

**Personal Home Health Care Aides in Michigan, afc2017/018
Heather Zielinski. Belmont. 6.9.18**

I: Okay. I'll check this once in a while to make sure they're still running. Okay. We're ready whenever you are.

I2: I'm so close.

I: And the microphones are good?

I2: Yes. That's good, and I'm just about to start this here.

P: Oh, I have dog hair on me.

I: You can't see it. It's nice advertisement though [H had a T-shirt on with the name of the agency she works for].

P: Well, one of my—I work kind of for two offices. She goes, "You can go ahead and bring her home [inaudible – 57.17]." I'm like, oh, good 'cause then I don't know what to pick out to wear, you know what I mean?

I: It kind of matches your glasses.

P: And I actually, technically I don't even like purple, so isn't that funny?

I: Oh, it's gotta be one of my most favorite colors. I wear a lot of purple.

P: I like sage.

I: I love sage. Sage is a great color.

P: Yeah. It's a great color. Very veggie worthy.

I: We're on.

P: Right.

I: Okay. We're going to start, and we're here with HZ. And the first thing I want to say is thank you so much for doing this with us.

P: You're welcome.

I: Thank you for the work that you do. We're doing this because we believe what you do is valuable, and we want other people to hear what you do and get a sense of why it's important. So, thank you.

P: Thank you for having me.

I: We're here to hear your stories, and I'm going to jump right in and ask you about your own personal story, and how you got into this kind of work and why, how long you've been doing it?

P: Well, I actually was in school, and I actually went to school to be a certified medical assistant. And I only intended to do this [laughing] job for about 6 months, and technically at this place I have been there almost 4 years. So, 6 months turned into 4 years, but I love it. I love my job [55.55]. Let's see, so I'm sorry.

I: So, what do you love about it?

P: I love the one-on-one. I love going into people's homes. I love learning different cultures. I love—'cause I've had several different cultures, and I love like the different religions and the different thoughts on things. Just the diversity of people that you run into. It's similar but not at all in [at] the same time. It's very hard to explain, but I love helping people, and actually I love Hospice people. And the reason why I—a lotta people say, "No. I kinda stay away from that," but I consider it a privilege to be there at the end of their life. It's a

blessing to me, and I feel blessed to have people let me come into their home and stay with their spouse or mom or whoever it might be, and they trust me to be with them, and I just think it's—it's an honor and it's a privilege to be able to do that especially, so.

I: So, you're right, that is rather unusual. Where do you think that comes from? Did you discover that along the way? Did you work with somebody who was dying, and?

P: I mean I've had, you know, my grandparents have passed, so that, you know, I'm a little bit familiar with death. I mean I don't know. I guess I just—I just realize that when I had—one of my first people that I had with the company that I'm workin' for, she was on Hospice. And I just felt a huge connection. I don't know. It's hard to explain, but I felt a huge connection, and just felt blessed to be able to be allowed to be there for her mom, and she was such a lovely lady, and in so much pain, and yet she smiled through it. And you know, she literally had cancer in her back, so she's laying in bed on her back, and you know, she was hurtin' so bad. But I think it's easier [53.16] when people are kind [laughing] to be—but—

I: How would you describe a person who's at end-of-life, in what ways are they different than taking care of somebody who's not Hospice or not end-of-life?

P: I don't honestly know that it's that much different. I guess maybe it's a little more—you're a little more sensitive to the needs maybe as they're—being more careful how you handle things. I mean if this is the end of their life, you want to make it as best you can for them. So, I guess that would be one of the things I would say. I mean, obviously, you do your best. I mean I would do my best anyway with caregiving 'cause I try to do my best. You know, I have my days, but I think that's the big difference is knowing that they are at the end of their lifetime, and I wanna make it the best I can for them. And that's why I'm there is to make them, you know, feel at ease, and feel better, and you know, maybe read or just sit and—I've sang, and some people it's very calming, and I think you just—it just depends. Each situation is very different, but I feel like maybe you put a little more of your heart into it when people are, you know, that they're passing.

I: I imagine that their needs are slightly different because they're processing their impending death as well.

P: Yeah.

I: They're realizing, well, this is it, right.

P: Yeah.

I: And try to figure out for themselves how do I make these last few hours—

P: Yeah. And I've had—your right, and I've had some people that were angry, and mad, and just say take me. Let me go, you know, whatever, that kinda attitude, or I've also had, you know, like I was tellin' ya the graceful gal that just was a sweetie pie, and you know, she was in pain, but she, you know, she just [50.38]—I don't know. The care can be different too, because a lot of people are bedridden—many of them. So, you know, and then if they're in pain you really have to be careful how you're handling them, too, because anything can just—I mean sometimes it depends on what's going on. But sometimes bones can break, things like that. You have to be very careful with them.

I: You know, in our culture we're so afraid of even talking about death. It's a special person who can actually talk about it and be with somebody as they're dying and be comfortable with that.

P: Yeah. I'm not afraid of—personally, I'm not afraid of death. I know where I'm [laughing] going. I'm okay with that, and I think that eases me into—I don't know. I guess it does take a special kinda person to be with

somebody like that, but maybe because I'm not so afraid of it, myself, that probably reflects how I can care for somebody who is at the end of their life.

I: And can you give us some examples of how you help the family?

P: Oh, yeah. Yeah. I think a lot of it is just respite for families, and some situations family members wanna talk about it. There's other situations where they just wanna back away and, you know, not say anything, and sometimes you feel like, well, you're gonna have to deal with this because it's coming. You know, it's coming [48.54]. I feel like a lot of it is just—it feels like by the time we get there, at that point, whoever is caregiving, like the mom or the husband or the daughter, you know, just depending on that is, they're so tired. They're just done, and I feel—like I said I feel privileged to be able to go in there and just go, say go take a nap. You know, just go—even if you're staying in your own home and you're not even leaving, go take a nap. Go read a book, go do something you love to do because they're fried. They're literally fried, and I think some of 'em just can't cry anymore, and they can't—it's very difficult. It seems like by the time we get there, many situations are like that.

I: Physically and emotionally.

P: Absolutely. All over—all through the board—physically, spiritually, emotionally. It's just they're done.

I: How does it affect you emotionally?

