27] Right? Or she'll look you in the eye.

[00:08:30] **Dana:** Don't bullshit me what's going on with you. I can feel it. You mean she knows?

[00:08:35] **Jessica:** Yes, all of that. I also think that, you know, while she doesn't have the language anymore, when she's energized and excited, you'll hear it. And when she's like, I don't want to fool with you, she was not gonna say anything.

[00:08:49] And I, I say this because I think that people. I've learned that people forget the dignity aspect because they've literally almost thrown my mom away or like, Oh, well, she's, she does not going to know who I am or like, she won't remember me. And it's like, it's not about you. Dignity is all about the other person.

[00:09:08] So yeah, I say this because I just think that like people make choices based off of how they perceive my mother to be. And when you think that she is not present or available or there or connected to you. You lose your ability to treat someone with dignity and respect. Versus when you see them as a whole human with a soul that's still there and is like still feeling joy, can still feel the music, can still smile and connect with you when she wants to.

[00:09:36] You, like, you hold so much space for them to show up as best as they can. And that's been the greatest lesson I've experienced, especially in these later years.

[00:09:47] **Dana:** Yeah. How you said you knew you had to say yes. And a lot of people can't be a caregiver. I talk about that on my show too. Like I, I could not have stayed with my mom, but I had a different relationship with my mom.

[00:10:01] My mom had a different illness. I knew I wasn't, I wanted to be the martyr and say I could do it. Right. But that's. Not true. So when you said, I knew that was my calling and yet I still have to step up. I have to choose it. Were you ever scared that you couldn't? What if I, this doesn't work. I fail. I, I, I, I'm not cut out for this.

[00:10:25] And what advice would you say to someone who's like, I don't even want to take the risk. And it seems selfish too when people say, I can't care. You have, we treat it like, well, they must be selfish. No, I think some people know they, they are not cut out for this. But I wonder what, what you would say to someone who, or yourself, did you ever wonder if you couldn't do it?

[00:10:44] **Jessica:** So all of this started when I was 25 years old.

[00:10:47] **Dana:** Oh, come on.

[00:10:48] **Jessica:** So I was very young.

[00:10:48] **Dana:** You are, yeah, baby.

[00:10:50] **Jessica:** And I was living in Texas and my mom was in Virginia. And so. I don't think there was ever a moment where I feared that I would fail or that I feared that I couldn't do it. I do think there was the real moment of two things.

[00:11:11] If I don't, who will? My mother is one of ten siblings, but I knew none of them were going to step in to help. Right?

[00:11:18] **Dana:** Is she in the middle? Old? Young?

[00:11:20] **Jessica:** She's on the older side. She's like number three. Okay. And so, you know, everyone is, everyone's up there. And so they all have their own issues. But I knew that there was no one else.

[00:11:30] And then I think the second thing, though, was like, what you alluded to is the only thing that led me to doubt was, I don't know if I can pay for this. How am I supposed to survive? I just started my career. I just, you know, am getting like into the groove of my own profession. My mom has a house. She has to keep working.

[00:11:50] There was that in my mind of am I capable and equipped with the tools to provide for her and to really make this caregiving thing work? But that, that quickly went away when I realized, Oh, but Jessica, you have all of these skills from being a teacher. You have all of these experiences, creating systems and routines, lean on that, right?

[00:12:12] Okay, cool. Jessica, your mom is still working. So let's milk that while she can still, you know, show up to work. Okay, great. She's on FMLA, but she has all this PTO. Thank you Lord for working that out. And so like they, a lot of things fell into place, but I think the thing that would have... the thing that really scared me was will I be able to care for her well and provide for her to keep her home that she built for me, right?

[00:12:40] All of that, I didn't have a plan for, nor was I in the place to, you know, keep that going at the time. I couldn't see it. Right. I would also say, I think that there, there were moments when I was in it. Right. I still ask this question. Why me? I, I, I didn't ask for this.

[00:12:59] **Dana:** Who do you ask that, you know, to the, to the, to the gods, to the spirits, to yourself?

[00:13:03] **Jessica:** I just let it out in the universe to like, you know, I spend a lot of time, I'm an only child, I spend a lot of time by myself, you know, and I just think that there are times that I'm in my own just emotional feelings and I'm just like, why me? Why? This is so difficult. I've, I've had to sacrifice not just my personal life, but, choices in my career. I've had to sacrifice even just where I, where I live and what I choose to do. I've had to sacrifice just, just my own mental wellbeing in many ways. Why me? And I really asked this question. My father died, my father died in 2020 and I'll never forget being by the water. And the water is just a great place to be just to let it all out.

[00:13:48] And I remember being like, at the time, thinking my mom was going to die by the fall, and I said, How am I going to be parentless by 35? What did I do to deserve something like this? Anyway, I'm on a tangent, but that's, that often goes through my brain as a younger caregiver. Who I felt like I didn't really, I didn't have a choice, but my mom had me when she was 39.

[00:14:10] I was her 39 year old surprise. She thought she had the flu.

[00:14:13] **Dana:** What? 39?

[00:14:15] **Jessica:** She thought she had the flu. Wow.

[00:14:16] **Dana:** Wow. Okay.

[00:14:17] **Jessica:** And you know, my mom was on birth control. Like she wasn't trying to have a kid. Yeah. And here I come and I, I shared that piece first because it's just like, uh, I defied all the odds to be here and I now understand why I, Jessica, am here because I've been able to now be there for her and support and protect and provide for her these last eight years, especially.

[00:14:40] And if she didn't have me, I don't actually know who would have done it. So, I know why I just, like, why Jessica is here. Now the question's like, why, why does terrible caregiving just experience, or just like this, you know, all this disease? And I do think part of it is the, Jessica, you're, you're bound to help so many other people.

[00:15:02] And I also think that there's something in here around, just like Jessica, this experience has taught you so much about yourself and what you're capable of and kind of unearthed my own just like power and strengths in a way that I think. I've always known, but have really seen come to light over the last eight years.

[00:15:20] And so I think that's, that's not the full answer, but I definitely think that's part of the lessons here.

[00:15:25] **Dana:** Did your mother ever apologize to you? Did she say, I can't believe that you're forced to take care of me? You know, was that ever that, that guilt? Did she ever, did you guys ever talk about that or say, I'm so sorry, I'm so sorry that you have to be here with me?

