

Welcome. My name is Jody Krainer and I'm with the Wisconsin Alzheimer's Institute. Thank you for taking the time to join us today for the webinar, Keeping It Real, Conversations That Matter. Our presenters today will be Wendy Bentley from the Wisconsin Alzheimer's Association, the Wisconsin chapter, and Kathy Glaser from the Waukesha County Aging and Disability Resource Center.

Wendy Bentley serves as a senior program director for the Alzheimer's Association Wisconsin chapter. Her path to this work began on the front lines of care, spending time on a 58-bed Alzheimer's unit at a long-term care facility and serving as an emergency medical technician. These experiences shaped the compassion and perspective she brings to the Association today. Wendy believes that when we truly listen to the stories of people we serve, we don't just meet them where they are, we grow because of them. In this field, it is easy to think of ourselves as the ones with the answers. But Wendy has learned that it is the people living with dementia and the families that love them who are really teachers. Their stories are what continue to shape her and why this work matters so deeply to her. Kathy Glaser is a Dementia Care Specialist at the ADRC of Waukesha County. She previously worked in that role in Ozaukee County. Also, her experience includes working with managed care, managing adult day programs, working with adults and children at risk of violence. Kathy believes the more we know about the various types of dementia and how best to support people in local communities, the better people impacted by dementia will be able to function and maintain their independence as long as possible. Now, it is my great pleasure to turn over the webinar to Kathy and Wendy.

Thanks, Jody, for inviting us to do this presentation. I'm excited to be in conversation with all of you about this topic. When we first started talking about what we wanted to cover in this presentation, we really molded how we wanted to do that and what we wanted to cover in what fashion. So, one of the things I want us to think about just before we get started is we're really asking people to tell us their story. We want to know what takes priority for them. We want to think about baby steps. Be as assumption free as possible. Prepare ourselves the best way we can for these conversations and check that the information that we have is accurate. So these were the topics that we thought were topics that mattered and conversations we should all consider throughout our lives that we best know about the people that we love and care for and that people also know about us. Um, we want to know if we know people's thoughts on these, positive or negative conversations that have occurred and who was involved in those conversations. How will you know if these things are an issue? I ask families that all the time. How do you know? People will say to me, they take their medications, fine. Okay, how do you know? Um, and then prioritizing. When we look at this list, it's quite daunting, right? Advanced directives are something all of us should think about. And I tell people a power of attorney for healthcare as soon as you turn 18. We don't often do that. We think of it as a device that older adults should use, but we all want to know who is making our decisions if we can't. So that can be a very natural way to lead into that conversation. But then that conversation of when life progresses and we're thinking about a living will, we're thinking about um DNR orders, all those kinds of things can be a continuation then of some of those conversations. Um of course finances and estate planning and then just this whole laundry list, right? Medication management, driving and transportation, alternative living options, planning and decision

making, assistance and support. If we ever went to somebody's house and said, "These are the things I want to talk to you about," I hope they would push us out the door because we don't want to talk about all of those things at once, right? We need to take things a piece at a time and we just want to have these on our radar as we are working with older adults and especially people living with dementia - because they can be issues that arise. Wendy's going to talk to us a little bit about what happens when conversations on these topics don't occur, and then I'm going to talk a little bit more about strategies.

Thanks Kathy. So why the conversations don't happen? So, Kathy and I mean we've had a lot of meetings on this topic and we literally could fill slides upon slides of why conversations don't happen. So we may not have everything listed here, but um I'll tell you we could come up between our experiences both Kathy and I both in the professional realm. We've been doing this for a long time and professional there was a lot I mean and family-wise there's a lot of things that did come up but so just to some of them um so the lifespan frame of mind. I don't know about you, but I've heard this: "I've lived my whole life just fine why do I have to talk about this?" "I am doing great there's no reason to have someone come in and talk to me about this doing fine." We've also heard you know: I'm retired, I've planned my whole life, I can do whatever I want now. I'm good. I've committed. I've raised my I've worked my whole life and now I'm free to do what I want to do.

