

Fading Memories Podcast – When & How to Choose In-Home Care

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JEN: Welcome to Fading Memories, a supportive podcast for those of us caring for a loved one with memory loss. Before we get into today's show I'd like to remind you to please follow me on social media you can find me on Facebook at Fading Memories podcast. Instagram is @alzheimerspodcast and our brand new YouTube channel where you can actually see all the exciting conversations and that is also fading memories podcast. Check us out and I hope to see you online very soon.

With me today is Gina Murray. She is with Aware Senior Care and she is going to talk to us about how to select in-home care for our loved ones and hopefully we can touch a little bit on when we should be doing that. So, thanks for joining me Gina.

GINA: Thank you for, thank you for this, Jennifer.

J: You're welcome. So when we had to do in-home care for my parents, we did not have the opportunity to do it, what I would consider, correctly. The hospital had said that they were done. They were releasing my dad. Basically come get him and I had to put the brakes on him being discharged because we didn't have anybody, anything set up for them in their home. My dad's memory had gone south because of the toxins from his, his donated kidney was failing and he didn't want to be back on dialysis. So when he left the hospital, he went on Hospice. But, we needed to also have in-home care for my mom who has advanced Alzheimer's and for him because he just thought he was getting over the flu.

So I literally had 24 hours to figure out what in the heck we were gonna do. So, I had to pick an in-home care agency with gut instinct.

G: Wow.

J: Thankfully, it wasn't a disaster. About a third of the caregivers were just fantastic. Maybe a little more than a third were good, you know, average to better than average and there were a couple that we had to say no we're not, you're not coming back.

And yeah, so it's like I guess gut instinct worked .

G: I'm glad.

J: Me too. Because it was really hard the first evening that we left my mom there with the caregivers or a caregiver and we had to drive away. And it was like worse than the first time I left our daughter with a babysitter, which was many years ago.

G: Right, right. It's that same feeling of "Am I doing the right thing?"

J: Well yeah, because they're so vulnerable. Like, my mom had no clue that what was going on and you know, all this upheaval and my dad had been in the hospital for 32 days. So, it was just, it was and it would have been traumatic even if she didn't have Alzheimer's.

G: Right. And you're also dealing with the whole hospice, realizing what's going to happen and-

J: Yeah, that was kind of a diff-, I don't want to say difficult decision. It was a little bit difficult to admit okay, this is his advanced directive. I actually had to fight a little bit with his kidney doctor, nephrologist. She knew what his advanced directive was and she called me up and said well now you know, because your dad's memory isn't back all the way. Not sure why she thought after 32 days it would come back 100 percent. It never did. Now, somebody's gonna have to drive him to dialysis and sit with him. And I thought lady, do I look like I am independently wealthy. Do I look old enough to be retired? I just turned 50 and I paused and I said you know he doesn't want to be on dialysis.

If somebody has to go and sit with him three days a week, then we need, then we need to call hospice. That's what he wants and her response was to hang up on me.

G: Oh, I'm sorry, oh.

J: Oh yeah, she better not ever walk in front of my car because she knew. It was his doctor. It wasn't the hospital's doctor. It was his personal nephrologist. So yeah, that was my, my first experience that I, I thought, oh this is great.

He did end up in the hospital. He was home for three or four days and he fell and the care, the caregiving staff that was there. The ones that I had to hire and a big panic and using my gut instinct. You know they called the hospital and I said send him to the, the one that was in their hometown. Not the one that was closer to my sister and I. And when the nephrologist from that hospital system called and said his, basically his heart rate would drop really, really low when they did dialysis.

And they were trying to balance it. She talked to me for 20 minutes. The first 15 probably, was on everything they were trying to do for him to basically keep him alive. And I just finally said you know, we're in a dark grey area of not honoring his advanced directive and she goes oh okay, left turn right into the hospice. I was like oh this is how it's supposed to work and then the day that I'd already done all the paperwork for hospice and stuff and that was a little difficult.

I went into his hospital room and okay, typical health insurance, they're doing dialysis on him. I'm like what the heck? You guys just trying to jack up the bill because that is the only reason I can imagine that you're doing this? Whatever. And so there was a different nephrologist in there and she's talking to me and I must have given her that look because she goes Oh, let's go talk in the hallway. Then I told her yeah, we're gonna do Hospice and she just goes that's probably a good idea.

I'm like oh, thank god like I don't have to fight with anybody ever again. So, that was the story of everything going on with my dad and when and how the circumstances of choosing an in-home care. So it was definitely not a scenario that I recommend.

G: Right, right.