[00:15:40] Like, almost like saying, why me back to you, your mom.

[00:15:44] **Jessica:** Oh, interesting.

[00:15:45] **Dana:** Yeah.

[00:15:45] **Jessica:** Never.

[00:15:46] **Dana:** Never.

[00:15:46] **Jessica:** My mom has always been gracious and just so grateful because, and I think that might be her way of being like, I know, I know. And so she's like, whenever, even in the early stages, thank you so much, Jessie. Thank you so much for being here.

[00:16:04] Every time I came home, you could just tell she was just like, Oh, I'm so excited to see you. So I think she'd never. It was always a, Oh my gosh, my person, Jessica, has got me, you know, and that's, that's how she's always oriented.

[00:16:22] **Dana:** Jessica's got me. Yeah.

[00:16:25] **Jessica:** Even that, so that, that phrase, I got you, like, even now, fully ambulatory, I'm rolling her in the bed, I'm changing her.

[00:16:32] And there's a moment when you roll someone, and they're like on the edge of the bed. And I'm like, I got you. I'm not gonna let you fall. She's like, you got me? And I'm like, yeah, I got you. And you're just like, yes. There's both like the actual I got you...

[00:16:44] **Dana:** and the literal...

[00:16:45] **Jessica:** I truly do have you.

[00:16:46] **Dana:** Yeah. For people who like don't know what it's like.

[00:16:50] To, to live with somebody dealing with Alzheimer's and they've never seen your videos and they have no idea they just walked off of a planet and they've shown up here. What would you, what would you say to that person? What, what have you seen? And I guess what kind of what you said about the misconceptions of they're gone, they're not here.

[00:17:07] And you're like, they're here, they're here. We think, oh, they're not going to, and that's true. Sometimes they won't remember you, right? Those, that's still part of it, but they're there. So what, what are other misconceptions that we might have.

[00:17:20] **Jessica:** I think people, when they hear Alzheimer's, they think it's a, like an old, an old person disease.

[00:17:30] My mother was diagnosed at 66. Okay. Um, she was still thriving, working, living on her own independently. I also think that people often think it's like, Oh, well, you know, it's a memory issue. And it's like, that's, that's one component of what happens in your brain. But I would honestly say the hardest part is actually.

[00:17:49] Seeing the behavioral and personality changes that occur with Alzheimer's disease, the emotional dips and like really strange highs. I think the, the, the memory of like people and forgetting people and tasks and things is one thing, but like memory of who they were. You know, how they, how they, how they were like, that's, that is really hard to witness.

[00:18:22] I also would just say like, I think Alzheimer's disease is, it's a long, long haul disease. And so it's like, we've been on this journey for eight years. It didn't get really bad to the last year and a half. And so you've got to be prepared for the long game. And it's, it's not just a one and done. You have a really clear end date.

[00:18:43] There used to be times that I would wish my mom had. I would say this a lot. I just, I wish she had cancer because at least I knew how that would end and when it would end, you know?

[00:18:54] **Dana:** Yes. Same. Same. Because my mom dealt with neuropathy and pain and addiction and I'd be like, can I get a clear, concise answer to what this is?

[00:19:04] And a doctor's note that this is that and this will come next? No. Mm mm. Mm hmm.

[00:19:10] **Jessica:** No. And so you are kind of left being like, okay, is this, is this the moment there's a lot of plateaus and dips and then your loved one rallies and comes back and you're like, okay, well, we're in a stable place and it's like a big dip.

[00:19:23] And so I think that that's probably the biggest misconception thing I would share with people is that this is a long game disease and you can easily be on this journey for 5 to 15 years with your loved one and the thing that probably took me the most off guard after the memory, the behavioral changes, like I could prepare for all of that, but the thing that I was not prepared for when it came to Alzheimer's disease was the brain no longer communicating with the body and my mother losing her mobility, my mother losing her ability to use the restroom, to feed herself, right?

[00:19:58] Like, I could mentally prepare for the cognitive changes that impacted the things that she did, but I, I was not prepared emotionally for how my mother would no longer be able to physically, like, function.

[00:20:14] **Dana:** Function. How do you, so how do you grapple with that when you're in front of her? Like, when those emotions come up and you are like, I don't, I can't acknowledge this.

[00:20:25] And if she can see you and hear you and feel you, and you're about to lose your mind, lose your shit, what do you do? What do you do?

[00:20:34] **Jessica:** You lose your shit. Oh, cool.

[00:20:35] **Dana:** oh great And scene. Great. Okay. Goodnight. Okay. Right?

[00:20:41] **Jessica:** No, no. I, I, there, there were moments when, you know, I would try to help my mom off the couch and she would like, resist or you know would feel uncomfortable.

[00:20:49] And of course what happens she falls, right? Or we'd be trying to walk to the bedroom and she wouldn't make it and she'd fall and you're just like you know you say there's so many things you don't mean but like when when you were just frustrated you're exhausted and stressed you're just like Why are you falling so much?

[00:21:06] You're just like getting off the ground. You know, like it is the amount of emotions that like just surge through you in those moments are very real. And sometimes they just come out. And sometimes that means I was in tears and my mom couldn't process the tears, but she could tell she did not feel good.

[00:21:25] You know, there were times my mom, there was because she was falling so much. My mom would be like, Oh no, not again. Oh no. Like she

would feel bad for falling. I think when it first started, I was so frustrated. Cause I was like, I wasn't prepared. I felt off guard. And I don't like to not be prepared, you know, no one told me that that was what I need to be, to be gearing up for, but then I do think there's a level of like sadness in her eyes that I'll, I'll never forget seeing when she was on the ground, helpless, and I don't know if you ever try to pick someone up off the ground that cannot help you.

[00:22:03] It is...

[00:22:04] **Dana:** Very hard.

[00:22:05] **Jessica:** ...very difficult.

[00:22:07] **Dana:** Yeah, my mom lost the ability to walk as well and fell and was distended her stomach and it's like I had to call a neighbor. I can't do it. And, and again, and you, and you do want to scream like, why me? Why this my job? Yeah. Yeah.

[00:22:25] **Jessica:** And then you start questioning. Is she safe at home?

[00:22:28] Is she safe here with me? Am I doing something wrong?