But we also have some where we have denial. Um I don't need to worry about that. It's not my problem. I don't see a concern here. I think it's your problem, not mine. So there's a lot of those kind of conversations that happen. So we also have that lack of insights, awareness, and knowledge. and you know not understanding that this may be a challenge for us especially when it comes to couples who've been living together for a very long time. They may be married for 50 you know 60 years and things start to change a little bit uh we may not always catch that and so um even as spouses they may not catch the changes that are happening so there's that lack of insight and awareness about what's going on and knowledge too. I mean like why should I be concerned about that I worked with a family um that was dealing with driving as the list of the multiple lists that Kathy shared previously- driving is one of those and the wife's like well he's a police detective he used to be a police detective for Milwaukee County, he knows exactly where he's going on the back of his hand, so her lack of knowledge of understanding the risks came to the forefront. So that's really important to remember emotions though I really think um there's a few emotions that come to the top for me on this one that people are dealing with but the biggest one I think is fear. That loss of independence.

Think about when when we're little, right? You know, at one point our parents are holding us, right? And we're fighting to walk and run on our own. We don't want them to help us. Um we can't wait for that moment in time when we can be home alone. We look forward to getting our driver's license. So, these are things of independence that we look forward to. Of course, independence looks different for everybody, but the idea of losing those abilities to do what you want to do can really be a fear that will also not allow these conversations to happen. The reality of one's own mortality may play a role - or other health statuses. Grief. Grief is also a big um component that will interfere or be a barrier to conversations and we need to think about that. So it could be losses, it could be physical changes, it could be friends passing, um it could be

the fact that now I have this diagnosis of Alzheimer's disease and um it's that's a lot of grief in itself just in that one category alone. The other emotion that probably pretty much ties with that fear is just being overwhelmed. And overwhelmed can stop a lot of things, right? That can be - people can feel stuck. They can have anxiety, depression that comes along with that that really doesn't allow um people to really move forward in um those kind of conversations. It's better. they almost want to avoid those conversations because it's too overwhelming for them. Um the fear that more is going to be added to their plate or you know there's just much more that they're going to have to navigate and deal with. So the other thing that we have to look at that we may not always think about is the lack of resources. People may be like oh I don't have enough money so I don't want to talk about planning for the future or I can't afford an elder law attorney u or a financial planner. I don't have the money for this. Um, I can't afford to bring people into my home for help. So, those are some of the conversations. Why even have a conversation about it if I can't afford it? Um, they may not have the support system around them either. They may not have family living close by or they are living in a very rural area of the community of the state and they just don't have those local resources right there as you would in some of the urban areas. There's also um we have to look at the cultural and social dynamics within families as well. Um we hear many times, you know, I don't want to burden my children. Um and so that becomes kind of that I don't want to talk about it because I don't want my children to think I need them. Um I don't want to put more on my kids. Family dynamics.

There's some families that I have worked with and I'm sure many of you have where it's like this is my business, not my children's business. I'm the I'm the parent, they're the child. They can't tell me what to do. So we tend to see that as well. Um and then there's lack of trust. Um lack of trust in the medical industry. Um lack of trust with government agencies, a lack of trust within their own families. um we don't always know what that is, but um of course they can be um true um barriers to having conversations. And then you have grapevine influences. Isn't that kind of funny? You know, people want to avoid the true hard conversations, but they're going to listen to the grapevine talk out there in the community. "Oh, that helpline wasn't very helpful to me." They didn't help me at all when I called. or um you know the big one I hear is when we're talking about end of life in some of these conversations you know: "don't use hospice, they just want you to die, they're just going to take everything away." So there's a lot of misnomers out there that do hold back these conversations or they're just like there's no reason to talk about it the other thing that can you know is the caregiver burnout I think that's probably another one of the top three that I feel really can

add a challenge to some of these conversations even happening. They're just too overwhelmed. Like I mentioned earlier, they just don't want to add one more to the plate or they've just kind of given up because it's just too overwhelming to what's happening. There's also a lot of complexity to a lot of the systems in the state. What we would think is very easy - these health systems to navigate - and sometimes it's just too challenging. They have to make one more phone call, they don't want to. They're tired, they're overwhelmed, as I mentioned. Um, and there's a lot of new jargon. So, there's just so much more out there that we may not as professionals always realize may be barriers to those conversations. So, Jody, you can go to the next slide.

