

Eldercare Panel of Experts Transcript

80 year old dad taking care of Alzheimer's mom

Voice 1(female): There are a couple of things that I wanted to mention too. When Meg was talking about the occupational therapist coming into the home I just want you all to know that you can talk with your primary care physician and your concerns about the safety of the home. And with rx written by the PCP an occupational therapist will be paid for my Medicare part B. that also goes into if your concerned about your loved one having a fall risk in the home they will also have a PT, Medicare part B will pay for a PT to go into to do a [gate] evaluation and a safety evaluation from a mobility standpoint so the reason I am saying is that I am encouraging everyone to be proactive. We consider it to be pre-habilitation rather than re-habilitation. You're getting in there prior to a devastating injury.

Voice 2(female): Quick question. My dad is primary care giver for my mom. She is early stages of dementia, maybe a little bit more than she thinks she is but, um, and um, I see the need for these kinds of things. My dad doesn't see the needs for these things he is 80, you know, so how do I, you know, she has just gone through a bunch of testing so we have been in this process. It... she stopped, no more testing. She won't do the [driver] evaluation, what she needs, but um, how do I get my dad on board cause it's like he thinks he is protecting my mom by saying we're done and I understand it's a long process and why do they need to test her for eight hours and why they need to do... so you know I am dealing with an eighty year old [cogie] old man. I'm trying to be the best interest for my mom but I am not the primary care giver...so...

Voice 3(male): Yeah. Yeah. So how do you [approach]?

Voice 2: It's, are there, I mean I don't know. I realize all these resources. He thinks they can do it all. They go out to dinner almost every night, you know, he doesn't need support groups, he doesn't need...anything, you know, he can do it. But not that he is patient not that he is the best care giver; that's not what I'm saying, he's not. So, you know we have these conflicting things going on. I don't know if any of you have recommendations for...

Voice 4 (female): Do any of you want to say something?

Voice 5 (female): They don't want to give up their independency and they don't want to admit that they need help.

Voice 1: I think that Dan hit on this, particularly for male care givers how have been working professionals; they really drive on data. So anything that you can give that is concrete, not a mushy care giver hand out but something that's very specific about...these...this is the literal progression of the disease, these are things that you can expect that will be changes in the brain, and we have alt of those you can access them

also there are great websites. The Alzheimer's Association website, the national website is very good for data driven specific information, and then, because one of the things with the driving is something that is truly called motion blindness with dementia. It is not that their eyesight changes, it's like a learning disability. The information that goes into the eye, that it is interrupted by the brain is very different. So their, their depth perception becomes very chaotic; and one of the things... and I also do a lot of trauma work and one of the...the number one reason for trauma related fatalities for older adults is turning left in front of an oncoming vehicle because they can no longer judge the speed or the distance of the vehicle. And so some of that data driven, things will help him and honestly one of the driving evaluation questions that I have asked and it was just by accident about ten years ago and it seemed to work, is would you let your grandchild ride with them, know most of us as adult children are probably stupid enough to get in the passenger seat but we're not going to put our child in the seat, nor is your father going to risk one of his grand kids alone with grandma in the car. Now asking that question may be a little bit of a dim light that goes off. You can then take that conversation further and what that means.

Who tells the parent that they should not be driving?

Voice 1 (female): My question has to do with the driving thing? And I'm in a situation were my mom is now alone cause I was in that situation that you were in and my father passed away; and she's still driving, so I am wondering if you would recommend we would have a doctor or a social worker, that we're working with, be the one to share, you shouldn't be driving anymore Mary; versus one of us kids because she is not listening to us and it's causing lots of emotional trauma that I don't think we need to have if we could have somebody else give that news.

Voice 2 (female): it becomes, it can [.....wreck a family]

Voice 3(female): ...Delivers the Cadillac to his house with a brand new set of keys, so there's no easy way...I just want to say there's not...

Voice 4 (female): I have one of those too

Voice 3: ...We're still blindsided, you know, with things, and we have certainly, I would speak for some of us I'm sure heard those that have had to stop driving and have lost a spouse said that is clearly almost equal to the grief of losing their spouse to lose the independence of their transportation. And honestly in Franklin County we're blessed with options for transportation but it doesn't give you options for quality of life transportation, it does not get your mom to the beauty salon to get her hair done every week or to got to Macy's or, you know to the senior center. It's thank kind of lose of driving that is the problem and the rest of the community, all of us service providers, you know with limited financial resources we tend to focus all of our planning on how do you get to a medical appointment.

Voice 5 (female): And my colleagues may disagree with me and that's just fine. But I think there's a lot of times when an older adult is so focused on staying in their home that nothing else matter, and there are choices, and those choices should often be thought of before they are thought of. It...may...you know I don't necessarily mean assisted living or a nursing home I mean you know when you are 75 and doing well, maybe taking some of Megs ideas, looking at your home, thinking about a condo that's really connected to walk-able connivances that allow you to survive and age in place in a better way. And so they driving really never becomes the issue, the family issue because there's choices because you thought about, you pro-actively thought about how you will, and we do that with our children...at that point in our lives. We think, now which gym class are they going to take when they're two and what pre-school and all these things we plan forward and often times with aging and thinking about how you are really going to do it independently. We don't plan forward.