[00:22:31] **Dana:** I'm an actor. I shouldn't be picking her up. What the hell? I don't know what I'm doing. She wants pills. Where are they? What are pills? No, yeah, I'm so anyway, yeah, that's different then well that kind of leads me to, then how in the world do you teach yourself that?

[00:22:44] How do you, the insurance stuff, I mean, we could, that's a whole other conversation, and the, right, you have to teach yourself and then get resources quickly to, to be a caregiver, like you're not a licensed nurse.

[00:22:57] **Jessica:** I will say, the greatest community happened, in the internet. Yeah.

[00:23:02] **Dana:** Yeah.

[00:23:02] **Jessica:** Because very few resources in person.

[00:23:05] People be like, Oh, we'll just call your local area on agent, your local area agency on aging. You're like, okay, well, their system itself is antiquated

and dated and they just give you phone numbers and who the heck just calls random phone numbers these days.

[00:23:18] **Dana:** Right.

[00:23:18] **Jessica:** Not me.

[00:23:18] **Dana:** Yeah. Right. Uh, so. 1 800. Yeah.

[00:23:22] **Jessica:** Yeah.

[00:23:22] Not helpful, and when you think about it, a lot of people, again, don't have a strong understanding of Alzheimer's disease, and so when you, when I would mention it to people, like, at her church, or family, friends, they'd be like, oh, really? Like, not helpful, just reacting. So, my in person community was limited.

[00:23:42] But I'll tell you, when my mom started falling, where did I go? Instagram. And I was like, my mom is starting to do this. And what happened? I had two different occupational therapists, physical therapists in my inbox saying, here's what you do. Or like, here's some videos for you to start with. I think that's, that's how I learned, especially moving into the more physical stage.

[00:24:01] Then honestly, like you realize, okay, great, videos are one thing. Your tips and tricks are one thing, but what's happening in this house at 2:00 AM when no one else is here? It's a lot of trial and error. Right. I would try something, it wouldn't work. Okay, great. Let's get creative. Let me pull you to the stairs.

[00:24:14] Use the, use the railings to get up. Right? Like you just as a caregiver of any type of disease, you become...

[00:24:20] **Dana:** McGyver

[00:24:21] **Jessica:** ...survival. 100% survival of just, not just the fittest, but just trying to survive. Yeah. Is really what, what. What brings out the greatest resource, to be honest.

[00:24:31] **Dana:** When did you start bringing in those in home?

[00:24:33] Is that usually just when you leave town, when you get the in home care? Yes, is that right? You go on a trip, you have a birthday, you... Then they come in and that's a complicated thing and finding the right person, right? I mean...

[00:24:44] **Jessica:** Well, I initially started all of that when I was still working. I was still traveling back and forth between Texas and Virginia, pre COVID.

[00:24:51] And I was, I was now gone for like at least a week. And my mother could no longer, like, entertain herself or keep herself in the house by herself. So that's when I started using care agencies. And then even once I started working from home, I kept them for four hours a day so I could focus on work. Um, and then of course, if I had to travel again, I would get them.

[00:25:12] Um, and so I've, I've been with agencies for like, I guess it's now four years now, but that in itself is probably a separate podcast episode because that's been up and down.

[00:25:23] **Dana:** And having to be like really kind, but firm and, you know, make sure they communicate back with you and you communicate what you need and they've never met your mom.

[00:25:33] I mean my grandma's in a nursing home and it's a constant battle of like her care and staffing and needs and it's hard and my grandma likes one aid and when that one aid isn't there you're like she has to go on a trip she has a home she has a husband she has to leave this building and my grandma's she can't she has to live in my room.

[00:25:52] **Jessica:** Right.

[00:25:52] **Dana:** So but I know how hard it can be and like and especially, you know, uh, when someone can't, my grandma can talk, but she can't always, you know, articulate exactly what she needs.

[00:26:04] So I wonder, yeah, like the stress that puts on your mom when you're not around, right? So do you feel guilty? Then does guilt come up when you're not there? Cause, or no, you've worked through that. You know?

[00:26:16] **Jessica:** Well, no, my greatest guilt happened when I, my last, my last big trip last February 2020.

[00:26:22] **Dana:** Okay.

[00:26:23] **Jessica:** And the care agency sent someone who was ill equipped.

[00:26:27] My mother fell multiple times. I came back home. My mother was dehydrated. She hadn't been changed clothes in two days.

[00:26:32] **Dana:** She hadn't changed clothes?

[00:26:33] **Jessica:** She hadn't eaten.

[00:26:34] **Dana:** What?

[00:26:35] **Jessica:** Correct. The, like the, the caregiver called the fire department to roll and change her because she didn't know how. My mother's room was disheveled.

[00:26:44] My mother honestly did not bounce back from that trip in February. And I know everyone's like, well, don't feel guilty. You had, and it's like, no, if I were here, yes, she would have declined, but it wouldn't have been, she wouldn't have lost a front tooth. She, you Like she wouldn't have been, you know, scared to get up and walk again.

[00:27:03] And so that, that guilt, I sat with that for months. Because even though I know now, a year later, she was declining, I, I, I very much believe that it was that event that triggered the steep hill we went down afterwards. This agency hired her, we were her first client, and just, this is how, this is why agencies are really tough.

[00:27:27] You're paying, I was paying this agency what, 27 an hour? But this woman's training had only been modules on a computer screen. And because she said, Oh, well, I cared for my parents. My parents had cancer. I cared for them as they were dying. I'd be a great caregiver. Now, this is no knock to anyone else who's been a caregiver, but just because you've been a caregiver of your parent does not mean that you were equipped to step into someone else's house to care for someone else.

[00:27:55] And that agency did not do their due diligence in training that person to be prepared for what she was going to walk into, even though I requested someone who had been there before, that understood the realities. I updated her chart with the nurse. I did it. I did my part. They didn't do theirs.

[00:28:11] **Dana:** Did they like apologize?

[00:28:12] Did they say...

[00:28:14] **Jessica:** oh, I got my money back. 100%.

[00:28:15] **Dana:** I was like, did you get my money back? Did you sue? What did you do? What is the recourse that you get? Yeah.

[00:28:20] **Jessica:** They were, they were so apologetic. They were like, well, oh, and they were like, well, you know, this, this, it sounds like she needs, she needs some more training.