So, we talked a little bit about, you know, um why conversations don't happen, but why do they need to happen? So when the conversations don't happen, what is the risk of that? Um when we have conversations before a situation arises, we're given the opportunity to understand the wishes of the person who's either living with dementia or other health chronic health condition that the person may be dealing with. But we can understand what their wishes are and what um they believe are their quality of life. So when conversations don't happen, crisis risks increase. Um we have challenges with ... let me just say we just open up to MORE crisis situations. So and some of that could be overuse of resources. So they may be going to the ER more often. They may be calling their doctor's office more often, but they're not really getting the assistance they need because the conversations are not happening. Um so they're defaulting to what they know best. Less focus on quality of life. As I mentioned earlier, if we don't have these conversations, we really can't understand what an individual feels is their quality of life. I think we all have our own personal feeling of what quality of life is for ourselves individually. I, for one, have my own what I believe is a good quality of life and I'm sure each of you have your own criteria what a good quality of life is. And so as professionals it's really um I think it's important for us to uh try to understand what that quality of life is for that individual so we can better meet them where they are at. The other challenge that we end up having when we aren't able to have these conversations is we actually have limited choice or input because we don't have those discussions. We don't understand what's important to that person. We don't know what their wishes are. Um if we put off conversations, we don't get the input that we need from that individual. So, we end up making decisions based off of assumptions, which of course assumptions are probably the worst thing to guide us, right? Cuz that's not truly understanding who that person is or what they want.

Probably one of the most devastating things I see as a professional around crisis and lack of conversation is the undesirable outcomes that happen. And we've seen it in the news. We've seen other things happen where an individual, you know, makes unhealthy decisions. They may um drive the wrong way and cause an accident with their car. The caregiver becomes extremely sick or passes away before the person that they're caring for, because they haven't had these conversations about the help that they may need or not need. There's injuries, there's wandering incidences, there's medication mismanagement. So, basically everything that Kathy listed um about all the topics that we need to talk about - there's risks to every single one of those. And then there's that risk for caregiver burnout. Um the caregivers are just tired. They're exhausted. I mean, I don't think any of these things come as a surprise to many of you in the field. And I it's very easy for us to want to avoid having these conversations as a professional with the family because we may not understand how to start those conversations. How do we begin those conversations? And so Kathy is going to step into that a little bit further.

So yeah, let's get these conversations going and think about how we can in the best way possible. When we're thinking about starting those conversations, I want us to think about very tangible items and what's most important to them, what their priorities are. Some questions might be, what has gotten harder or what makes something a bad day? So, you can be on the same page with them about a starting point. Using some of those conversation starters that

open a conversation instead of 'yes, no' conversations. So, I wonder about tell me more about: I hear you saying those kinds of things can help broaden somebody's conversation. Have them add to what they're saying to you so that you gain a greater understanding as you get started and they know that they're being heard. We also think a little bit about what does a backup plan look like? Because when we're thinking about the importance of these for example, my parents live about almost 2 hours away from me. So if I'm their emergency back-up plan, a whole lot could happen in the time from when something happens to them till when I'm there. So I'm often asking people what happens if something happened, who could be there in 5 minutes? Who could be there in a half an hour? Who could be there in two hours? Who could be there tomorrow or in a few days? And what might that look like in the meantime? People have all kinds of considerations. Something happens to the caregiver, what happens with the person living with dementia, what happens to your pet, you know, what happens um in an EMT situation. There's all different kinds of thoughts to start generating who to pull onto your team, who could help out in a short term, who would be responsible in the long term. We can talk about an overview of resources that people have used. But I also want us to be thinking about what they've used in the past, what has been good or bad, and what that might look like for them. So, we want to flesh out their story on what their um impression is on different options. We're going to talk a little bit about scenarios where conversation planning and decision-making did not occur. Wendy talked about what some of those could be. When we're talking very specifically about that, it can be helpful to people, not as a threat, but as an FYI, you know, learning from other people's experience. I often say, "Okay, I have gray hair. You can tell I've been doing this for a long time. I've seen this happen a time or two and these are some of the things that have happened that I would never want to happen to to a client again. So, let's think about how we can avoid that and what we might want to put in place for things to go as well as possible. We also want to start very simple. One or two next steps. Avoid overwhelming people. What are those easy wins that we can start with for people? Um, and then thinking about what does communication look like within that family. Is anybody a trusted resource on different topics? I often say to people because people always tell me, "We're not a perfect family." And and I say, "Well, I'm not from a perfect family, nor have I ever met one in my life." So we all have ways of communicating, ways of understanding each other, past history that can come into impact these conversations. So the more that you know about some of that, the more that you can observe about how does communication go, the more you hear, well, we couldn't make that decision unless we talked to our son about finances, unless we talked to our daughter about home care. She's a nurse. she knows about medicine, you know, who are those people in the family and also um has anybody burned any bridges in having those conversations early? So that's um earlier in the discussion. That's all good information for you to have and digest as you're best trying to help people continue the conversation. Next slide, please, Jody.