Chances and Risks with the Elderly Driving are Similar to being Teens

Voice 1 (female): There are choices that out loved ones are going to make that feel like the risks if we have teenagers, that they were taking. Their just...they need...it's ok, their, they need to make those decisions and if they're alert and competent to be able to make them they may choose to live in a situation that we know we could have a crisis tomorrow and...

Voice 2 (female): I think it's very hard to think forward and put yourself in their situation but I think that's and important exercise. You know, for us to impose what we think is quality of life is sometimes not completely fair. We have to think about it and that needs to be a piece of the puzzle but there's something that we teach the students about the "right to folly," you know, you have the right to live your life, they did until this point the way they wanted to, so it's again finding the balance.

Safety Alert Button

Voice #1 (female): ...I also wanted to add on to something that Lia said about in-home, cause I did use this strategy, I had my doctor ask, it was pretty almost said to my doctor, "would you write a script." So we could get in-home OT but particularly PT and then in that process learned that would also cover a safety button.

Voice #2 (female): Emergency response.

Voice #1: Emergency response, which I didn't know and that was wonderful so the period of time that was covered also covered emergency response and then we just kept it going.

Voice #2: And that is generally one of those services, if you will, that most people will accept, and is probably...

Voice #1: Well, I found it sitting on her bedside one day and I had to have a little talk with her...but you're right.

Voice #2: It is probably one of the best things I think they can have.

Voice #3 (female): I don't know what that is?

Voice #2: The emergency response button. Like, "Help, I've fallen and I can't get up."

Voice #4 (female): I just want to say Lia that my mother laid on the floor for hours because she refused to push it because she did not want people to know that she had fallen.

Voice #1: Yeah, I've had to keep reminding my mother, don't call me, push the button.

Voice #5 (female): My dad wore his button and then crawled to the phone to call 911.

Memory loss and grieving the loss of capabilities

Voice #1 (female): The one thing I think we need to recognize as care-givers, and I, and this is very personal I felt this big time is that if you are dealing with a parent that is having memory loss...is that a lot of you dealing with that? There is a time when you feel like you've lost the person; but the person is still here. And so there is a grieving process that you go through that just goes on and on and on. I likened it to, and hopefully I can do that without tears, to going to the funeral home for visitation but never going to the funeral; because the person is pretty well gone.

Voice #2 (female): That's, you've articulated exactly what I've been realizing that I can to the physical things, I can put the plan into getting her, I can get the strategy, I can call all the services but I am walking the path to my mothers death; and so it is the emotional part for me that I'm finding is becoming more and more difficult.

Stress of being a caregiver

Voice #1 (female): I just wanted to say as a caregiver each time we step in to try to help fix things we feel we're adding quality of life. What I think the way it is often times perceived is it's just another loss, because I wouldn't need this service if I didn't have this loss and now my son or my daughter now realizes that I have this loss, it's kind of a vicious circle. So our intent to help is sometimes I think perceived differently.

Voice #2 (male): Just monitor that you don't over extend yourself. A lot of caregivers when I'm talking with them, they talk about the weekly routine and some of them are more involved than they should be, they are over extending themselves; their exhausted. They're worn out, and so those are signs you need to slow down and step back, focus mor

on your needs. You have the right to do that, give yourself permission to do it. You'll make a better care giver, so keep a little bit of a healthy distance there when it's necessary. There's a lot of good healthy life style activities to give you rest and help you stay connected with other people. So just keep that in mind as you're caregiver whether at the beginning, middle, or the later stages where you're having to explore assisted living, nursing home care. You probably have other family members that you have to care for, job, just keep that in mind, the caregiver literature highlights that over and over.

Voice # 3 (female): I'm going to be very honest with my mother; it's really over the last year in seeing, especially when there's times when, you know some kind of in home situation that she's just not comfortable with and I've said mom you know this is something that I need. I need for you to do. I know, I understand it's not your preference but if we're going to be in this together then this is what I need, and you know I think for her that was kind of a way of taking that. Because absolutely what Linda said in terms of, cause she has said to me. If you have to do my banking that means that I can't do it. I agree with that, I understand that but if you don't let me do your banking and things get messed up it's going to be really hard on me. And so it's that kind of, you know, and she is you know, she has dementia but she is lucid enough to understand that so it's kind of a guilt card but it's the truth, I mean its just telling her the truth. I can't, in order for us to do this, in order for us to fulfill your wishes of being able to stay at home. I need you to be able to do this. I am, I can't especially after this past year it was so horrible that I just decided that I have to be truthful.

Voice #2: Yeah, that straight forward strategy

Voice #4 (female): You approached that as kind of a negotiation, that's a healthy way to do it

Voice #3: Yes, it has sort of become a negotiation.