[00:28:28] We'll give her some modules around whatever it was at the time. And then I said, you know, what is your specific training around supporting patients living with forms of dementia? Oh, well, we should get something scheduled with the Alzheimer's Association. Now, how are you going to be an agency that, that literally has commercials about working with elderly people, people who are living with forms of dementia, yet you don't even have a training on the book for the people entering your home.

[00:28:56] And so that, that seemed like brand new information to them. And then they went to say, Oh, well, we can't always guarantee and you're just like that. No, I get one mother. Yeah, I get one mother and I trusted her in your care and you let me down and that is unacceptable. And so I, I, I, like I said, I refuse to pay for a service where I came home.

[00:29:17] My mother was dehydrated, lost a tooth and her room was disheveled and I have it all on video evidence. So please refund me my money. So yeah, I walked away from that real quick. But, but that, I'm, I'm one of probably many stories. I am a, I'm a highly involved caregiver who has cameras to have all that evidence.

[00:29:34] **Dana:** Articulate. Resources. Internet. Like, whatever it is. Yeah, the cameras. You think about all the people, yeah, who have none of that and have no one advocating for them. That's the other thing. When I go to the nursing home, I'm always like, well, at least she has me. You know? Right. If, if I wasn't here and I can see these bruises on her wrists or cuts and it's, and again, I, I don't like to always jump to abuse.

[00:29:56] I mean, I think you probably feel the same way because you go, okay, we could jump to that, but I don't know. makes me uncomfortable to always go there, but maybe this caregiver, right? I mean, they were ill equipped, but I just don't ever want to think it's

[00:30:12] malintent, you know?

[00:30:14] **Jessica:** I don't think it's ever malicious.

[00:30:15] Most people aren't doing it maliciously. There's like a, probably a 2 percent that are, but like 98 percent of the time it's not, but you're just like, you're not. And that, that's enough. If not being trained or equipped is enough, that's unacceptable.

[00:30:36] **Dana:** I love how you talk about, and other people say this too, I feel like online, about don't forget about us. Like, you should still check in on your caregiver friends and your loved ones. It's like people almost forget about you just like they do about the person you're caring for. So deeply moving and sad.

[00:30:52] And yeah, so when you like leave the house to go to a birthday or whatever, it's like, she's out. Yay. Jessica has a life and people are checking on her, I hope. And what we can do better is people to care for our caregiving friends, I guess.

[00:31:06] **Jessica:** Yeah. It's don't forget that we were, we were people before we became caregivers.

[00:31:11] Like we were, we were your friends before this new responsibility. I was at it. You know, I still love concerts. I still love trashy TV. Talk to me about Real Housewives, right? Talk to me about the ways in which I am taking care of myself. Don't forget the person underneath this responsibility. I will tell you if you're reaching out too much.

[00:31:31] Like, I I have no problem being like, Girl, I'm good.

[00:31:33] **Dana:** Really?

[00:31:34] **Jessica:** You can slow down on the text messages. But I've never been in that position because... It's not enough. They don't come that frequently.

[00:31:41] **Dana:** Yeah.

[00:31:42] **Jessica:** But, but trust that the caregiver has enough ability to say, okay, I'm, I, I'm, I'm setting a boundary now. I'm okay.

[00:31:51] I think that sometimes, sometimes people put limits and boundaries on me as a caregiver. Like they take away my autonomy to, to choose or to say what I can and cannot do. And, and, and that actually prevents me from actually engaging or, or, or being able to say yay or nay, and I, I just think that's so unfair.

[00:32:13] And I know it's coming from a good place, but that those well intentions actually show up as isolating and isolate, yeah, isolating is the word. And I think the last thing is that like friend, acquaintances, loved ones, it's okay to just, you don't have to know what to say. I think that people sometimes get.

[00:32:32] I don't know what to say, like, you're just like, girl, I just, you can actually just sit here. It's more work for you, for me, if you keep asking all these questions for small talk.

[00:32:41] **Dana:** Yeah.

[00:32:41] **Jessica:** When, you can just come and watch TV. That's fine.

[00:32:44] **Dana:** Just sit here or do a dish. You want to clean up and just, yeah, hang out.

[00:32:50] **Jessica:** Because that's actually what I need. Like I, my mind goes a million miles a minute, right? Like I'm always in doing mode, but I never get the space to just relax and be. And if you can be that person for me or create that condition for me, that in itself would be game changing.

[00:33:11] **Dana:** How do you and your mom talk about death?

[00:33:15] Haha.

[00:33:16] **Jessica:** Ooh. That's good.

[00:33:17] **Dana:** Sorry, I waited 35 minutes to do that. I was like, wait, what time is it? Yeah. No, you, do you? Do you, my friend? And in the dark of night, what do you, how do you speak to your, to your mom and, and, you know, like, into the energy of what's coming?

[00:33:32] **Jessica:** I only, I smirk because, you know, I went on a, well, first.

[00:33:38] My mother never has talked in when she could speak about this we, she never really talked about her own death or just death in general.

[00:33:47] **Dana:** Ever.

[00:33:47] **Jessica:** But like ever that I can recall. So that's point 1. Point 2 is August 2022. I went on family care leave from work. I had 10 weeks of sabbatical slash. It was 10 weeks of sabbatical and family care leave.

[00:34:05] So it was paid time off and I will never forget because I thought that my mom was not going to make it through the Fall. I spent the first few weeks of my time off planning and thinking about her death. Planning and thinking about what, like, how I would want to celebrate her, how I would want to make sure that her personality and the ways in which she showed up would live out in, in how we, how we thought about her life, you know, and so I visited three funeral homes.

[00:34:40] I thought about cremation versus burial, thought about where I wanted her to go. I had the entire event mapped out on a piece of paper. Like, I, like, I went through that whole process.

[00:34:51] **Dana:** Musicians, like, what you want there for the party, the food. Yes.

[00:34:55] **Jessica:** Music, you know, programs, how I want the flowers, like, literally everything.

[00:35:02] And I did this and people were like, why are you doing, you know, even my hospice nurse was like, why are you going to a funeral home? And I was like. Because I want to be prepared. And so for me, death and thinking about death was doing that now. I, I know myself and I know myself. If I fast forward to the time when my mom does get to the point of her actively dying, I'm going to want to be able to snap my fingers and say, okay, great.