But I want you to think about some cautions. Expect several conversations, not one. Just like when I was saying, if I gave you that laundry list of topics that need to be covered and thought I was going to do that in a couple hour visit, um that wouldn't that wouldn't happen, right? And even with one topic, our conversation will be um uh multiple conversations just to check up. How are things going? it. What's going on with this? How is that working out for you? Is it doing what you hoped it would? Is a caregiver stress decreased or not because of having some

respite? Um ... is somebody wearing a lifeline necklace? You know, whatever the case might be that somebody tried how we are then um having more conversation about it. I want us to be very conscious that waiting too long limits involvement of the person living with dementia because when we wait until very far into the disease process, talking about rationale and talking about options might not make sense. It might be way too overwhelming. And people might also be trying to get buy-in from their loved one about making a decision and their loved one completely disagrees with it being an issue. I had a conversation with somebody whose daughter said, "You can't drive anymore because you were in an accident last week." And his response was, "No, I wasn't." What happens then? That - that's a conversation ender, right? because otherwise the answer is "Yes, you were" and "No, I wasn't." You know, back and forth. So, we just want to think about if we're laying the groundwork for people in having some conversation or understanding early is best. I also often think about when situations happen in other families and we can talk about how things went and is that what somebody would want or not want. You know, the most important thing is that we live in town as opposed to being relocated out of town if we ever had to go to some type of assisted living. You know, those kinds of things. um so that we can say "I know you really want to be in town. These are the options that are available to you." Um and have those kinds of conversations. Everyone's time frame differs. We know that, right? Some of us are very fast to make decisions and some people need to be mulling things for much longer. And um that sense of urgency can cause some people to act and it can cause some people to retreat. And you'll see that when you're in a family meeting and you're dealing with multiple people that somebody's like, "Okay, let's hire somebody tomorrow." Somebody else is saying, "Let me do more research." Somebody else is saying, "Let me think about it." You know, you can be all over the place. So, everybody's time frame is different. We also know decisions can be forgotten. Um, I can't tell you how many times I've been in a meeting with somebody and the answer is, "Dad, we talked about that." Or, "Mom, you said yes to this. That's why we're doing it." And those decisions might be forgotten. So, we need to be dealing with that too when we are talking about these different issues. We know that caregiver buy-in affects follow through. Um, if you are telling somebody that their doctor has said they cannot drive any longer or that they shouldn't be driving, or that they should be driving in certain areas and the person that lives with them wants them to be driving still for various reasons, what do you think will happen with them? They'll probably keep driving, right? If the person that's living with them is still encouraging them to be driving, they will probably keep driving. So that caregiver buy-in, who lives with them and are they agreeing with what the plan is is really, really crucial. We also know that adults retain the right to risk. How can you stop them, right? There are times when people will throw out ultimatums that we have no ability to execute or to enforce. I think of a woman who was not supposed to be driving and the family took away her keys. She had ... I would say moderate stage dementia. I mean she was fairly forgetful. The daughter was over there multiple times a week. There was a lot of assistance being provided. Um then the daughter got a call about 3 weeks later that the police had seen her mom driving. They didn't pull her over, but they called the daughter to say they had seen her driving. So, come to find out, she was able to contact the dealership and get a new set of keys for her car. I was pretty amazed by that. That was quite a demonstration of problem solving and execution that I was surprised that she was able to manage. But it is interesting when you are in some of these scenarios to see what actually ends up happening with people. We want to be