J: And so I've been trying to find somebody that would talk to me and the listeners about exactly how we should go about doing it. And what are the signs like if you're the spouse's caregiver, when should you bring in help? You know, these kind of you know, we want to make sure we're doing the right thing for ourselves and our loved one and we don't want to spend money sooner than we have to. But we don't want to wait too long. That's kind of what I wanted to talk to you guys about today.

G: Right, it's because sometimes bringing you in a little bit of help early prevents the falls. Prevents some of the big you know, disasters that can happen. So, I think the best time to start is right now when

there's no crisis you know? Just to start getting information when it's nice and calm and you can collect information and learn what's out there.

J: That's kind of what I thought. You know, obviously you don't want to wait till someone's in the hospital or you're there at the point if they've got memory loss like my mom-

G: Yeah.

J: That you can't leave them alone at all.

G: Right.

J: But I wasn't you know, because I didn't have the opportunity to do it quote right, I wasn't sure how early in the process it would really be smart to start. So, earlier is definitely better than-

G: It is. We, we wholeheartedly encourage, we, we do educational seminars in our community and we tell, you can call our office just to ask questions. Just to say you know, what services do you provide? Do you have minimums? So, you just store all the information away. Hopefully you never need it. That's what we tell them. We hope you never need our services. But, if you do, you can make an informed choice. So when you when people do have time, many times they turn to trusted friends, the clergy, your physician for recommendations. Which you know, people being individuals what I might need for my parents might be very different from what the next person needs for their spouse, so.

J: I think it would be easier to determine what you like, we had to just figure it out on the fly.

G: Right.

J: As most of my listeners know, my husband and my daughter and I were, had planned a lunch. An afternoon right after Thanksgiving of 2016 to spend time with my parents and do some Christmas decorating for my mom. And my husband walked in the door and my hus-, my dad said so how's the credit union business treating you? And my husband was like oh crap. He had not been in the credit union business for 13 years.

G: Wow.

J: And so he knew something was wrong. And if I had known what was going on if I had known what had been in his mind previously, I would never have taken him to the hospital. I would have called hospice right then. Which would have been a challenge because of family and stuff.

G: Right.

J: He just assumed without dialysis that he would pass away within a couple of weeks. Which wasn't really good planning because my mom would have assumed that he was asleep until somebody else showed up. That would have been really not good. So, I, I think his memory was not fantastic probably in the last six months. Maybe longer. Of his life. But she is so bad or was so bad that it, it was really easy to miss it. It was after he passed away and I was looking back and it was like oh yeah, that was a sign and that was a sign.

G: Right.

J: The, the biggest struggle we had with him and the in-home care givers was he didn't realize he was on Hospice because his memory was bad. He thought he was getting over the flu and being you know the typical male of that generation he didn't want any help from these ladies.

So, he would, you know deny, refused help. And he basically lived in their living room. Which was a step down. So, getting out of the living room, down the hall to the bathroom required stepping up one step and he obviously miss, misnavigated it one evening. Hit his face and that's how he ended up back in the hospital and that's how he ended up actually on hospice, but.

G: Wow.

J: Yeah, he fought with them about help all the way until the end.

G: Right.

J: It was not fun.

G: Well, it's not uncommon, honestly. In fact that's like, that's very common. It's, that's what's hard. So sometimes we say well we're here really to help your wife. We're here to help you give your daughter some peace of mind. You know your daughter just wanted us to be here. You know we know that you don't really need help. But, while I'm here, what if I do X Y & Z for you? So, we do understand it and that generation is not used to accepting help. Sometimes they can be really resistant.

J: Oh yeah, he was all that, like literally until the last week. It was I mean, ugh. It's, it's only been two and a half years. So even thinking back it's like, ugh. It was not a pleasant time.

G: No, no.

J: You know and then of course well that he was because he was diabetic and his blood sugar was completely out of whack all the time. He wasn't exactly pleasant and I don't think I've ever told this story. But there was one day, my sister wanted to keep him on the insulin because obviously your blood sugar's out of whack, you don't feel good.

G: Right.

J: Hospice would have preferred just to stop because it was an injection with a needle and the caregivers couldn't do it. They had to help him do it and one day he was just obstinate and obnoxious to this poor gal. And she was one of the better ones and you know, he was just exceedingly rude and obnoxious. So, I thought let me go, before she like packs it up and leaves which I would have been perfectly understanding if she had done that. I said let me go in and see if I can diffuse the situation and help her help him. And I did and he barked my head off and I thought, I don't need this crap. And my husband and I were in the kitchen and we had our heads together and we were talking probably about dad and what we were gonna do. My mom pokes her head between the two of us and says well you know, you can just go in there and tell him to drop dead. I was like, oh my god.