[00:35:24] Plants already in place, right? I can be fully...

[00:35:27] **Dana:** Here it is.

[00:35:27] **Jessica:** Yes. So that I could be present with my mom. I don't want to be, to miss a thing. And I know that's like, I, I, I follow Barbara Karnes, who obviously is a hospice nurse pioneer. I've watched and understand how the ending is going to look for people living with Alzheimer's disease.

[00:35:46] And I said, I don't want to be thinking about any of that during or post. And I want to be fully like locked in with CG, my mom. And even once it's done, I want to be able to like. Let the chips fall and book my flight to Mexico and go sit by the water. Right? I'm not, I don't, I, so anyway, that's a tangent, but I think I spent a lot of time in this summer, getting really close to the experience I wanted to honor my mom, but also what it was, what was Jessica going to need to be able to show up really well so that I could be really like proximate and present to, you know, stewarding my mom home like that, that mattered so much to me.

[00:36:30] I think what's also interesting is that I did all that work and CG is not dying anytime soon.

[00:36:38] Part of me is that like my own process? Like, I was like preparing her to die and she just, you know,

[00:36:43] **Dana:** Yeah, you're like, put the Mexico tickets in the cart and save it. Can't buy them yet. Plane tickets. No, but that makes sense that that's so, so beautiful. It's such a planner. It's such an only child. And it, and it's such a, I escaped to logistics too.

[00:36:56] I was like, oh, logistics, I can stick to, and maybe it's an escapism of, you know you're saying you want to be present. But for me, when she died, I leaned into logistics so that I could kind of delay, um, potentially this, this, this, you know, this ever empty chasm of this new part of my life, this limb that has just been removed. But, but I love that you're saying you want to be present for those last stages.

[00:37:20] Cause you've heard what it's going to be like. Will you tell me what you mean when, when Barbara's talking about this and what these last stages could look like, then I don't know if it's extremely difficult. I don't know. Yeah.

[00:37:33] **Jessica:** It's not difficult now that I'm not haven't gone through it right now. It's like a, yeah, these are the steps, right?

[00:37:38] **Dana:** It's all... it's all like conjecture, right? Yeah.

[00:37:43] **Jessica:** But I will say this felt very real when I put my mom on hospice because for, you know, once you sign up for hospice, you're basically saying, your loved one could die within six months or less and you get really like you, you get the, the care pack, you, you get the weekly visits, they start to

say these are things to look for and so I didn't get proximate to this conversation about death really until we started hospice, right?

[00:38:08] And that's okay, let me go down this hill of being prepared. But I say this because things that I do, one is my mom's going to stop eating. She's going to stop refuse. She's going to start refusing like liquids and foods. From there she's going to just start to get a lot more, just for lack of a better phrase, just like still and start to her breathing will change.

[00:38:28] Her skin color will change. A lot of the ways in which she's, like, engaging and moving, all that will go away. I also know that, you know, when we get towards the end, right, like, her body temperature will go up and down, her pulse will get slower, and then she's going to eventually, you know, take her last breath.

[00:38:46] And for some people, right, it's really dramatic and it's, like, extreme. And for many people with an Alzheimer's disease, it's a pretty, like, quiet, peaceful transition. I pray that that's what it is for my mom, but who knows? But yeah, and so I, I, I, because I knew that, I was like, okay, I want the last days and weeks to be filled with gospel music, to be filled with good energy and vibes.

[00:39:12] I want no stress. I don't want people's guilt all up in the house. Like if you ain't been here all this time on this eight year journey. No, no, you're not welcome. I'm making decisions on her behalf based off of how I know she was in her most vibrant days. My mom was a hair salon owner. She went to hair shows.

[00:39:35] She organized fashion shows all over Europe, you know, like my mom was flamboyant to a tee. And so, you know, she was also my mom would tell you my mom put you in your place real quick. And so part of me is okay. That has to live out in just like how we show up for her. So I, I, I know that I can't ask her burial or cremation, but what do I know?

[00:39:58] I know that C.G. always wanted to be seen. Therefore, I know I have to have an open casket for at least the service. I also know that C. G. would probably haunt me in my sleep if I cremated her. And so I know that I have to bury her, right? Like, just because that's just, that's her personality, you know?

[00:40:15] **Dana:** Haunt you in your sleep?

[00:40:19] Yeah. So it's like, making sure that she's, is it for you too? Seeing, you know, her most vibrant days for her and for you?

[00:40:30] **Jessica:** Oh, for sure. Yeah. Yes. You know, even down to the, who do I want to be singing in the choir at her funeral, right? Like my mother was former choir director of the church choir. My mother was someone who was always like recording the latest gospel song and getting people to sing solos.

[00:40:48] And so I'm like, okay, great. I need, you know, these people to be in the choir. If they're still living, I need for them to be the choir director, right? All that. I thought about, because I was like, oh yeah, and we need to be a choir with old school choir robes on because C.G. was extra and she would want you to march down the aisle in those choir robes.

[00:41:06] So, ode to her, and like, for me. It's like the things that stick out in my brain most of what I remember about essence of my mom.

[00:41:17] **Dana:** Yeah. How do you guys talk about objects and inheritance and, you know, getting rid of clutter and starting to downsize while she's alive? Or what object, do objects mean a lot to you?

[00:41:30] Are you a, less is more, let's hoard it all, let's burn it, what's gonna happen? How do you guys talk about that or how do you feel about that? That weight of of inherited things.

[00:41:44] **Jessica:** You know, it's interesting is so, you know, my mom was with it for a long time in the early half of this disease. And so I could not get rid of too much stuff because she noticed when I was moving things, right?

[00:41:56] Or she would be like, that's still mine. Don't touch it. So I had to be really sneaky over the years. But for those of you who don't know, a symptom of Alzheimer's disease is something that happens that they start to hoard stuff and they start to hide things. And so I would come home from work trips and she would have banana peels in her closet or orange slices tucked in a pocket.

[00:42:16] And so a lot of my early purging was to help reduce the clutter. So that she would have fewer hiding places. You know, finding mail in the most random, you're like, Oh, you were trying to hide this maybe? Or you didn't, I don't know, I don't know. So that was phase one of decluttering. And so every time I would come home from Texas, or be home for winter break from work, I would declutter a large space, whether that was the basement, to get the big pieces.