thinking a lot in these conversations. So, I'm going to go back just a second about um listening and reflecting, knowing when to switch topics or to switch a conversation. Okay? When things are getting heated and things are not going well, we are going to say, you know what, let's think on that and talk about something else for now. or we're going to agree to disagree on that or we're gonna um uh all think harder and talk about that again. Because we know that if we end up with ultimatums or we have this loggerhead kind of conversation, our relationship with people may end and family relationships can get much more strained. And so if we can back away before it gets to that point, the better. Um, we also know our words can get twisted. And so when we're thinking about options we've talked to people about, I always say, um, these are options you could consider. I try not to use the word should. I have jokingly said to people, I won't 'should on you' and you don't 'should' on me. Because often times when we tell people what they should do, if they don't do it, they're more hesitant to come back and talk to us again because the answer is I know you told us this is what we should do and we didn't do it. Um so we're going to think about options they could do. And one of the things that I've learned is when we've talked about a number of topics, writing a written summary back to people about a topic that we talked about and options they can consider is really helpful. It's helpful for me to keep me grounded. It's also helpful so that my words and my recommendations don't get twisted to other people. Next slide, please. So, how do you get there? You know, Wendy and I would probably say, uh, 30, 40 years of experience. Just kidding. Um, so, but what we would say is practice. We do have to practice these hard conversations. We do have to be willing to weigh in a little bit. And sometimes they go bad. I have conversations still go bad on a regular basis because there's so many other stressors that are happening. So ... it's the point of being able to divert back again. Um if you have the opportunity to observe people that have been in these conversations in the past, that's great. You know, if you're watching webinars, if you're watching if you're on... you're um watching a Teepa Snow video or you're watching other kinds of of people talking about these different issues, you can gain language that is helpful to you. So, um I always hate things that are scripted because it often isn't in my wording or my tone, but if I can gain phrases that feel comfortable to me that I can use, that can be really helpful. I want you to think about: what is a retrospective analysis. Look at that interaction. So, what went well? How did they communicate? What might you preface in future talks to help things go better? I am often saying to people when we have a first meeting with someone living with dementia, I say to people, we're not going to challenge what's being said here. Our first meeting is relationship building and having an understanding of where they believe things are. If we constantly are correcting or saying, "No, that's not true." or you're wrong. That will not help our relationship. We can always talk after that about what was or was not accurate about what was being said, but we need to gain that understanding to start. Um we also want to think if there are family dynamics happening, how are you going to deal with that beforehand? I generally tell people, I don't care if you two don't talk to each other. Um, we're having one family meeting. I'm not going to have a family meeting here and a family meeting here. Everybody can be present and can be part of the conversation without you two talking to each other. Um, and so that that generally speaking is how I how I address that. If people opt out, they opt out. and that certainly is their choice. But that that's my mindset in talking with families because otherwise things can get so easily triangulated and you can't remember who who's using this, who's doing this. Uh people aren't working together. It just ends up way too convoluted. So that ... that's that's how I