G: Oh.

J: Like, this is really sick humor. But, it was pretty funny. It did sort of lighten the moment.

G: Right.

J: You know, in a really morbid kinda way. But yeah that was, that was what we all got to put up with was you know, just he kept saying I'm trying to get over this cold or over this flu or whatever probably based on how he felt at the moment. He was just obstinate. He was obstinate all his life but it definitely didn't get better when he was on Hospice.

G: Right.

J: So, what, what should I have looked for it-, I mean we got so lucky. There's, there was like three. There was one gal who was actually like a retired geriatric nurse and she came in on Monday and Tuesday mornings. She would come in on Monday. She would make sure the pill boxes had been filled over the weekend, which we did. She took inventory of the food. She, I mean it was like she had that place running shipshape.

G: That's great.

J: Yeah, she was wonderful and my brother-in-law at the time worked for a grocery store. So, she would take an inventory of what was available and what they needed food wise and then she emailed my sister and my brother-in-law would, you know, get it while he was at work and deliver it on his way home. It was a great system.

G: Wow.

J: So, we, like I said, we got very, very lucky. I guess my gut instinct is pretty good. But, you know looking back I think, like you're saying, I don't, I don't remember other than the two, two gals who were just beyond above, you know, just fantastic. I don't think any of them ever, ever talked to my dad like you were saying. Well, we're really here for your wife and so you know, is there a way of I don't know screening is the right word. But how would you go about, well, why don't you tell us how we should go about selecting?

G: Sure, sure. So if you have plenty of time and you're not in that scenario and you're looking for information, a really good place to start is reviews on third-party websites. Places like home care pulse, caring com, senior advisor dot com. So these are where you know, the clients or families can post reviews. You're, you know not necessarily solicited. They're honest and you get real feedback from real people. You can type in your zip code in these and find the best of home care in your area. They'll give you the reviews. They give you insight into the quality, what the families are saying, any awards the companies have won. You know kind of validating their quality. That helps you narrow the search. Like, okay, now I have five companies, three companies I'm gonna talk to. I think it's important to decide what some of, what's most important to you and what do you want to know from the company. Personally because I had a situation with my dad. I took care of my dad at the very end on Hospice and I didn't even know there was such a thing as home care. This is 13 years ago. So I was like how are we gonna do this? This is, this is crazy. So I would want to know why the home care agency owners are doing it?

J: That's a good question.

G: You can teach skills, I'm a registered nurse, but I can't teach someone to care and I believe-

J: That's true.

G: It trickles down from the top. That if whoever's running this agency is doing it because they care, because they've had experience, because they sat in your seat and walked that walk. That's the way they treat their employees. For us, there's nobody more important than our caregivers. Quite frankly it's harder to find great caregivers than it is to find clients.

J: I've heard that.

G: So, you know, we know the most important thing is to take care of our caregivers pay them the best we can, the benefits, make them know that they are so appreciated and it's trick-, that's, that's what trickles down. You take care of your caregivers and you teach, make sure they have the right skills, you know? How do they, an agency know the caregiver has the skills to take care of my dad? Do you know how to handle dementia and how to just roll with it when dad's saying "Have you seen your mother" and "Well, mom's been gone for ten years?"

J: Yeah.

G: You know? Well, you know I haven't seen her right, you know, recently but are you gonna be in the living room? I'll let her know you're in the living room if I see her and you just enter their world. So, those aren't really things you learn in a book. But we make sure our caregivers are equipped with those tools when they go to someone's home where there's you know, folks with memory issues.

19:09

J: Yeah, because asking somebody with a memory issue or asking them questions or saying the wrong thing can just trigger-

G: Oh.

J: Very negative situation that you don't want to deal with.

G: Right. The last thing you want to tell someone with dementia is well, you know your wife's dead? What?

J: Yeah.

G: When did that happen? Why didn't they tell me? And like you said that could trigger a horrible situation, so-

J: My mom is always saying we've had to do several extra doctor appointments this past summer and whenever it's, it's always when I have to take her to the doctor I get "Oh, why is my husband not doing this? And she just, she just rants and raves and it's it's already stressful to take her to the doctor and having to listen to her you know basically complain that her husband-, she's actually told me, "Well, I don't know why he's being such a lazy son of a gun (noises)." It's you know it's just like every nerve is just getting scraped at that point and I've learned to say when she says "Well why is my husband blah blah blah? I'm like I don't know, you tell me.

G: Yeah.