P: Well, it depends on the day [laughs]. I have some days that I come home, and I just want to turn on the TV and be in somebody else's world because I have had some humdingers [laughing] of days where just emotionally—I feel like emotionally, spiritually, like I said, emotionally, spiritually, physically—I actually was gonna say that sometimes when you work a 10-hour week, it's 20 to 30 hours for a normal person because you—you get invested in these people, and it's hard. I mean it can be very draining. It's draining and it's joyful all at the same time [46.35]. I don't know how else to [laughing] describe that.

I: Tell us about one of your humdingers.

P: Oh, the humdingers. Well, in a nutshell, here we go. I've been screamed at, spit at, sworn at, swung at—those are the Ss [laughing]. I've also worked for somebody that ended up being convicted of being a pedophile. I've had a drug deal done in front of me [laughing]. I was listing this, and another lady goes, "Really? I have had a list that long. [laughing]"

I: So, these obviously aren't all of the Hospice clients? These are—

P: No. This is just a whole realm, and I just—it's crazy. So, you can see why you're done at the end of the day. Sometimes my husband will look at me and go, "What's wrong?" And I'm like, you just don't even wanna know [laughing]. And with HIPPA I have to be very careful what I share even here.

I: Sure. And I want to—I'll circle back in a few minutes, and maybe ask you about some of those specific stories, but one of the things we're hoping to achieve here is to let the world know what it is you do. What is a personal care assistant? I think a lotta people don't understand. When you say, yes, I'm a personal care assistant or what do you call yourself?

P: I call myself a caregiver.

I: Okay.

P: That's what I say.

I: So, when you say I'm a caregiver, they don't understand what that means. Can you explain it to them?

P: Well, first of all it's investing in people's lives, helping them with day-to-day activities—people that can't bathe themselves. I have stroke people. I have people that have MS. I've had Parkinson's people, so I mean some of it's severe, some of it not so much [44.19]. So, it kinda depends on, you know, where they're at, but I mean all over the board. It's helping change people. You know, dress, brush your teeth. It could be just reading a story to them, making meals. I've done a lot of—I mean sometimes it's somewhat respite for the caregiver—the daughter or the, you know, whoever's in the home caring for that person 'cause I do mostly in-home in my job. I have done some where they've needed extra help in like a nursing home or a care facility as the person didn't think that they were quite getting enough one-on-one, so I have stepped into those situations, and those I would—the one gal I would sing hymns. She loved hymns, and so, you know, it's all over the board. It's personal care. It's investing emotionally, and you know, you try not to bring that stuff home [laughs], but you do. It's a little bit of everything. I mean—and it's hard work, but I love it.

I: What's hard about it? What are some of the biggest challenges?

P: Well, I think when, you know, that you're doing your best, and you're doing the right thing, and people still don't like you [laughs]. It's hard to—I don't like to not be liked. I don't like that. I don't know if there's other people that have broader shoulders than me, but [laughing] I'm a very sensitive person. I wear my heart on my sleeve. I think many caregivers do. You probably have found that a lot of them do [42.23], and I think we're a different breed in the fact of, you know, we have to be careful. We have to set our boundaries [laughing] because we just wanna give. We want to give so freely, and sometimes you can't do that and go home to your families and be able to give them what they need, too. And I have found that to be a struggle. I'm learning. You know, pushin' that 50 number, so [laughing] I'm not there yet, but you know, I've learned a lot, and I've learned—I'm still learning, but boundaries, and you have to be very careful about that.

I: So, can you talk a little more about the boundaries—the professional boundaries that you have to cultivate and...?

P: Well, I mean first of all, you have to be very careful what you say when you go home. You know, as far as HIPPA and stuff. You really need to—it's hard because sometimes you wanna talk about your day, and you have to get specific in order to make yourself feel better, but, you know, you just have to be careful about what you're saying because, you know, you're going into people's lives, and that's their life, and it's not yours to share. It's their story, not mine. And so, boundaries, oh, there was a person that really, really wanted me to kinda counsel him and his wife or get advice and things like that, and I'm like, I am not a counselor. I am a caregiver. That is not my role, and I actually had to step out of that situation because it was getting to the point where that's all he wanted me to do was—and it was just a really strange situation. So, I had to step outta that one, but you know, sometimes you get pulled in, and you don't even know you're getting pulled in until it's kinda like, whoa. You know, what am I—I need to draw the line here.

I: Can you give us an example of that? Does something pop to your mind?

P: I think that situation is one. I just felt very uncomfortable by the things this gentleman was telling me about him and his relationship with his wife, and things like that, and I know, you know, we get personal—we get up close and personal, and we get invested in people's lives, but it was just way too over the boundaries as far, you know, they needed counseling from a professional counselor, and I think he thought because I was the giving and the caregiving type, you know, I was caregiving. But see [laughing], the issue is, you know, I'm helping him with personal care, so then we're talkin' about marriage and issues with the marriage, and marital activities [laughing]. And when you're doin' personal care for somebody and they're talkin' to you about that, it's just not appropriate. It's just not something—that's not my job [38.48].

I: So, how did you handle that? What did you say?

P: I did—I literally did tell him that you need to seek a counselor, a professional counselor that can help you with this. I don't know, he's kinda manipulative. Kind of a victim, if you will, so in being a caregiver you kinda get sucked into that thinking, well, I feel sorry for you. You know what I'm saying, but whoo, it got weird. This was the person that ended up having issues later. I said one of those things in my list of things [that she made in preparation for the interview]. That person was one of those things [laughing].

I: Hmm. We'll have to come back to that one.

P: Uh-huh.

I: So, do you work with a team of people, so that if you're in a situation like that you can call for help? You say you took yourself off that case. You must have talked to a supervisor about it.

P: Yes.

I: Can you explain?

P: And I will tell you that my boss, as of 2018, amazing. Open-door policy. He is—I've talked to him about things that—concerns with either clients or caregivers, you know, 'cause sometimes you hear from—things aren't quite up to par with some caregivers, and you kinda just wanna make sure that things are going well for your company because if somebody's doing something—you don't wanna be associated with that.

I: So, we're talking about other caregivers now?

P: Well, sometimes.

I: So, you sometimes have concerns about your peers—your coworkers?

P: There's been a few times where, yeah, actually a couple in the past probably 2 months [laughs] that there was a smell on somebody of a certain kinda smoke that was not okay [laughing] because the client was actually telling me this. And so, you know, sometimes you get into that too, and it's a very difficult situation because you don't wanna go kinda tattle-telling, you know, [laughing] but you also wanna make sure your clients are taken care of, and if you're in the same company that they're in, I could—we could lose that client because of, you know, the care that's being give or [35.56] or the lack thereof.