[00:42:43] Then there was a phase of, Jessica, you know yourself, when your mother passes, you're not going to want to deal with decluttering the house, you're not going to want to go through her closets, you're not going to want to go through these photos. And so, the last couple of years, I cleaned out both of her big closets and gotten rid of most

[00:43:11] of her clothes. Like, her dresses I still kept, I just couldn't give those away yet. But that's all that's left in her closet. I went through all the old photos that didn't have albums or places and did that already. So that's like photo albums complete, scrapbooks complete. I've already gotten rid of the things that don't mean anything so that I know exactly where the meaningful things are. I know exactly what I want to keep, what needs to be thrown away or donated so that I can do that in one fell swoop and not be surrounded by it.

[00:43:39] So maybe for my own protection, I spent a lot of time getting rid of things, but I could not do that until she was in a place of not noticing me getting rid of stuff, because I think her things did matter to her.

[00:43:51] **Dana:** Hey, I can see that. I can see you moving that. That's mine. That's mine. Yeah. If your mom was on this call and I said, tell me your favorite thing about Jessica.

[00:44:01] What do you think your mom would say?

[00:44:03] **Jessica:** She would say, Jessica's so smart. Don't mess with Jessica. She is, she's a natural born leader. And she doesn't take any mess. Like my mom, my mom said those things. My mom was the first person to brag about me all the time. Have you did you know about Jessica? Well, Jessica's at Dartmouth.

[00:44:20] Then you're just like, okay, she's so, she was so proud. So proud. And so she would say the same thing, she's, I'm so proud of Jessica, she's a natural born leader, don't mess with her, is what she'd say.

[00:44:33] **Dana:** You knew right away, you're like, I know the answer, I know, yeah.

[00:44:38] **Jessica:** Well, when you talk to anyone who like, even now, I'll talk to people who knew my mom, and they'll be like, oh, she was so proud of you, and I'd be like, really?

[00:44:47] Yeah, she would always talk about you, you know?

[00:44:52] **Dana:** Did she push for you to go to college? Was that a big thing? I mean, as her only child was like, we got to get you to school. I want you to have a higher education. I mean, was that a big deal or was it a given?

[00:45:02] **Jessica:** Yeah, my mom only had a high school education and she went to like trade school.

[00:45:06] And so I think it was always you're destined for greatness. You're going to be great. And you're going like, there was no question you would be going to college. I think my mom did struggle. When she realized like, oh, you're going far away my entire life. And she never said these words, but it's clear that this was, she was, what she probably meant my whole life was wrapped up in Jessica, every recital, every concert, every you would enter the thing she was there.

[00:45:32] And I remember getting my big, you know, college letter at this time, it was to Dartmouth and I was so excited. And I said, mom, why aren't you excited for me? And she said, cause you're leaving me. And that's when I realized like in hindsight that my mom had literally devoted her entire life to sacrificing and, and, and, and showing up for me.

[00:45:53] And she now had to figure out who was she going to be now that I was no longer here. And I think my mom struggled for a long time navigating that. She never told me that, but I can, I can see it now. And I think, while I don't think that that's what caused her dementia, I do think the loneliness, the not having me around, played a significant role in her forming this.

[00:46:16] **Dana:** That's real, right? They do say that's real. Yeah. I've learned that more and more. I keep hearing that about loneliness. Yeah. It's funny you said that because I was thinking and I know this is I'm not revelatory in my thought, but that idea of when the caregiver loses the person they're caring for, isn't the question always, what's my identity?

[00:46:36] **Jessica:** Yeah.

[00:46:37] **Dana:** And so your mom, you left your mom and she's who am I now? And. Your mom will eventually leave you. And I wonder in 20 years when someone says, What are the jobs you've had in your life? Is caregiving still this, this time in this eight years of your life? Is that, that's part of your legacy, right? Like that's part of who you are.

[00:46:55] That will forever, history forever changed you. And will you say, yeah, I was a caregiver and then I had this day job and then I did this and then you're going to go run for like public office probably, I bet you're going to be like, I'm like, look out, something I can see it. No, but it'd be because you are a leader.

[00:47:12] That's so interesting that there's a parallel there, but I don't know if you feel that way about identity and caregiving. I don't want to assume.

[00:47:21] **Jessica:** I, I sort of do. I think I naturally, because I here's the other beauty of social media is that you watch a number of your friends lose their parents and so there is a benefit to that.

[00:47:32] Not that anyone's losing their parent, there's a benefit, but seeing deaths so closely and then seeing people, you know, pretty well lose their parent and then go through this, who am I phase? It actually sparked in me to start figuring out who do I want? Who am I now? Because I am more than a caregiver, right?

[00:47:48] My identity, yes, this is, this is, it takes up a large slice of my little pie chart, like, it's a big chunk. And, if not the only pieces on my pie chart... And so I've been really intentional about what am I doing now to set me up for when this, when this part of my life is over, not that I'm not saying I'm not going to grieve, I'm not saying I'm not going to be, you know, need to take time away and pause, but I want to get the ball rolling so that I have a clear purpose.

[00:48:15] Again, there's actually a, there's a trend here. I'm preparing, I want to be prepared for what I know I'm going to feel. And so I've been thinking a lot about who does Jessica want to be now so that I have something to hold on to when that time comes.

[00:48:30] **Dana:** Yeah. Who does Jessica want to be? If you could put it in a sentence.

[00:48:35] In Mexico.

[00:48:40] **Jessica:** Yeah. Living by the water is clearly clearly what I want to be. Yes. But no, I think, you know, who does Jessica want to be? I mean, I, I I'm still working on it, but I do think there is, there is, there's a desire to be someone who is seen as a leader in a trailblazer and advocate for people in this dementia caregiving space to ensure that they feel equipped and empowered to be badass caregivers too, right?

[00:49:13] **Dana:** Yeah, yeah.

[00:49:15] **Jessica:** For some reason, that just really, that, that matters a lot to me. But I think the other half of it too is Jessica wants to be someone who tears down inequitable systems within our healthcare system. Because the ways in which our families are treated right now are unacceptable and completely just inequitable and backwards.