J: So and that usually shuts her up because she doesn't know why she's thinking on it and then you know in a couple minutes later she's complaining about him again. But it's you know I could only imagine what would happen if I said you know dad's dead?

G: Right, right.

J: First off, that would probably confuse her because she thinks I'm her best friend.

G: Right, because you're way too old to be her daughter.

J: I guess so.

G: Yeah.

J: So you know, it's a norm. We're going to the doctor. I'm already a little stressed which of course she's probably feeling and if I said well you know Chuck's dead? Oh. Well, that would just be terrible.

G: Right, right. Because you know, because you know her brain is broken. You know she has brain failure and she's remembering the best she can and it's really hard it's uh, you know, I lived that with my mother-in-law. Because I've always known to be an extremely intelligent woman and on and on and to have her say "Now, who was that nice man with you?" "Well that's, that's your grandson who's just 34. But you know." "Well he's, he was very nice and I'm thinking, oh. Oh." You know? You used to read to him and took care of him.

J: Yep. My mom doesn't remember my daughter who's the oldest of the three grandkids and she's older than my niece who's the second grandchild by 14 years. So, she had grandma to herself until she was, you know, an obnoxious teenager and I'm sure she was happy that Grandma got to deal with somebody else because you know at 14, we don't really want to hang out with her grandmother too much. She did because they were so close. But she can't, she doesn't handle that grandma doesn't remember her at all well.

G: Oh, it's heartbreaking.

J: It is very hard and she is a good support for me because she'll say things like "I don't know how you do that every week, I don't know how you put up with that" and it's like well you know I can't just abandon her in the memory care residence because that's not right.

G: Right.

J: You know, there's days I want to.

G: I hope you take care of yourself because that's really important.

J: I do. I go to the gym every like three days a week. I ride my bike 4 days a week.

G: Good.

J: I'm very, I'm very militant about my exercise because if I don't, I start feeling kind of bleh and I start getting really kind of not nice. So.

G: Right.

J: Self-care is definitely important and my husband and I were just in Colorado for five days. He went for a conference and I said "Well I'm coming, too." He's like why? You're not invited. I'm like I don't care

G: I can do my own thing.

J: He said what are you gonna do with yourself? I'm like have camera we'll find things to do. It's like no big deal. I am resourceful. I'm sure I can find things to do and I did and I had a great time and then I come back and this week is bonkers, so.

G: Right.

J: It's not always the way. So, we're looking online at third-party review sites if we don't have friends and family that can make recommendations.

G: Right.

J: So, now you've narrowed it down to you know three to five companies you want to talk to. So, what kind of questions should people be asking? Because I don't think I asked enough. Because like we got lucky.

G: Right.

J: Just in this short time we've been talking I'm like oh yeah there's some questions I should have asked

G: Um, what, what specific services do you offer? Some agencies only do companion care, where they'll come in and do household tasks, transportation, make meals. Some do personal care as well as a companion care. We added nursing services onto our, we do personal care in home and companion care because like you said, the nurse, the caregivers can't administer the medicines and we do a fair number of Hospice clients. So, they'll hire us and we'll have a nurse overnight so the family can sleep and if the client needs medication administration, the nurse can do that and the family can actually sleep. We, sometimes we have nurses around the clock because they're giving injections. They're doing IVs things like that. I would ask if there's a minimum number of hours. What's the shortest visit you can do? Can you come for two hours or does it have to be four? Can I do two hours once a week or does it have to be a certain number of days of the week? So, different agencies kind of specialize. We decided we have longer cases. So we have caregivers that want to work like 8 hours, 8 to 12 hours so that's what we do. But there's other agencies that'll do you know, two, three hour visits because not everybody needs a lot of time. It's important to know the costs and that way if you're asking several agencies, you can compare their hourly rates. But then ask them, too, is it a different rate at night? Is it a different rate on the weekend? Some people do that, some don't.

J: Yeah, the three I talked to were all the same price. It was one price for one person. It was a minimal amount extra when my dad was, we started with them before my dad was out of the hospital, I think for about close to a week. So it was just mom and then he was home for about a week and was in the hospital for a week. It was a little confusing with the billing because it was like, well you're only billing for one right now. Now you're billing for two. Now we're back to one, now we're back to two.

G: Wow.

J: It was crazy. But yeah, they were all the same and I never asked about minimum hours because we needed 24. But I've got I know, there's a gal in my support group that needs, she needs a couple hours a day. Not every day of the week and she's just had nothing but trouble. So, I'm gonna suggest to her she's at the group meeting tonight, to check these third-party review sites and I think she's only been able to find companies that will do a minimum of four. Which I guess she thinks is too many.

G: Yeah.