I: It sounds like you feel you have a very supportive boss/manager?

P: I do. I do, and I feel like—I'm actually borrowed from another office too, and I feel the same way because actually that office—the owner actually moved from the office that I work out of—she actually is the owner of the other office—the other franchise, and so I know her very well. So, it's a good relationship, and actually her and the—and my boss are working together, and it's lovely because they're sharing insight on business and the insight on, you know, that type a thing.

I: So, it sounds like, you know, you're suggesting that management and their approach and the open-door policy, makes a big difference?

P: Huge.

I: In what way?

P: Huge difference. Well, I mean man if I have a problem, I have to be able to go to somebody and talk to 'em about it. I can't go to my spouse and talk to him about it. I mean you're breakin' all those, you know, rules and regs that you're not supposed to step over those lines. You need to be supported. You need to have somebody have your back. I mean cause the job is hard. I mean they're, you know, it's a hard job. It's very fulfilling, but it's hard, you know, all at the same time. And you know, when somebody's got your back and

they're hearing you, they're not just taking the phone call and going, okay, whatever. You know, la, la, la, la, blah, blah, blah. They're actually hearing you, and telling you, "My door is open, and whatever is said here in this conversation is not going to go beyond except for what I have to with, you know, this situation, obviously, but our actual conversation is not gonna go anywhere." And it hasn't, and I like that because there's huge trust there. I don't do liars. I [laughing] don't like liars. I'm a trustworthy person, and I expect my management to be trustworthy, and they have definitely been that.

I: So, trust is a big issue with management as well as with your clients. You've mentioned trust several times.

P: Yeah. Absolutely. I just had one not terribly long ago that was just randomly lying to another person, and I know that they were on the phone. And it didn't involve the situation that I was in or any kinda care, it was another issue, but I mean just lying [laughing]. And I'm thinkin', okay, so if you're gonna do that in that situation, what are you doin' if somethin' doesn't appeal to you in this situation. And are you lying to me about who knows what? And so, it really becomes an issue because you don't know if somethin's said about somebody else is the truth? Is it embellished? Is it a lie? I mean, and I'm not talkin' dementia. I'm talkin' about, just you know—these people know that they're telling a lie. I mean dementia's a whole nother ballgame.

I: Hold that thought. We're gonna take a short break, and I want to come back to dementia and other scenarios, okay?

P: Okay. Did I do okay?

I: You're doing great. You're doing really, really well.

P: Okay. It felt like I stumbled a little. I was trying not to look at ya.

I: [Laughs]

P: While you're wandering around, I'm like [inaudible]. I'm glad you told me that because otherwise I would have been like, what are you doing?

I2: [Laughs].

I: Yeah. You're doing really well. And I know we jumped right into the Hospice stuff which was great, but we'll come back to some of these things and you can tell more stories.

P: All right. Yeah. You know, I'm just trying to be careful because I can't, you know, some of this, you know, how you have to be careful what you're saying.

I: Well, it's really clear that you're trying to be respectful of confidentiality and HIPPA and your clients' privacy as well as your coworkers and your supervisors and everybody, which we honor that. You know, we're honoring that. We don't want you to—

P: Absolutely.

I: --violate any confidentiality.

P: No, 'cause I could get in trouble for that [30.58] [laughs]. I mean obviously I have a Home Instead shirt on. They're gonna kinda know, you know, if you're in Grand Rapids—Home Instead. Okay. There's only two [laughing].

I: And we're really well aware of that too. We have a responsibility to make sure that people outside of this room are not identified.

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P: Sure. Right. And I think I've done okay with that.

I: No. You're doing really well.

P: Okay. Cool.

I: As much as we can, we'll get to the stories without violating people's privacy.

P: Yeah. Yeah.

I2: I'm ready to go.

I: Okay. Great.

I2: During the interview, if you could—put it back right now [a coffee cup], but during the interview if you could move it over here, but not right now. The reason is because then it has continuity. Like that you moved it and not that it just shifted all of sudden.

I: Oh. I didn't quite get that, but that's okay.

I2: While you're talking, just move it this way.

P: Okay. I'll move my napkin now.

I2: Okay. Now, begin. That's fine.

P: But I'll move that.

I2: That's good. Everything is good, yeah. I don't want you to worry too much about these [inaudible - laughing – 29.30].

P: You want me to pick the whole thing up and move it in a minute?

I2: Exactly. Yeah.

P: I can do that. I can follow directions sometimes.

I: Is it like those where there's two pictures and they're almost identical, and you're supposed to figure out—

I2: Well, it's just because it's a video, and then all of a sudden this is gonna shift, and I don't want it to distract at all.

I: This conversation might be kind of distracting.

I2: It's going to be cut.

I: [Laughing] okay.

I2: For my part anyway [laughs].

I: Okay. Here we go. Ready?

P: Ready.

I: Okay. Back on the air here. I want to make sure we cover a couple of facets of your job that we didn't get to. One is training. You mentioned that you're a medical tech assistant? You've had special training, and I think you said you're also a CNA? So, you've had some training for this work?

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P: Yes. I'm technically a certified medical assistant through the state of Michigan, so yeah, I have had a lot of training. I did—back in the day—I did certified nurse aide too [28.19], first aid, you know, all the stuff that goes along with that.

I: And the value of the training?

P: Well, invaluable, actually, especially like the blood-borne diseases, and those kinda things. I mean obviously those are very important. Universal precautions, obviously very important because it's interesting when you start getting into people's homes and things like that, and things will come out like, "Well, I have MERSA," or have hepatitis and you're like, okay, well, you know what, and nothing was said in paperwork or anything, and they looked normal because I don't know what you would expect [laughing] that person to look like, but you know, just don't know, and for your own protection you need to, you know, be protected. But just those types of things as far as training goes, it's very important that you know what's goin' on—what you're gettin' into—or you could possible get into in a work situation, in a home environment because I've been in all kinds of scenarios where it's been this absolutely million-dollar home, and then the person—I actually had a person that I found out had AIDs, you know. And you just don't know what you're walkin' into, so it's just good to have knowledge just all over the board [26.38]. I think another—we just went through a situation where it's troublesome people, and how do you deal with scenarios that could go south [laughing], if you will—

I: You had training on that?

P: Yeah. Just recently.

I: What do you mean by troublesome? Give us some examples.