[00:49:36] And I, I really care about tearing down that system to create a better life for so many people after me. I think that's two things. I need to make it more succinct, but yeah,

[00:49:46] **Dana:** those are, those are both pretty good. Yeah. Yeah. Oh my gosh. Yeah. I want to, I want to help with the equitable part. Tell me what, yeah.

[00:49:51] Tell us all what to do when you just, when you, when you've solved it or you've got some ideas. I'm, you know, what can we all do to help? It's. Yeah, it's real. What about dating? Can I pivot? How do you date? How do you do it? You know, do you? Can you? Right?

[00:50:10] **Jessica:** So dating is not happening. I, but I, that, that does not mean that I'm not open to it.

[00:50:17] I have plenty of friends who have found they are now like partners using dating apps and all the things like that's not me. I'm not feeling that either. Right? And it's a funny story. I was, I was in Dallas for a work event and we had a post work happy hour. And I'm just minding my own business and this person comes up and they're like, Oh, I'm interested in you.

[00:50:36] And I was like, what? I'm wearing a mask. You don't know. You can't see me.

[00:50:39] **Dana:** Came right up to you? Yes.

[00:50:41] **Jessica:** Yeah. And he's, he was like, you know, I, I want to get to know you. And I was like, Um, I don't live here. Like I was so quick to be like, I don't live in Dallas. Well, I don't live in Dallas either. Now I was, he was like, well, I'm willing to travel to you.

[00:50:54] And I said, he was like, he was like, here's my number. You call me. I did. I ever call him? No, no. But I think what was an interesting reflection of that experience, no matter how like awkward that was, was like, Jessica, are you

even prepared to let anyone else into your world right now? And I think the answer is no.

[00:51:12] **Dana:** No. Doesn't mean that again, forever. And this isn't your identity forever, and you're more than a caregiver. And, but I love this person. You wearing a mask, you weren't even in your home state. And it's, let's get it, it on, you know, you're like, no, but you mean, yeah. You don't have the capacity, right? Yeah.

[00:51:31] **Jessica:** Yeah, yeah.

[00:51:33] And I think I will, something that I do feel a lot is like, uh, I am doing this alone. Like, I know, I know I'm an only child, single mom, all like, yes, that. Like, I'm 35. Majority of my friends are, like, seriously partnered or married. And, you know, a lot of my friends now are, like, in the phase of having kids.

[00:51:55] And it's, you know, your friends change. Yep. As they should as people mature and all the things. But I was like, I don't have a person. I don't have someone to, like, talk this through with. Whether it's a sibling or a partner or whomever, but there is no one in the trenches with me. And that I feel now more than ever, I don't think the answer has to be someone I'm dating, but I do feel that void a lot more now.

[00:52:20] **Dana:** Yeah, like who do you, who do you call? Who do you reach out to? Who, a really good friend? Or a local care nurse? I don't know. I am like, who do you somebody at the church or somebody? A friend of hers? Your mom?

[00:52:34] **Jessica:** Yeah.

[00:52:34] **Dana:** I was like, who would it be?

[00:52:37] **Jessica:** You know, I've got it. I've got a set of friends. But you also learn that you should not be trauma dumping on your friends because they don't have space to hold it either.

[00:52:43] Right? So you can only say you can only say so much to friends. And I'll be honest...

[00:52:47] **Dana:** Or a therapist.

[00:52:48] **Jessica:** Well, that's what I was gonna say. Therapy has been really helpful. And at the same time, sometimes you just want someone to be like, This shit sucks. You know, like, you just want, like, to let it out. And so I think that's where some, Like, social media, online friends, Who are also caregivers in the same boat, Like, there's nothing like talking to someone who gets it. Who sees you, who is not judging you, who is not gonna be like, well, have you thought of this?

[00:53:11] No, I don't actually need to do anything, but just listen and affirm. And that's what a lot of my caregiver friends do for me, which I think has been really helpful. And that's also why I started sharing my story so publicly.

[00:53:26] **Dana:** What does your mom think of your online presence? That's what I wanted to know too.

[00:53:29] Does she know that she's on there? Does she know that you're kind of blowing up? Does, what does she know?

[00:53:35] **Jessica:** My mom, so, listen, C.G. Loves posing for photos. C.G. Would always say, take a picture of me. And so. That's, that's the world we grew up in. And so when my mom could comprehend, yes, I'd be like, Oh, I posted you.

[00:53:51] Look, all my friends are saying, you know, you look so nice. She'd be like, Oh, let me see, you know? So the early stages, she, she knew that I was posting her. And I think that I'm, I'm also hyper cognizant of the things that I do post, like it's actually, you probably see more of me on social media than you see my mom and that's, that's intentional to protect her.

[00:54:10] But she, when she knew she was a huge fan, she would love, she loved all the comments and people liking, you know, her poses of the day, you know, so.

[00:54:20] **Dana:** Her outfit. Yeah. I ask my guest to tell me their mom's name and how they're feeling about her today in this moment right now, after this call with me eight years in.

[00:54:32] Right after your birthday, what are you, what's your mom's name and how are you feeling about her today in your relationship?

[00:54:42] **Jessica:** Mom's name is Constance Guthrie.

[00:54:47] And today I am feeling, I'm feeling really grateful for her. Grateful for her strength. Grateful for her personality that comes out in the quirkiest of ways. Whether it's a, a raise of her eyebrow, you know, or like a, you know, or a little chuckle. I think I'm also just grateful for the fact that my mom is sticking around for something.

[00:55:18] I don't know what it is. But it's, it's not lost on me that she has defied the odds and has said, no, I'm still here and I'm still ticking. And so yeah, I'm grateful just for her presence and her being, being so strong and sticking around for me. And I think she's sticking around for me. For the what, I don't know yet, but she's sticking around for me and for that, I'm truly grateful.

[00:55:52] **Dana:** I outsourced my caregiving responsibilities for both my mother and her mother, my 96 year old grandmother, Donna, who passed away this summer. My mom was in good hands with her caretaker. And even if my mom overpaid her, which she did, and verbally promised her she could have her SUV after she died, my mother's caregiver was still a good person, and she truly did the best she could to help my mother, way more than I ever could.

[00:56:21] In 2016, about a year or so after my mother's death, I went on Facebook asking for some help, finding some part time support for my aging grandmother in Wheaton, Illinois, which is my childhood town in the western suburbs of Chicago. My nana lived alone in a retirement community at the time, was still high functioning but struggling with mobility issues, and she couldn't drive to get groceries.