Voice #4: If sounds like you've said things in a loving way too. You know I know sometimes when I am talking to caregivers, how frustrated and worried they are

Voice #3: I find myself getting angry with her, and I don't want to be angry with her. Especially at this point when we don't know how much longer we have together. And so it is like, ok, anger is not working for either of us so let's just go with the truth.

Voice #5 (female): The other thing I found with my mom, I was trying to get a point across to her and she would be nodding you know what I was like. And then she would go, "why can't I drive there?" and then I'd go, "mom we just talked about this for ten minutes." And then finally I just burst into tears and I said, "you got to do this for me." And I just started crying, and I think that was an impression that hopefully stuck with her more than me just saying the same thing in a different way and so I kind of found that helped me a little.

Voice #6 (female): The science behind what you just said is absolutely true. Individuals with dementia will maintain the memory of an emotional communication whether it be good or bad more than they'll maintain a memory of a conversation; because it imprints on a different part of the brain. I don't encourage you to put yourself in a position to cry all the time.

Others/siblings who "help" with care-giving

Voice #1 (female): I think the other thing is that you all have other people that could help you with the care giving, now some of them haven't stepped up to the plate yet for one reason or another and I think you need to be frank with them and say as Lia did, you know she drew her sister-in-laws in to come and talk to mom. I mean you need to say to them, in a very concrete way too, I need help, I can't be there every weekend. I need you to come and then you say specifically, I need you to come once a month and help out on Saturdays or that kind of things, don't you think Patty?

Voice #2 (female): Absolutely. No failure to ask for help here, you know, it's a sign of strength. I think a lot of folks don't reach out for help because they think they should be able to do it and those shoulds can get you into trouble. And really, it's so important it's a sign of strength to know your needs and by all means to be concrete when you tell someone your needing help and give them tasks that you specifically need help with. Maybe that's even a vacation, maybe that's pulling people in at a certain time of year so that you can get a complete break. I know some families that have organized that sort of thing too.

Voice #3 (female): I did that with my brothers. The only girl. But somehow I got blessed with taking care of them and my father was told not to drive two years ago, physician wrote it out and that is when the doctor that knew everything all of a sudden was stupid and didn't know anything, according to my father. My brother I told, my one brother I said, "you got to help me." "Ok fine." He helped to the driving for two weeks, gave the keys back to my dad and said "that's it. No more help." So we had a person out there driving who shouldn't be driving. And I'm the bad guy like everybody else. And I've told him, when the phone rings, you've wrecked the car, don't call me. Call the one that gave you the keys back. I can't deal with the guilt so what do you do? Ask for help, they step in and then walk away and made it worse than it was before because he had accepted not driving.

Voice #4 (female): one of the things we all have these fabulous siblings and we come with a lot of history and a lot of baggage with these siblings and I think the reason, I have a brother as well and my mom has been frail this past year and daddy still goes down home to Kentucky quite a bit and so this particularly weekend she shouldn't be by herself, Rachel had a cross country meet, you know how it goes. So I called Greg and I just didn't give a choice. I said Greg, "I've got her on Sunday you've got her on Saturday. I don't care how you do it, get there." Because all of our old history of being, I mean it wasn't bad, it was just brother-sister stuff, you know I'm bossy, he's this; so

those don't go away. The old relationships you had with your parents when you were 18-22, that's probably what your going to feel like at this stage in the game. All of a sudden you think, I'm 47 years old, why do I feel like I'm 16?

Legal Liabilities of Caregivers

Voice #1 (female): Quick questions, do any of you have any experience with any legal liability that's been transferred on to caregivers when an elderly person has been in a car accident that has really caused traumatic if not death to another person where that's come back to someone like in her or my situation where the car keys have been taken away but they still continue to drive and they somehow come back and?

Voice #2 (female): I'm thinking as hard as I can. I did have sort of um, some literature on that was from the legal perspective that I can pull out again for you. But Yeah, that it is a real possibility and that is a way, my father in-law is 90 post polio syndrome, I mean should not have been driving for like 10 years and there's just no question that he is going to continue to drive and so we have gone to that discussion

Voice #3 (female): You're in charge of him

Voice #2: Oh, I know, Yeah. But we've gone to that discussion that the real truth is you can lose everything and that has made a big difference with him. And it has made a scar tactic, it is a fact.

Voice #4 (female): That is him losing everything

Voice #2: Him. Yeah, him losing everything.

Voice #1: My layer has told me that I'm at risk as well

Voice #4: In the state of Ohio, that curious to me because in the state of Ohio

Voice #1: She lives in another state

Voice #4: Oh, well...

Voice #1: I'm her executor, I'm her power of attorney, I'm her power of healthcare...

Voice #4: But she's competent? The only time your power of attorney, your healthcare power of attorney comes into play is if she's not of capacity to make a decision, as long as she's of capacity to make a decision and a physician has not said that she is not competent it is her liability.

Voice #1: That's what I've been saying too