P: Like if somebody refuses to take a bath, you know, and just trying to work with them, and trying to—because they're getting angry about it 'cause you keep going, okay, we'll we have to do the—so how to go around about nicely, but gettin' em in the bathtub 'cause they stink. You know, so you have to—but you can't say you stink, unless if that's the end and they need that [laughing]. Some people need to just be [laughing] told that they stink, but that was one of the scenarios is how to get Mrs. S in the bathtub 'cause she doesn't wanna go. And so, I think it's a lotta psychological—trying to figure out, okay, what is the reason? Is he afraid of the water? Has she been—can she not swim? You know, I don't know. It just sounds funny, but there might be a strange reason why she does not want to. Maybe she's embarrassed about her body in front of you. It's a lotta psychological trying to figure things out, and I think that's why it's really good to get to know people. First—especially before probably before doing the personal care. A lotta times I'll just have a get to know you when I first meet somebody, and just instead of doin' the bath thing, we'll just talk. I'll try to get to know 'em, and some of it's written in the paperwork, but some of it's just a one-on-one [24.34]. And sometimes you figure out what the problem is and kinda can skirt around it or like one of the solutions was, okay, she loves apple pie. Okay, so say, hey, we're gonna, you know, and I set out your clothes, and I set out your favorite flowered shirt that you love, and we're gonna put that on after we take a bath, and then we're gonna have some apple pie. So, it's like—it's kinda like a child, sometimes. But you just have to figure out what works, and I feel like a lot of those types of trainings, like I said as far as personal protection, but also a lotta psychological figuring out what works without being a booger about it.

I: What do you think it would be like to do this work without training?

P: [Big sigh] much harder. I think—personal life and going through life I think I didn't get it when I was 20 [laughing], you know, but now that I'm older I think life obviously has taught me a lotta things. My mom has taught me to get over stuff, and I think, you know, if you've had some good upbringing, it definitely helps in your culture and you're, you know, where you are spiritually, whatever, but I definitely feel like training is important. And it also kind of brings the caregivers together. You can kind—'cause sometimes we don't know each other in our office until we have like a meeting or a 24-hour client where we're overlapping. So, I think it's

important just to know there's other people that we can talk to that are doing the same thing, you know, and various age ranges. I have people that are quite a bit older than me. I think a lady was 72 or somethin' caregiving. So, it's interesting. You can go from like 20 to 72 and they're still caregiving, and insights from different people I feel like. So, those trainings I feel like are important especially if there's a Q&A after, and you can kinda bounce stuff off because I've heard a lotta cool ideas just from other caregivers. They say, "Well, I did this instead." I'm like, I'm gonna try that because that would, you know, it's a new thought, and I love learning things that work better.

I: You mentioned a culture and just for a second I want to touch on the fact that you self-identified as Native American with Cherokee in your heritage. Do you feel that that's influenced who you are, the way you approach caregiving?

P: I feel like my family is kinda closer. That was kinda the feeling with my great grandma. She was pretty cool. She was very down to earth. A very loving gal, but I feel like—the close-knit family, that kinda has left—she's left that legacy of closeness, and the love and kindness that she—you know, I just remember she was really awesome. She was a cool, cool lady, but very unique, very independent, and I guess I feel like, yeah, that definitely did influence understanding other families and how they work in the—and also being open to learning other cultures because I'm very interested in, you know, her—how she grew up and things like that, and I did a paper on it. But it's interesting to me learning other people's cultures, and not too terribly long ago I had an orthodox. He was Greek Orthodox [19.59], but he actually said he was—they were from Lebanon, and they did things very differently, and I was just—I was intrigued. And, you know, some of that comes from the fact that I'm not just a white woman [laughing] - that I do identify with being a Cherokee, and I wanna learn about other cultures too, and you know, I guess because of the way that Indians were treated I wanna learn about, you know, other cultures and figure that out too because I like history, and I like learnin' other cultures. And there's a lot out there.

I: So, the paperwork that you get, I think one aspect of personal care work is you get a piece of paper, like a care plan, that tells you a little bit about your client.

P: Yes.

I: But not everything about your client.

P: Right.

I: And so, you go into different people's homes not really knowing exactly what you're gonna find. There was a pretty stunning example you gave earlier about going into a home and learning that the person had AIDs. You didn't know that before—

P: I did not.

I: --that was not on the paper?

P: No. I did not know that, and I can't even remember. Hell, I don't even remember how I found out, honestly. It might have been a paper sitting there, and I was cleaning or something, and I can't even remember that. But that gentleman did pass away probably a few months after—'cause he went in a hospital, and it's just—yeah, it's pretty incredible 'cause you can have things written down on a piece of paper, and then you go into the house, and you're like [laughing] this is so not how—it says, you know, they had five dogs and two cats, and they have nine dogs and seven cats. I mean it's just—it and, oh, I had this one lady [laughing] her dogs were peein' all over the floor [17.34] because she couldn't—she had cancer, and she couldn't let 'em out properly. She just was so weak and couldn't always get outta bed, so you know, so that's an issue too. So, you think about caregiving for our people, but it's what they need. And she needed us to let her dogs out, so what I kinda did was—it was fall I think, and I just kinda propped the door open with somethin' and so her dogs kinda

went in and out. Well, then she stared complaining about the flies. I'm, oh, sorry [laughing], but it worked, and they loved the independence of, you know, I suggested a doggie door, but I think she passed before she could do that. But, you know, it's just kind of—we have to remember that just because it's a piece a paper, it doesn't tell me that's what it's gonna [laughing] be when you walk in. Trust me, whoo! It's, yeah.

I: So, can you tell—I'm gonna throw out a couple of several scenarios.

P: Okay.

I: Because I'm sure you've walked in and you've seen the million-dollar house all the way to the opposite end of things. What's the most extraordinary thing that you didn't anticipate? Can you think of a story where you kinda wanted to go, I didn't expect that [laughs]?