[00:56:44] A former high school friend responded to my post, as she still lived in Wheaton, and said that she had the perfect person for my grandmother. Her name was Paula, and she became my Nana's part time cooker, shopper, cleaner, hairbrusher, errand runner, and friend. Paula worked for my Nana for seven years, and was even in the room with us as she took her last breath.

[00:57:05] Paula wasn't a nurse, she wasn't even certified, and she never slept over. But she was a ten minute drive away. And if she wasn't out of town seeing her friends or grandkids somewhere, she was at Target buying my Nana Activia and helping her with anything she needed. Lucky for us, when the pandemic hit, my Nana had already been transferred over to the nursing home that was connected to the retirement center as she had started to need more care.

[00:57:32] She got situated in her eventually permanent room in the nursing home in March of 2020, just as the world was shutting down. I remember visiting Nana in her room on a Thursday and giving her an elbow bump instead

of a hug, just in case, and said, I'll see you soon, even though I knew I might not be back in this room for a long time.

[00:57:55] And I wasn't for over a year, but I did drive from Chicago every Sunday with my husband to visit her at her nursing home window so that we could talk to her on her cell phone and she could see our faces. Sometimes Paula joined at the window too. It wasn't the same as being in person, but it would have to do.

[00:58:13] My Nana actually seemed more upset that she couldn't get her hair done at the beauty salon than us not being let into the room. But after months of only window visits, that slowly faded. And you could tell she really missed human connection and was getting used to having flat hair. During the pandemic, I did quarterly check in calls with the nursing home staff about my nana's care, about her diet, her physical strength, her bowel movements, and COVID updates.

[00:58:40] All on speakerphone, remotely. I would have to advocate for her care from a distance without being in the room for over a year. I would have to ask the staff about bruising on her arms that I would hear from my Nana via email. I would have to tell them that my Nana said she spent 10 hours in her wheelchair before anyone came and took her to the bathroom.

[00:58:59] How she was yelled at by an aide. During a shower, I had to call the executive director of the nursing home more than once to speak on her behalf, because the only person who knew the truth of what happened there was my Nana. I wasn't in her room, ever. I was miles away during a very isolating time, and even Paula couldn't advocate for her in person.

[00:59:20] I know, I know that many places were short staffed and struggling before the pandemic, and being a nurse or an aide is a lot of exhausting, thankless work for little pay. I know this and trust me, I was always hoping for the best case scenario and reminding my Nana to be patient, even when she had every right to be at her wits end.

[00:59:41] During the last days of my Nana's life, I was in person by her side for five days. A lot of nurses and aides and staff would come up to me and mention medications or adjustments that we needed to make. And when hospice was brought in, they usually would defer to me instead of to Paula since I was legally family.

[01:00:01] And at times I felt embarrassed because I didn't know all of my Nana's medications or her daily routine. I didn't know if something was normal or different because I was new to the in person bedside caregiving role. Sitting bedside, touching her, helping her, monitoring her. This was new to me. It felt like I was just swooping in in her last hours to play the role.

[01:00:25] There I was, the dutiful granddaughter who usually visited for two hours a month was now sitting bedside for five days. But like, well, see that, even that wasn't true. I wasn't always at her bedside. I still went out to dinner with my husband, had a cocktail at the hotel bar, and never slept in the room with her.

[01:00:42] I am not a caregiver, and I don't believe everyone is cut out to be one. It takes a certain resolve, skill set, patience level, and relationship with the person you are caring for to take on that responsibility. My Nana's favorite nurse, Maria, who took care of my Nana for three years, was there up until the day she died.

[01:01:04] And Maria told me, Dana, your grandmother waited until you got here from Michigan. She knew you were coming and she waited to let go. Maria saw my Nana intimately every week for three years. She knew my Nana. She knew her routine. She knew what she needed and she knew my Nana was tired and ready to let go.

[01:01:29] Maria also said, why does your Nana have such nice clothes? They just keep getting ripped when we help her out of her wheelchair. I said, oh Maria, Maria, Maria, she will never, ever not wear Chico's stretchy black pants. Ever. I am not my Nana's caregiver or her nurse. But hey, I can still advocate for her favorite clothes.

[01:01:57] Before I leave you, I wanted you to hear Jessica's voice one last time. Every night when she was a kid, Jessica's mother would sing this song to her. And now Jessica sings it every day to her mother, Constance. Good night, sweetheart. Talk to you soon.

[01:02:16] **Jessica:** Good night, sweetheart. Well, it's time to go. Do do do do.

[01:02:22] Good night, sweetheart. Well, it's time to go. Do do do do. I hate to leave ya, but I really must say, Good night, sweetheart. Good night.

[01:02:40] Goodnight, sweetheart. Well, it's time to go. Goodnight, sweetheart. Well, it's time to go. I hate to leave you, but I really must say goodnight, sweetheart. Goodnight. Goodnight, Constance.

[01:03:20] **Dana:** The third season, which is crazy to say, of I Swear on My Mother's Grave podcast would never be possible without our editor, Amanda Mayo from Cassiopeia Studio. I also want to thank our music composer Adam Ollendorff, our graphic designer and illustrator Meredith Montgomery, our copywriter Rachel Claff, and Tony Howell and Jonathan Freeland for all of their work on our beautiful website.

[01:03:42] And as always, thank you to Heather Bode for her emotional, spiritual, social, physical, for, well, for all of the help over all of the years. Thank you. And all of you, thank you for listening, for subscribing, for reaching out, for telling all of your friends. I know that this club, this complicated, messy club, isn't fun to be in.

[01:04:04] But I'm so glad that you're here. I couldn't do this without you. So thank you for being a part of this community. And if you haven't signed up for our newsletter, please do so at our website, which is DanaBlack.org. Not just because I want to sell you stuff, but because I want to keep talking to you and you talking to me.

[01:04:21] So go check that out. There's personal stories. I'll tell you about the season and you'll learn about the live retreats that we're curating, one retreat at a time. So, yeah, thanks for being here. I hope you'll come back. Will you come back? Don't leave me like my dead mom. You know what I mean? Come back. Please. I'll talk to you soon.