do it. Um we also always want to increase and maintain our current knowledge regarding resource services and processes. So that's a big learning curve, right? What all is out there? What might they be using? What are they experiencing? I do not have a problem saying to people, "I don't know, but I can look into it" or "I can connect you with somebody who does know." I often say, "I'm not the expert on transportation. I'm not the expert on long-term care." You know, whatever the case might be, but I do know people. I have good connections and so we can get that information. I would much rather say, "I don't know, but I can get back to you" than give people wrong information. It is not a slight on you to say you don't know. Providing wrong information is harder to back away from. So if you know often we might say something and it might be a slip of whatever or we might realize later that is not the case and we can always correct that. So feel confident in your ability to do that and say where your knowledge has limits too. Um, when we're thinking about revisiting the outcome of the experience and knowing this conversation is not a one-and-one, we want to include what they have utilized. So, what did they try? What did they think about? What did they pursue? And what was the experience? Um, I might say, did you get any home care? And they might say, nope, we didn't. The question is, you know, what did you try? Because I tried to call this company five times and they said they I never got a hold of anybody or I called these three places and they require a minimum of 10 hours a week and we don't need 10 hours a week. So, so crafting what they're looking for and knowing then what resources might be appropriate for them or helping them um craft their questions before they pursue resources can be really helpful. We have some different pieces that talk about um if you're thinking about home care, questions to ask and and what that might look like. So, be thinking about what was the outcome of the conversation. Um what did they try? If it didn't go well, is it worth trying again with another resource? And what might that look like? We always want to remind people of what's been accomplished. When we again think of that laundry list of topics to be covered, people get so overwhelmed that even when they've made progress and have um moved the needle on certain topics, there's still a lot to be done. So when we can be saying the last time we talked this was happening, you know, and and they can say to me, "Yep, that's all done. Yeah, we got our powers of attorney done or we talked to our financial planner" or whatever the different pieces were that were accomplished. Um what what happened with that? You know, um we're not going to say did you get it done necessarily, but what happened with that? We talked about this and then changes that you've noticed over time because it is easier for us to look at things from an outside perspective. Often I think about when I was managing adult day centers and we were doing care plans on people and caregivers would say to me, "I'm way more tired and I don't know why." And my answer would often be, "I do. Pick me: Um, here's all the different changes that have happened with your loved one over the last 6 months." You know, continence is more of an issue. their um transferability maybe has changed you know um they are um uh the ability to engage them might be for a shorter period of time. So there are a lot of other things that can come into play that we can be the reflection point for people on and um use our skills and expertise and assessments to help them understand where they might be at and what might be helpful for them moving forward.

We can go to the next slide. Wendy, maybe you want to start with this because we have a lot of resources to think about that people can um use to um address some of these different

situations and then we want to talk a little bit about what you're all seeing and conversations you've been in that might be challenging. Yeah, Kathy and I wanted to just put, of course, there's probably a lot more resources, but we felt that these were probably the most helpful um and things to consider to look at when you're working with a family in some of those challenging um situations. These are also some resources that you can share with the family to utilize for themselves. So I believe Jody's going to be sending this out. So, you'll actually have direct links. Um, so you don't have to go quickly, you know, figure all these out, but, there's things on, you know, caregiving safety. Um, there's the Alzheimer's Association has something called ALZ Pro. It's for professionals only to look - tons of resources. The NIH has wonderful, um, tools. If you've not been on their website, they have great resources to on almost everything that Kathy even talked about um from driving to med management and then you know the considering a financial uh caregiver know your options: an emergency planning workbook and I think that's some of those conversations that are really challenging is because the 'what ifs' as Kathy said you know what if this happens what is your plan um and a lot of times families just don't think beyond that uh just because they don't think that's going to happen and so it's just really good to have um that in place. So that emergency planning workbook is good. Um you know help from others and the legal financial plan and then the ADRC's have a cost calculator, which I love for the considering a move. Um but I think you're the piece that's not on here. It's your fellow colleagues really. As Kathy alluded to, you know, we've been in this field for a while and there's still times I walk away from these meetings with families going did that go right? What did I miss? it's like this isn't, you know, and it can take quite a few months to, you know, have any little movement with a family member cuz you're just waiting for them to be ready for it. But um our colleagues, there's nothing better than be able to reach out to whoever's and just have those conversations. It's not admitting that um you're not capable of doing your job or a weakness or whatever. It really gives strength to us all to be able to rely on each other to help us through these because everything's a little bit different. I mean, I, you know, I'll hit situations where I'm reaching out to other professionals and other agencies. It's like, you know, have you seen this before? I don't know how to approach this, you know, or looking for different resources that might be not a typical resource. So, um, utilize the people that are in Wisconsin that are doing similar jobs to help us through this because it takes a team. It takes a village to really help some of these families that are going through this. So, um, I still step in that mud puddle. I'm going to tell you as a professional, I'm stepping in that mud puddle, but, you know, wash myself off and try it again. I mean, um, that's how we learn sometimes, too. So, um, yeah. So, I'm sure Jody will be sharing some of these. Um, did we want to open up before we do closing thoughts or