P: I think probably with the Lebanese person. I just had no idea, and we were—they were talkin' about pasta and that they weren't—they said, "Well, we're gonna eat this on Monday, and then on Wednesday we're gonna have this," and I was like—I didn't understand why they were being so funny about the food choices. I was like is it a big deal, I mean Taco Tuesday, you know? Weiner Wednesday? I don't know. I'm just, you know, and but I didn't realize that there was a purpose behind what they were saying [15.21]. Like, again, just learning cultures, and that was a surprise to me. I did not know that, and they basically—people call them worshipping under the Greek Orthodox, but he said it was the Lebanese, and said it's very close. And it was very interesting to me. And I was like, well, you know, are you okay with me—'cause I'm not a vegetarian or anything. Are you okay with me eating like a hamburger on Wednesday when you're not supposed to, and they were fine with that, but I wasn't sure, and I didn't wanna be offensive, and it was a learning experience. And you just have to, you know, go with the flow, and I would have sat there with nothing, if you know, that would have been okay.

I: Have you ever been in a situation where you felt unsafe?

P: [Sigh] I don't know that I felt unsafe. I felt uncomfortable a few times. There was a gentleman that was told, [laughs] he needed to not do his activities in front of the caregivers [drug sales]. He'd already been warned, and he basically pulled out a baggie and started separatin' stuff, and I'm like—and I didn't realize what was happening. And then I did, and I was so uncomfortable, and this person says [laughing]—sent their son with the separated portion of the baggie down the road and said—and this son was underage, and said, "She paid for this, so you just deliver it to her." And I'm like [laughing], okay. Yeah, so I called my boss at that point. There was one other time when I didn't realize that this gentleman could get violent, and he had fallen, and we needed the EMTs there, and it was an apartment and whatever. He kind of had a volatile relationship with his girlfriend I think it was. Anyway, and the EMTs weren't coming, and they weren't coming, and they weren't coming. I'm like, oh, my, goodness this is taking forever. You know, I'm just talkin' [12.36] to him while he's on the floor because, you know, that's what we need to do. It wasn't just your average fall, it was we needed to make sure that he was okay. So, I was not gonna pick him up and, you know. So, finally, the cops come. I'm like what is goin' on [laughing] here. Well, apparently, the last time that he had the EMTs there he was tellin' em he was gonna kill 'em, and dah, dah, dah, dah, dah, dah, and there was—apparently there was a firearm there. I didn't—I wasn't aware of that, but so, yeah, that was a little—it was fine. I mean he did get a little bit [sigh] sassy with his girlfriend, but it didn't seem—I mean they would say a few words at each other, but it didn't seem volatile, to me, so that was kinda surprising because I learned that when the [laughing] cops came because the office did inform me at the door. I said what is going on 'cause I had no idea. And then he had said that previously that he—and I think what it was people will do strange things when they're in pain, and he was in pain, and he was angry, and he probably just lashed out with that foot. I think those are the two scenarios that were I think the most—

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I: You talked a little bit about dealing with death, can you think of a time when - I'm sure you get very close to—you probably have had some favorite clients—where they passed, and you were there, or you were close by?

P: This gentleman, I was with him for quite a long time, and just a super nice guy. Just a super, super easy/peasy, was more of a respite for the daughter. And he was just kind. The time that he would be sassy, I think, a little bit 'cause, you know, I mean you get sick of havin' somebody always havin' to help ya and stuff, but it was very, very few and far between that he would say—he would go, "Well, I'm trying!" [Laughing] but that was so not often, and when he passed away I was heartbroken [9.48]. It really, really—I don't remember feeling that with anybody else in all of my years besides, you know, my grandparents, obviously, but not with a client. I think part of it was—I guess you just get so invested in the families, and with the daughter, she was—I was her person to talk to. You know I was like the sounding board, and she would talk to me a lot, but I was devastated, devastated, and his funeral was out of time, and it was very difficult for me to get there, and it was early, and so I felt very badly that I couldn't go to the funeral either. But it was just really not a convenient situation, and I felt bad later, and I was talkin' about it, but yeah, I was a mess for a good probably 3 weeks, and I actually called into my office, and I said, you know what, I am a mess. I cannot stop bawling. I was bawling my eyes out, and I would just sit there, and then I'd be fine, and then I would just start crying. I'm like oh my gosh, so I was definitely grieving. And they got that, but this one gal, she was very funny about how many people she had coming in, and she wanted a limited number of caregivers, and I was her person, and so I had to go, but I told them, man, if I sit on the [laughing] and cry, I'm sorry 'cause I am just a mess. And she got that, and she understood, but I went there, and I was a mess [laughing]. But I did my job, you know, but I just, you know, I think—actually one of the girls at my office, she's actually the—she's the gal that deals with the caregivers, like the one-on-one—the hiring, and the chatting to, and you know. She says, "You know, I think we need a—not a class, but like a come together when people have losses, because we don't talk about it. And then, you know, we're just messy, and I think we just need to get together and be messy together, and share those stories, and grieve and talk about it." And I said, you know, that's a really good idea [7.10] 'cause that would have really helped me because I was a mess.

I: Have you ever had that? Did they form a group? A way to share?

P: I had—after my loss and I had shared that and somebody else said something. That was at the group I was tellin' you about, the troubleshoot—the troublesome people and what to deal—the lady with the bath thing—that was there, and she said—I don't think that they formed one yet, but there was talk about it.

I: And you would find that helpful?

P: [Whispering] oh, yeah. Yeah. You know, I think—I just never felt that way. I don't know—there was just some kind a bond, and you know, I've had a lot of losses. I mean I have lost a lotta people, but that one hit me.

I: It got to you.

P: Mmm hmm.

I: You also mentioned having to deal with people spitting at you, biting you, kicking you, you wanna talk about that for a minute?

P: Not really [laughing].

I: Got any stories you want to share?

P: Well, people that—kudos to the people that work in the nursing homes, okay. Because I can kind of choose my clients as an in-home person, they're stuck with them, and that was in that scenario mostly. This gentleman was—he was I think a Vietnam vet, and he had one good arm and one bad arm, and the bad arm I

considered the one swingin' at ya. And, yeah, he was saying every word in the book because he was very angry, and was trying to spit, and it took two of us to hold him down just to change him, and see I had the privilege of being able to step away from the situations, but those people do not [4.57]. And so, I'm not that person [laughing]. I don't do well in a scenario where I have 13 people I have to take care of, and those people are so underpaid, and understaffed always, and it seems like you can't get good help, and you're—then things start happening. You see things going south with those situations because they are understaffed, and it's terribly sad.

I: So, we're gonna stop again in a second, but before we do, have you ever been injured or do you worry about injury on the job?