J: And she's had a lot of problems with agencies.

G: It's, you know, the shorter the hours, the harder it is to get a consistent caregiver. That's a pretty universal thing. We have a four hour minimum and then we start to tell the clients what, what else that caregivers can do. What el-, what other burdens can they take off, say the clients like, you know, we let them change the sheets and prepare get dinner started so when you come back home, the house is kind of straightened up. Dinner's ready and you can have dinner you and you've had four hours to yourself, so.

J: Yeah. I know her husband goes to the local Adult Day Program at the Catholic Church that's close by. So, that's probably the biggest reason she doesn't need as many hours.

G: Right.

J: And I've told her you know, go through the church. There's probably a you know, retired gal maybe you know a younger gal with kids in school that could help you know a few hours a week. It doesn't they don't need full time, they don't want full time. Because I know my grandmother's friend did that before she passed away. She had a from her church that was her like in home companion at the end. I don't think she I don't think. It increased as the as the years went on.

G: Right. There's a website Care.com that's for private caregivers and they run, they run their own background checks.

J: She would like that. She's pretty regular in our meeting and it's tonight. So, I'm writing down notes and I could take it to her and say hey I talked to this person today and here's what, here's some things you might want to try.

G: Yeah that sounds like the perfect scenario for a private caregiver. It's you know, you're still then you're, you've got to be careful because you got to check your homeowners policy that if that person gets hurt in your home and you've employed them. Does your homeowners policy covers their, their injury and what if something gets stolen? You know because with agencies, our caregivers are bonded. We carry the liability insurance. We are the back-up plan so that if a caregiver is sick, we are responsible for making sure somebody gets there. So that the person gets the care which can be challenging.

J: Yeah I mean it's hard enough with just regular employment with people. And then when you're dealing with somebody that's got you know special circumstances like memory loss or lack of mobility you know they're vulnerable people.

G: Right.

J: You know, it's, it's a really scary decision to have to make.

G: It is and you should ask the agency what if I don't like that caregiver? You know how responsive are you to say okay, I want somebody else. This person is not, not a good fit you know? Whether it's just a chemistry thing or I don't like the way they treat my dad.

J: Yeah, we had one gal. She was younger and nobody and we did a little research on essentially dying from kidney failure just so we were aware of what Dad would likely go through. And things happened

that were never on the internet and I would think everything ugly would be. But he ended up with so much fluid like in his legs. This is a warning. It started leaking out. So he would walk from the living room to the bathroom and there would be puddles. And the hospice nurse said this is how we take care of it. Which of course he didn't like. It was a big problem. Well, one of the caregivers I think she was there in the evenings because I rarely saw her she did not want to deal with that at all which I don't blame her I had to read the note from the caregiver if the company we used had an app. So I was always getting no notations on the on their time with them. So I got notes three times a day and I read that one during breakfast it was like oh my god this is disgusting. So, I don't blame her for not wanting to deal with it and like I said he was very obstinate and refusing help. So it was gross and he wasn't cooperative and she just basically said I'm not gonna deal with it so I just called up the the manager and said you know this is what needs to be done and she doesn't want to do it. So, please don't send her back. It was very simple.

G: Right.

J: Because I wouldn't have wanted to have to say that to her face. I was already stressed out enough. I didn't need that and that was enough.

G: No.

J: I think there was one overnight gal that we basically said please don't send her back either. That was at the very end and it was obvious that she hadn't been taking care of him well because the gal that was the nurse that came in on Mondays and Tuesdays came in my dad was completely drenched his sheets were drenched and the overnight gal said she had just changed him like an hour or two before. It was like you know and the the really on top of it gal, she didn't even bother to call me or my sister. She called the hospice nurse and they all dealt with it and that was about it was like a little less than a week and a half before he passed away. So we were at the very end. But it was a lot of drama between dealing with that situation and dealing with him and yeah, it was.

G: Oh.

J: But you know having telling the agency don't send that person back made it, man it was already hard enough because you know? You don't know exactly what had gone on and you didn't, I don't want to accuse people. But it was just easier to just say please don't send them back.

G: Right, good.

J: Make their own investigation or whatever.

G: Yeah. And that's important. That's the last, you want to be the daughter. I mean because it, in everything you're handling this is still your dad. This is you know and you have, it's a it's like, it's a sacred time and that's a lot that you went through.

J: It was a lot harder because he, we were following his advance directive, following his wishes. But he didn't know that. So, it was just a constant battle and he and I went from having a good relationship to one where I'm like I went once a week, I took his mom. She outlived her oldest son. She's my Nana is still with us. She is 101 ½.