because I can do the closing thoughts. So, yeah, go ahead. Okay. So, um, some closing thoughts before we move to open a bigger discussion, which I'm really kind of excited to hear some of the things that you guys have learned and dealt with just to share with each other because I think that's where we learn the most from is from each other. But, um, we have to remember to be person centered and not professionally centered. I really think sometimes, you know, um, we think we're being person centered, but we may be bringing some of our beliefs and what should happen. Again, there's that 'should' comment rather than what could happen. And sometimes we need to really take a step back and reflect on that a little bit to see where is

this. And I'm sure I've done it. Um, you know, this isn't easy, this isn't, you know, a black and white journey. This is very gray - these conversations can be. So, there's not anything that's written in the one, two, three format. You know, um, start where the client is. I will tell you I have had many conversations where families aren't on the same page. They're not even in the same chapter. They may be on two different books! They just .. you know they have different expectations. And you know and as a professional we can't force them all to be on that same page. We're not going to get anywhere. it's going to create probably a little bit more challenges um and maybe some misunderstanding and maybe even some trust issues with us and that family member. So, we really want to make sure that you know we keep pace to where the client is and where the family is at and do our best to navigate between the two. And I think some of the pointers that Kathy mentioned in the last couple slides are really important to help us guide them um rather than, you know, question. Um which is very different. I believe in these conversations. Emotions are going to run high. They're going to happen. And it's not anything you did or didn't do. It's it's just going to be part of the discussion, especially if it's very personal for that person. Um, ultimatums often backfire. They usually backfire. They don't go anywhere. We don't typically want, you know, 'I'm being told I have to do this. Well, I don't want to do it then.' Um, but we also have to maintain a respectful, resource-based role. And again, that can be challenging. Um, but it's it's what Kathy said, you offer the could, not the should. Um, provide multiple. Don't think that, you know, they're going to just pick the one that you want them to do. Um, and it's going to take some time and but end of all, you know, people are really doing their best. Um, we're not, you know, no one wants to, no one goes, 'I'll sign up, I'll be a caregiver for somebody with dementia.' I mean, that just doesn't happen. Um, and we learn as we go. And so, um, people, majority of the people that we work with are really trying the best that they can. Um, it's not purposeful neglect, it's not purposeful ignorance, it's just lack of knowledge. um and they're doing what they're capable of doing. So yeah, so I hope I hope that Go ahead, Kathy. Often also grieving, right? We know that grief is part of this too. And and as anyone who knows who goes through grief, that does change our our ways of thinking. It does change so many things in our life. And we know that people are grieving this diagnosis and changes that they're seeing in their loved ones. So, so that piece of compassion of communication is certainly something that we're always keeping in mind from that standpoint, too, even when we get really frustrated. And I I think on a personal note, and I Kathy and I talked about this a lot over the last few months, is what I did when I first started out in this profession, I was pretty green. I didn't, you know, there's probably some things I've said to families that I regret saying, you know, 'take care of yourself.' Um, I don't know if we fully understand everything until we're in maybe a similar situation. And I'm not saying we fully understand it either, but it gives us a different perception. Um, because when I was in a caregiving role, someone told me to take care of myself. I'm like, I'm doing the best I can. I'm barely holding on right now. So, if I'm not eating healthy, if I'm not doing the things that I need to do for myself, just let me be cuz this is what I can do at this moment. So we have to give people grace in this journey. Um because you know but like what we said ... what I said early in my career is probably very different than what I say today just based off of personal experience as well. So

well with that I'm going to turn off the recording but before I and we'll open up for questions and discussion. Um, but before I do that, I do really want to thank Wendy and Kathy for sharing their

wealth of experience and tips and ideas. Um, so with that, I will turn off the recording and we'll go to an open forum of questions and discussion.