P: I was stuck with a needle once, so yeah, it can happen. I was tested once, but the only problem with it was that you're supposed to be tested like 6 months after that just to make sure, and the insurance, whatever, the company did not cover that, which I was very disappointed because it did happen on the job. So, that's something I definitely really feel like, you know, if you're stuck with a needle, you need to have the right coverage to make sure that you're okay. I mean the gal had been married for a long time, but you also don't know what is in their past or in their life. You don't know for sure [3.19].

I: Well, we also hear about back injuries and...

P: Oh, yeah.

I: Just from all the transferring.

P: Absolutely, and I actually [laughs], try not to do Hoyers anymore because they're very hard on my back, very hard. And I have—when I was first married I was moving living room furniture around, I hurt my back, so that's kind of an ongoing thing with me. I built it up a lot, but, you know, it still bothers me. Some days when it's tired, man, I can't. A lot of the housework—vacuuming [laughing], vacuuming's like the worst. So, I don't like to vacuum.

I: I don't know too many people that do.

P: [Laughing]

I: My 2-year-old grandson loves vacuum cleaners.

P: Hey, more power to him, right.

I: So, we're gonna take another just brief break, and then switch gears again. So, if you need to move around for a second this would be a good chance, but just don't walk away with—you're tethered.

[transcriber left out bathroom break discussion]

I2: There's such a psychological and physical toll in this job, and like, you know, learning all these stories.

P: Yup. Yeah, but you know, I mean like I say, well, I don't know if I said it, but just other people have worse problems, you know, than I do in my job. So, I mean refugees. So, they have no place to go, you know. I mean I need to think about other people, and I think I have it so bad some days. My head hurts, and feet hurt, and I'm thinkin' you have people running for their lives, H, they have no shoes on. You know, and so [laughs] you know, I know what we're doin'. We're trying to, you know, educate people, but I also have to remember so much worse in some other places. I heard Venezuela is just a mess. They ate all the zoo animals. I was like, oh, my, gosh! 'Cause they're starving. I was just told that.

I: I hadn't heard that part. I wish I hadn't heard that part.

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P: I'm sorry. I didn't mean to—

I: [Laughing] it's okay.

P: But the political—it's just so corrupt and so politically—'cause Venezuela they used to be like, you know, pretty awesome whatever.

I2: Wow.

P: Isn't that terr—you're gonna have to check that out 'cause I was like that is terrible.

I: All right. I'm gonna turn this off.

P: Like don't walk your dog because it's gonna—Fefe is gonna be somebody lookin' at hamburger. Walking hamburger, sorry. The grass is all gone because all the vegetarians have eaten it [ends tape 1].

I2: --how you [inaudible] your whole life, you know. Like one day you're like, oh, I'll do this with Archie Green folks.

I: I noticed it too. I noticed she—

P: I was like—I'm Jeff Waxworthy quality [group laughter].

I: Now, what we're gonna do here is shift gears a little bit and talk about the work that you do, and how that fits into a larger context. As we talked about at the very beginning, there's a pretty critical shortage of direct care workers, caregivers, PCAs, and we need a whole lot more, and we want qualified works. So, it's difficult to recruit people to this line of work because—for a lotta reasons, partly the pay. Can you talk about the pay for a minute? Are you able to make ends meet? How much do you get paid?

P: [Laughing] what pay [laughing]. It's pretty pathetic. I just got a raise to \$10, and I was on the low scale--\$8 somethin' for a long time [28.30]. No, you can't live on that. I have a husband that works fulltime, and God bless him, he works—he's a truckdriver and he does—he's not over the road, but anyway, he's the one that, you know, brings home the bacon basically, and I kinda do the extra stuff like phone bills and that kinda thing, but it doesn't—the people that I know that are trying to make ends meet, they literally—this one lady, she has three different companies that she works for. So, she's working like 60 some hours a week doing this job, and I'm like so when do you sleep? Because she says she's been doing it a long time, and she just recently got hired with our company not terribly long ago, maybe last year. But I don't even—I have no idea how she does that, but she has to do it, or she can't feed her family, and she can't feed herself, and she can't pay her rent, which, you know, I don't know—I don't know her education level or whatever, but that being said, it really doesn't matter. If she's been doing this for 20 plus years, and then she gets hired in at my company for under \$10, I mean you're seein' the problem here. It's—she's got a lot of knowledge. She's got work experience, you know, a lotta work experience, and I feel like that should count for something too. You know, when you're on the job experience or even if she was just doing it privately, as 20 years of experience even before she got hired through our company, that should count. But it doesn't, and you know, I'm underpaid. Way underpaid.

I: How much do you think a personal care worker should be paid?

P: Oh, my, goodness. That's a tough one. Probably at least \$13 an hour I would say. Of course, depending if they have had—it depends on your level of experience. If you're walkin' in green, probably a little less 'cause you don't have on-the-job experience, and don't have the education level. I feel like that does count, but I do definitely put in [25.59] there years of experience because if you worked for 10 years helpin' your grandma, and 5 years helpin' your aunt, I mean, and you can, you know, go back that and prove that you have done that, I feel like that's fair. You know, that should count almost as much as education, but you know, maybe a little less for somebody that's very green.

I: So, the income that you bring into a home, as you indicated, is it's not just about the pay rate but about the number of hours you get as well. So, you mentioned a colleague who has to work 60 hours, partly because the pay is too low, but that's what it takes—

P: That's what it takes.

I: --to make a living wage, to make your ends meet.

P: Right. And I'm able to, you know, I can kind of pick and choose what I am doing, so like weekends—right now I don't work a whole lotta weekends. I'm very busy, but I also have seniority in my company, which makes a difference, but like I said I have somebody that, you know, he does provide for our family. And so, I'm kinda the part-time—the extra stuff, but you know, if I had to it would be very difficult for me to make a living off of what I do. I would probably just have to go somewhere and probably have to work in a factory or something just to make ends meet. I don't know how you do in this—with the wage that I'm making, and the issue is with this type of job, people pass away, so you lose clients. People decide that they don't want or need the service anymore. There are people that—this is what I find difficult is that people—and it's not really their fault, but they go through the whole thing and they're trying to work it out as to, "Okay, is this gonna fit? What's a good fit for our family?" When they're newly thinking about how mom needs care, they go through the whole thing and we get all set up in the [23.31] office, and then they decide to put 'em in a facility. So, it's like hours and hours of working for these gals in the office, and we're all set up for schedules, and we're thinkin' oh, great, we're gonna get a 24-hour client level—na, na, na, na—and then it's gone. And that's, you know, so that's really frustrating as far as scheduling goes because you kinda planned out this, you know, this next couple months or whatever, and then it's just not there. And it's—it's really nobody's fault. It's the way it goes in the business, you know, there's nothing—they made a different decision. You know, I was almost thinking that maybe, [laughs] if you have so much hours in the office that you had to work on something, maybe you should charge, but then people—I don't know. I don't know how that would work, but.