G: That's great.

J: Yeah, a little onery, too. That kind of runs in the family but that's okay. And it's just, I just, I went for about half a day once a week. That was all I could take because he was just so rude to me. Just verbally abusive. Not abusive to my sister verbally and I thought man is this just like when we were growing up. My sister's younger and it, it was hard and it's, when I think back on it I'm like man, you know, I put up with a lot of nonsense and I don't, you know obviously he, he didn't appreciate what we were doing for him because he didn't, he wasn't aware.

G: He didn't, right. It's, it's so hard to look at your dad go that's, that's the disease talking. That is not my dad talking.

J: Which was on November 1st 2016 and he seemed like my daddy. He definitely did, wasn't well but that wasn't a hundred percent of surprise. And so three weeks later we go and he thinks it's 1998. It was like oh my god.

G: Wow.

J: So, it was panic mode from that point forward and it was hard to see, look at him and go this isn't him. This is the disease.

G: Right, it's too, yeah. It's like no wait, he was just here a minute ago.

J: Yeah, it's like why did you have to revert back to this onery person? It was not fun. So, at least now I know different things to look for for hospice for my mom because obviously she would be clueless as well.

G: Right.

J: And we're not up to that point yet thankfully. But at least having gone through this experience the hospice company was great. My friend recommended them. She said I used X company for my mother. They were terrible. We used Y company for her husband's mom or dad, I can't remember now and they were great. So, I just called them and I talked to one other briefly. But, they were very pushy and my dad was still in the hospital and my sisters like we're not up to that point yet and I'm like yeah, that's what you think. I think we're a lot closer than you want to admit. So, it was a miscommunication maybe. I'm not sure if they realized I was just trying to get information.

G: Right, see that's another thing that, talking to any agency whether it's hospice or home care, how does that person make you feel when you're talking to them? When you call into the office, are they welcoming and they're listening and you know, maybe on you're not ready for home care. But you know what? Have you considered this to give you other options? I mean, my husband and I own the company we started it five years ago. And we will never have a sales position. I said there's no room for sales in this agency. It's about information and this is what we can do and if we can help you, we're going to be happy to. But we're never gonna sell because I personally hate that. I hate pushy.

J: Yeah, they weren't really I don't if, this might have just been just a bad vibe combination. I don't, it's hard to think back about it because I also was trying to gather information without upsetting my sister and she came in and realized who I was talking to. It was like, blah. So it was kind of not a great situation at all and maybe that had something to do with it. But

G: Right.

J: I've learned you know that you need a different kind of hospice care if somebody's got memory loss and definitely want people that understand how to deal with somebody with memory loss as a caregiver. That way they don't say something that triggers something unpleasant.

G: Right, right.

J: Which I don't think ever happened with mom and well like my dad was easily triggered. So, that's, that's not a fair comparison. But I don't think they ever said anything that upset my mom and I know he passed away late in the evening. It was like 10:30 at night and so my husband, my sister, and I ended up there really early the next morning.

G: Yeah.

J: And they were comforting my mom and talking to my mom. I mean, it was very obvious that they were handling the situation really well in our absence and I think that gal had only been there a couple hours. I'm trying to think. They were like 11 to 7 AM. So, she'd only been there like maybe an hour and a half. She walks into, ah! I'm assuming they told her before she showed up. But, still it's like that's gonna be a really tough part of the job.

G: Right.

J: Is dealing with somebody with memory loss and you know the spouse just died and the kids show up and the yeah, yeah, yeah. I was like yeah.

G: Yeah, you don't need a sales position when you're talking about people in vulnerable positions and at the end of their life. Yeah, no it's not.

You know, one question you ask is how do you know when you need care? How do you, and that's, we designed an assessment. We have it on our website and you don't have to put your name in. You don't, we don't ask you for your personal information so you can take it and we will never contact you. But under our resource page, it's our take our home care self assessment and it helps you kind of paint a picture of some of the issues. And it's interesting when we have adult children assess their parent and the parent takes it. It's like no I don't need help with that. No that doesn't happen to me. It's really quite fascinating. It goes through everything between the activities of daily living. You know, the bathing grooming, dressing, and then the independent activities of daily living. Managing finances and transportation and shopping. So I mean we found that Tim's mom had memory loss when after his dad died, the bills weren't getting paid. There was collection notices and it mostly not because she didn't have the money. She just never did the bills and she didn't know how to write the checks. It was like, uh-oh.

J: And that's such a common scenario. That's usually one of those, you know, red flag warning signs that you miss until it's like a nightmare.

G: Right. When did this happen?