I: So, stable hours are not guaranteed. You can't rely on set hours?

P: I mean not really. If you're in a facility, yeah, 'cause there's people there 24-7. The in-home stuff, no. I mean it's—it's a [inaudible]—

I: One thing we hear is that most people need help in the morning—getting up, dressing—and then help at night with dinner, getting undressed and getting into bed. So, there's like a split shift. It's not like they need somebody, you know, from 8 to 8. How does that work?

P: It depends on the person, and it depends on if it's like a respite situation for other people. So, my gentleman that passed away recently, his was more respite for the daughter. But she kinda wanted to make him feel—I don't know, not uncomfortable around somebody else. Like having him get ready in the morning, so she would actually do that. She took on so much, and she put him to bed. As he got weaker, I would help put him to bed, but [21.27] I mean she did that every day, 7 days a week. So, with his situation because she chose to do that, it was more respite just for her to go to the store or go you know do whatever. So, it does depend on the situation depending on what the care level is there. There's a lot of bathing needs, but yes, you are correct. If people especially are living on their own or, you know, that's what they need help with 'cause they just can't get to their toes and pull their socks on, or they have edema in their legs or they've had a stroke, you know—struggles—

I: How is health benefits or any benefits? Do you get any benefits through your job?

P: They were offering a little bit of stuff. I didn't really look at it because I'm covered through my husband. I'm fortunate too. The health benefits I think if they [laughing] are there, they're very minimal, and some of it I think is just not even worth looking into. So, I'm not real educated on that part of your questions, but I feel

like—it depends on where you are. I think if you're with a company that's like—when we're in-home, I think it's different than if you're like in a nursing home or in assisted living. I think they probably have different packages. Ours is—I don't know that it's great, but I'm not—

I: And you just don't know much—

P: But I'm not educated enough to answer that [19.41].

I: So, when we look at reasons for why personal care workers leave the field, you know, the turnover rate is so great, and it keeps the system churned up. Some of the reason—it's clear it's not all about the wages and the benefits and the lack of guaranteed hours, but there's also concern about respect. And their relationships with their supervisor or just—can you talk a little bit about how do you think other people perceive your job? I don't want you to necessarily talk about supervisors, because I know you—you're working with a company that you really respect right now. But what about society in general, how they feel about the work that you do?

P: I think if they have had a loved one or have had a friend or whatever that has needed care, they get it, or if they have done it themselves, but [laughing] I think as a general rule people just like, "Oh, a caregiver. Oh, that sounds fun—read stories and care." You know, [laughing] that's not really all it's cracked up to be. When I say that, when I tell people I'm a caregiver, the people who respond like, "Oh, yeah, my dad was in Hospice," or "Oh, yeah my aunt had somebody come in and help her do her housekeeping and helped her in the morning and whatever." And they get it, but I think unless if you have actually had a person that needed the care or have seen somebody, like a neighbor or whatever, you were over there, and you saw the person, whatever—I don't think people get it [17.38]. Because it's not just you're giving 'em a bath or you're not just vacuuming their house. It's like you kinda get involved in their family. I mean because, you know, let's just say, E, she's, you know, really mad at her son because he took her car away [laughs], you know. And so, yeah, you're just there to give her a bath, but you're hearin' all about, you know, G, her son, took her car away, and she's lost that freedom, and she's ticked! However, she got in three accidents in the past year, and needed to have her keys taken away. So, then it's, you know, then you're kind of siding on the very emotional side of that, trying to take her down, you know, slowly. But hearing her, listening to her—but sometimes I mean if that's—if you have several people in a week like that, it is so draining—like recently I have had a lot of people that just are draining. So, you're exhausted. It's not, you know, it's not just giving E a bath. It's all the other stuff that goes along with it.

I: And what would these families do if—clients and families do if they didn't have personal care workers? What would they do?

P: Oh, my, goodness. Well—

I: What's the impact of the work that you do?

P: People would not be able to stay in their homes. I think that—I'm not saying that all assisted living or nursing homes are bad. That is not what I'm saying, but I think they would pile up, and they would start just putting people in homes. The people that were in the homes I feel like many, many times do not do well. They do not, in my opinion, 'cause I have worked in them—they're angry. They don't get the care that they need—the one-on-one because the people in there are overloaded with—they've got nine other people, and somebody just had diarrhea all over the room, so that takes extra time. You know, it's just things like that. So, you just—I feel like it would just [14.58] be—maybe a real problem. People would not be able to stay in their homes, and I think people wanna stay in their homes. They do better in their homes. In my experience when they come home from the hospital, they send 'em home, they do much better recovery in their own home because they can sit in their own chair. It's, you know, they can do their own thing within reason, but they're comfortable. They've lived there for 30 years, they know it. You know, at the hospital there's like people

running by and they don't know who they are, and who knows, you know, it can be scary, and it can be very uncomfortable.

I: So, with this shortage, we need to recruit people. We need a lot more people doing the kind of work that you're doing' so that people can stay at home. How are we—you said the pay is unsustainable. How are we gonna recruit people? What would you say to people that might encourage them to consider this as a profession or a career?

P: Well, I guess it's going to be—much more difficult in this day and age with or cell phones because people are always on their cell phones, and they don't know how to do the one-on-one. I think that's what's coming up, and I think it's very hard, in my opinion, it's much harder for kids that are growing up to relate to other people, to actually have a conversation [laughs]. I feel a little bit like, now this is a generalization, but entitlement a little bit. So—but that being said, not everybody's like that. I think that it does take a certain kinda person. You're not gonna always find that person, and maybe you've hired the wrong person. We just found that out at my company [laughing]. Its someone who is not doing—

I: Wrong in what way?

P: I think they were an alcoholic [laughing]. Didn't know that, and just kind of—just felt like they could do whatever they wanted to on the job and taking a nap there after hours—

I: So, you said it takes a special kind of person. What kind a person does it take?