J: Collection notices or the bank's about to foreclose of them on the house that all they owe is property taxes like blah.

G: Yeah, yeah.

J: I was in a caregiving class you know for family caregivers over the summer and one gentleman, he took family leave because he was going through a lot in his life. But, he had to get his dad's finances straightened out and it just it was so many hours on the phone. Which, to me is just immoral. It's like you should not have to jump through 15 hoops to get stuff taken care of. But what happens and I've talked to a lot of people where this has happened. But, they don't have the authority to transact on their parents financial behalf.

G: Right.

J: And so they got to go through all that nonsense while they're trying to hold off you know collections and foreclosure.

G: Right.

J: You know.

G: Yeah, that can be a full time job.

J: That's kind of what he was finding and you know, I think it took him a couple months to get everything straightened out to get, you know, like a process in place and just kind of get everything kind of calmed down. So, and of course his Dad didn't really think he needed a lot of help either. Which is pretty typical.

G: Right.

J: Like they don't know they have memory loss.

G: Right.

J: Which is really interesting because I know when my brains not working right. If I'm tired or stressed out. I mean I could feel it. It's like I need to sleep or I need to calm down because brain processing is not working at a hundred percent right now.

G: Right.

J: So, it surprises me how often, like my mom now says things like and she's at the stage of Alzheimer's where she uses the wrong words a lot. It's actually gotten a lot worse in the last month.

G: Aw.

J: So, sometimes she'll say things and I'll just be like what? And I try to say things like I'm not understanding what you're asking or I didn't quite understand that or I try to always put it on me but she still gets really frustrated.

G: Right.

J: Sometimes she'll say, she'll get frustrated and say my brain is just not working right and then the other day she actually said well my brain is just dying and I thought that's self-awareness or is that just a comment?

G: Wow.

J: Yeah, it was kind of like okay, I don't know how to take that statement. She made the comment my brain doesn't work so well anymore a lot.

G: Aw.

J: Monday was the first time I'd ever heard well, my brain is dying. Like oh, you think?

G: Wow.

J: Yeah, that's really where the brain is so fascinating and strange.

G: It is.

J: It's you know it's definitely our final frontier. It's not space. People think it's space. It's not space. It's our, it's I don't know how many decades or more decades it's gonna take to discover everything there is to discover about the brain. It'll be a, I bet it'll be a really long time.

Yeah, I think we're just scratching the surface. So, let's see, so you got this, so what, can you like kind of give us some examples of what's on the assessment so people can kind of think about you know, sometimes you got to convince yourself you got to fill those things out before you actually do it?

G: Right, right. It's like I, I manage my finances on my own. If you could no longer drive your car. could you remain in your home? And it's pretty amazing I mean, where we are, we have very little public transportation and it's like oh, you can't walk to the store and very few of our clients can figure out Uber. So, well that's okay my daughter will do it. That's okay my daughter I'll handle that. How many times have you heard that?

J: A lot and because of my grandmother has burned out my aunt.

G: Yeah.

J: For that exact reason. My grandmother bless her heart thinks that families should handle it.

G: Right.

J: And, you know I'm almost 53. My sister is four and a half years younger than me. She has school-aged children. My husband and I are both self-employed. I'm like I, I don't call her as often as I think I should because I know if I'm not careful, she will suck me in. I need this, I need that and it's like and how do you tell somebody who is 101 "I don't know time for that, thank you." I don't have that kind of spine. I just you know, I can stand up for myself pretty well. But you know, if she needed something I would probably kick and scream and carry on and handle it for her and not let her know I was kicking and screaming and complaining.

G: Right.

J: You know and that's what's happened with taking my mom to the doctor. They just think, oh we need to have this ultrasound done. Well it's like a three-hour process to drive over there pick her up, take her to the get the process, take her back, get her settled. You know I don't have three or four hours every week to just dedicate to taking her to the doctor and the doctors don't seem to understand that. It's, I get, I get the impression they think I'm not being very smart.

G: No, it is. It's looking at what is taking up your time. So, we've had folks say now if you could-, I just, my mother wants to go out to lunch. If you could just take her out to lunch I just you know, when I go over there I do, I clean. I have to you know, do this, I have to do that. I said, well what if you had a caregiver that did the tasks and then you would have time to go out to lunch with your mom if the laundry was done when you got there. If meals were prepared when you came over, then when you got there, you can actually enjoy being with your mom and do some of the things that you know, relax together. Because she's said oh, whenever I get over there, I've got ten thousand things I have to get done.

J: Yep. That's pretty typical and I think there's like volunteer type agencies in different areas that would do the take out to lunch. But obviously your mom would rather go to lunch with you than some church volunteer that she may or may not know.