P: Well, I think somebody that can relate to other people that actually has caring and compassion. I, unfortunately think, I think a lot has been lost as far as that goes. I feel like—I don't know. It takes a compassionate person. Somebody that can really empathize with their situation. There was a gal yesterday I was talking to, and she was another caregiver from a different company, and she said, "You know what, I really appreciate the older generation. First of all, we have a job because of the older generation," and she says, "But just the lessons that we can learn and the insight that we can get from them, and the life that they've lived, and the history, we can learn from all those things," and I just really appreciated that [11.24] she—and she was very serious when she said this, and I was like, you know, it's nice to see that with people. 'Cause I think we forget. People have stories and things we can learn, and what we shouldn't do, [laughs] 'cause history is full of things that we shouldn't have done [laughing], you know. So, I think we can seriously learn. Going back to that, pay, I don't—pay is definitely an issue. I think you definitely need the trust in the management. You have to have a place you can trust. I don't know maybe a grant of some kind, maybe working towards a goal, like a positive thing at the end. Like the gold at the end of the rainbow kinda thing. Maybe, like I said, a grant or some kinda positive reinforcement I think would get people in there. I don't know. You know, that's a really tough question, but the right people I think you'll figure it out if you hired the wrong person [laughing] pretty fast. But you don't really wanna hire the wrong person, especially in an in-home, I mean. But I think a lotta people that do go into the business they—if that's not cut out for them, they usually don't last very long.

I: So, talking to young people, trying to recruit them in, it's more about—it's not just about the technical skills, it's about the relationships, and the—

P: Absolutely.

I: Yeah. The rewarding part of things, maybe not the pay, but you maybe have rewards.

P: I think that probably would help. I mean like just maybe at the end of their month or whatever, say they weren't late or whatever, and then you get like a \$10 gift card or a \$50—I don't know. Just even a small thing I think—it's nice to get those little rewards, or you know, maybe have—I know some of the offices they have birthday lunches, which is very nice. And you know, when we have meetings, usually we have food, so that's inspiring. I mean to me it's inspiring [laughing].

I: So, let's go to the other end of things and start talking to the young people trying to recruit them, let's say you're talking to the policymakers, people who can maybe make a difference—improve the job conditions of personal care workers, what would you say to them? What do you wanna tell them in terms of what you do, and the value it has?

P: Well, I think it's, honestly, it's just as important as the fire department. I think it's just as important as nursing. I think it's just as important—maybe if not more because if people aren't being taken care of, and they're caregivers, their daughters or sons or whoever that person is, they're droppin' like flies. It's not health—then they're not being productive in what they need to do, so that's a problem right there. They're not doing their best in what they need to do in their everyday life, maybe for their family, maybe at their job or whatever it is they need to do, they're not doing the best, and they're [7.22] obviously not doing the best for the person they're caring for 'cause they're fried; they're done. So, that's a problem right there. The next problem is if we're in there and have enough hours with people, things can go south. Like maybe a wound that, okay, well, I only see you twice a week for a couple hours. The next time I see you, you've scratched it off, and it's down to the bone. I mean those are kinda things that, you know, I think—those are, you know possibilities, whatever that can happen. I feel like it needs to be a higher priority because I think—like that situation, if that didn't get to that point, they wouldn't be goin' in the hospital. You know what I mean? Maybe we could have done something different, and you know, that's kinda healthcare stuff, and I'm not necessarily healthcare in mind. I'm more, you know, just the care part and bathing and things like that, but my point being is we could have noticed it before it got down to the bone, and not to the hospital because then you got all these other expenses. And it didn't have to go that way, so I think it's just preventative. It's better for people in the end I think as far as emotionally, spiritually, physically to care for people in their homes. I think it's the best solution. If we can keep 'em in their homes, I think it's better for everybody.

I: So, in the last few minutes what recommendations—do you have ideas for the policymakers and how they can fix this? Any recommendations?

P: That is a deep, deep thought. Well, I guess, you know, like one of the things I said, maybe if they can do any kinda grant or I don't know maybe put a little more money towards caregiving. I don't know how that works.

I: Wages.

P: Wages, for sure. A support system [4.52] maybe for people who have had losses in, like I was talkin' about earlier—losses in their—from their clients. Definitely—I know that there are things out there, but definitely for the caregivers that are in the homes that are calling us in, like the families, they need help. I mean they need help desperately, and I think one of the hardest things that I have seen is the transfer from, okay, E is independent, and she has been, you know 75 years, and now she can't be by herself anymore 'cause she almost burned the house down. You know, and then so that transfer into, okay, the next step, so now have to have a caregiver. How do we go about that? I think there's a missing middle piece there. I don't know if somebody else has any ideas of how to fill that middle piece in, but that's a problem because it's a hard transition for everybody because the caregiver's feeling guilty that she has to, you know, take some freedom away from her mom, and the mom's mad because she got her freedom taken away. So, it's—there's a lot of animosity sometimes, and I feel like there needs to be a bridge there, somehow. I don't exactly know how to do that, but I know that can be a missing piece.

I: Anything I haven't asked you that you wanna talk about? Are there final words that you wanna make sure that the world hears?

P: I guess just be nice, be kind, take some time to listen to the grandmas and the older people, and you know, go to a nursing home and just find a lonely guy and talk to him. I mean or somebody on the street. I do

that often. I'll just start talkin' to [laughing] somebody, just the world is so ugly right now. It seems like everybody's pickin' up a gun or a knife, or you know, we hurl words at each other, and try to laugh a little more. Try to show kindness. They've started saying be kind or be nice. I like that. I like that, and I like seeing the communities coming together and doing things, and I just think it's important though because our—I feel like there's a huge gap between the young people now, and the seniors, and if you don't stop and listen, you're not gonna hear their stories. We're gonna lose the past. It's just gonna go bye-bye, and nobody's gonna know about it, and there's so much to be learned—to learn from them.

I: Those are really wise words to end on, and I want to say thank you so much, H, for the work that you do, and for sharing your stories with us. That was wonderful.

P: Thank you. I have one last little thing that I kinda made up, so I just wanted to read this. You love them, you lose them, God gets to choose them, it leaves a bruise then.

I: You wrote that. Yeah. Well, it's bringing a tear to my eye, so that was beautiful.

P: Thanks, [laughs].

I: Yeah. Very nice. Thank you for writing it and sharing it.

P: Thank you, for having me.

I: Yes. I'm going to move out of the way now, and let K work his magic.

P: Take my 150 pounds off.

I: So, thank you, that was great.