G: Right, right. So it's looking at that. It can just be overwhelming. I just say start before there's a crisis. Ask, ask, ask and yeah.

J: Yeah there's so many things I've learned in the last two years doing the podcast, about 18 months.

G: Right.

J: On what you should do. I mean we, my dad did not ask for help. He did not want help. He did not accept help. So, it was very easy to say things like, I would tell my husband you know, my parents are definitely getting worse. I'm getting worried that they're gonna need more help and how are we going to balance this? They were 20 miles away. It was about 35, 40 minute drive. You know, how do we do more for them without losing time with clients or time to take care of ourselves or our own household and I never found that answer. So you know it just, we ended up in the crisis scenario and now I realize that was there's a lot of things we should have done. You know like the, he and I or my sister and I should have talked about well I, I guess we just figured dad would be invincible. I mean, it was, he was had chronic illnesses. It was obvious he would not outlive mom.

G: Yeah.

J: But, we never ever like I guess-

G: Talked about-

J: Admit it. Yeah, we didn't talk about it. We didn't admit it to ourselves, much less each other. So yeah, it's like yeah we kind of kind of failed on that one. But that's pretty typical from what I've understood.

G: Well, you don't know what you don't know.

J: That is true.

G: So you get into it you're like oh.

J: You're like oh yeah, duh. Well it's smart to do plan ahead I'm and I'm a planner. I like to have everything lined up. I want to have contingencies built. Like what's the worst-case scenario? Okay this, I will handle them. This is how we're gonna hit-, I'm a planner so to have zero plans going into this, this time of life with Dad was, it was not fun. Gina is with Aware Senior Care. Is that Aware Senior Care.com?

G: It is.

J: Okay, so you guys can check out their web site and that assessment and have everybody fill it out so you can average the answer.

G: We actually even have a section under resources of the questions to ask a homecare agency. There's a lot of things under resources on our website.

J: That sounds very useful. I will make sure that you guys or all that is on the show notes. So, people can just click through and fill out those forms. Read those questions and if they have more, they can call you?

G: Sure, sure.

J: Is there anything we missed in what people should be thinking about when we're getting to the end of our life with spouse or parents?

G: I think the hardest part is that everybody's journey is different and what works for one family may not work for another and there's no book. People keep saying well, how am I supposed to do this and I said it's a day at a time. It's constantly changing. I mean our care, our client's needs, we have to keep changing and evolving as our clients needs change, so.

J: That's the one thing I've noticed with my mom. She's always been very physically healthy and we thought she had a bladder infection and that led us down to this other path where she's got, she's got issues that are not related to the Alzheimer's. And it's, I'm glad we have our support group tonight. I'm gonna talk to our facilitator who's a retired nurse and I think I'm mostly looking for her to validate what I'm thinking. But I'll obviously listen to her opinion. But I never expected all these doctor visits and I just expected my mom to go from Alzheimer's or maybe pneumonia.

G: Right.

J: Not either a cyst or a tumor. They don't know what it is and they want to do a biopsy and I'm like I don't think so.

G: Right.

J: So it's been an interesting journey. It's like and she declined quite a bit at the beginning of the summer and then she declined some more at the end of the Summer, which is unusual for her. She's always declined and then plateaued for a long time. We've been doing this for about 20 years.

G: Wow.

J: Yeah and I've told people I'm done. I'm ready and now we have this other health issue I'm like well maybe I'm not.

G: Right.

J: I mean I am but I'm not it's like okay wait a minute now I have to it's like reorient my thinking.

G: Right.

J: And it's amazing. It's just like you know you think you bring home the baby, you get them on a schedule and just when you think you got it all down, the baby changes.

G: Yeah.

J: That's how it's been with mom, so. It's helpful to talk to people like you so we know what to plan for because trust me, you guys do not want to have to pick a home care agency in a panic. It is not fun and I, I'm glad that we got very, very lucky. And we didn't have, we didn't have issues like I've heard. You know the horror stories that I'm sure you've heard and we don't want to repeat because we don't, we don't want to talk about those.

G: No.

J: So, I really appreciate you taking the time out of your day to talk to us about this.

G: Sure.

J: It's definitely an important conversation and it's probably easier to listen to us talk about it then to bring it up with family now that people have listened to it. They can bring it up with the family. Bring up that assessment and say I did this. What do you think?

G: There you go.

J: That sounds awesome. Well, I appreciate your advice and you have a fantastic afternoon.

G: Thank you. Thank you for inviting me. I enjoyed it. Have a great rest of your day.

[outro]