

Episode #06 of Intentional Wealth: Dementia Care with Carrie Chiusano
A Podcast from Braun-Bostich & Associates

Welcome to Intentional Wealth, a monthly podcast where, alongside notable financial professional guests, Private Wealth Advisor and Founder of Braun-Bostich & Associates, Amy Braun-Bostich, delivers useful insights and strategies that help YOU live your best financial life! Remember, when your goals are meaningful and your wealth has purpose, you can truly live with intention. Now, here's the host of Intentional Wealth, Amy Braun-Bostich.

Amy Braun-Bostich: Good morning, everyone. And welcome back to intentional wealth! Here with me today is Carrie Chiusano, executive director for Presbyterian Senior Care Networks, Dementia Care Center of Excellence. As a bit of a background before we get started. It's good to know that Presbyterian Senior Care Network is a non-profit charitable organization.

Established in 1928, they are the largest elder care provider in Western Pennsylvania, and the second largest healthcare and social service nonprofit in the Pittsburgh area, caring for over 6,000 seniors and their families in 56 communities in 10 Western Pennsylvania counties.

Additionally Presbyterian Senior Care Network is a Dementia Care Center of Excellence that has been building its reputation as a dementia care expert for over 30 years. In 1991, they developed the Woodside place, one of the first residential personal care communities of its kind in the United States. It was designed specifically to meet the physical, social and psychological needs of persons living with Alzheimer's disease and was based on a prototype facility developed in Birmingham England. From its inception, Woodside place challenged the traditional nursing home model of care of hierarchal staffing patterns, structured care and limited architectural modification with a new social model of flexible care program and an architectural innovation.

The Woodside place model remains relevant and has been replicated more than a hundred times around the world. So with that as a backdrop, welcome Carrie, and thanks for joining me today.

Carrie Chiusano: Oh, of course. And thank you so much for having me today Amy.

Amy Braun-Bostich: I really appreciate you spending time with us. How about kicking off this podcast by helping our audience understand the difference between dementia and Alzheimer's disease?

Carrie Chiusano: One of the first questions that I always get. Well here at Presbyterian Senior Care Network, we know dementia to be an umbrella term which under Alzheimer's and many other cognitive conditions reside, we have vascular dementia, Lewy body dementia, frontal temporal, just to name a few. You know, those are the types of dementia that we see most in the work that we do.

But Alzheimer's is by far the one that we see the most and it's a progressive disease and symptoms, they vary depending on the cause. But a lot of the common signs and symptoms,

aren't always easy to recognize, but here's a few first and foremost, the one that everybody that everybody thinks of is memory loss.

A lot of times, which is noticed by someone else, the spouse, the children, the close friends, there's also difficulty communicating or finding words. Now we, well, at least me, I have trouble sometimes, but I'm able to recall the words that I'm looking for in my conversation, folks living with dementia, aren't always able to do that or they'll make up a new word and, one of the things that we need to do is, know their language and use the new words that they are using.

Amy Braun-Bostich: You mean like 'thing-a-ma-jigger', or something like that.

Carrie Chiusano: Well, 'thing-a-ma-jigger' or one of the things that we get a lot... For example, we have some of the ladies that use sweet and low in their coffee, and they don't refer to it as sweet and low anymore. They use the term, you know, that pink stuff. Could you get me that pink stuff? And they'll point to their coffee cup. Sometimes there's two ladies in the that I can think of off the top of my head. They use quote unquote, the pink stuff as the sweet and low that goes in their coffee, but also as their cranberry juice that they have with their breakfast every day.

So you kind of have to know the individual. If it's one thing that we take away from any of these education opportunities is know the individual living with dementia, just enter into their world and leave your reality at the door and enter into theirs.

Amy Braun-Bostich: Yeah, that's totally customizable or personalized for the patient, right?

Carrie Chiusano: Absolutely, for sure. Some of the other symptoms that people will recognize visual and spatial abilities, a lot of times individual, you know, the family caregivers or care partners will say, oh, no, they can take a walk. They've been there. They're fine. They've been doing this for 40 years.

They'll get back, they'll get back fine. They always do. My fear is the day that they don't. When they're, when they get lost walking that walk, that they've walked for decades or, or driving to the grocery store and don't remember how to get home. Now, that's very different than driving to the grocery store and not remembering where you parked, because if that was a sure sign, I'd be in a lot of trouble.

Some of the other signs and symptoms reasoning or problem solving. That becomes much more difficult handling complex tasks. They're still able to do the task and I highly recommend we encourage them to continue to do the things that they love to do. They just might need some help initiating whatever that project is and they're going to need step-by-step directions to complete the task.

It may take a little longer and it's going to take up some of your time, but you know, the old saying when you don't use it, you lose it. So planning and organizing has definitely taken a

back seat. Initially, because they're afraid to do it because they don't remember the steps in the early stages of dementia, they know what their deficits are, and they don't want others to see that. So they kind of step out of the spotlight a little bit so that others, others can take the lead with that, which is sad. That's a sad one for me when they really know their deficits and they try and hide it from the people that they love.

There's difficulty with coordination and motor function. So as, as dementia, as the dementia progresses and it is a progressive disease, it gets harder and harder. So I like to recommend to family members, you know, going back to the offering directions one step at a time. Wait, if you ask them a question wait for them, at least 20 to 30 seconds to answer you, because what we find is, you know, the brain is deteriorating.

You know, there's, there's gaps in there and, it's trying to get from A to B... only, it's not a straight line anymore. They have to, the message has to get around those gaps. So we have to wait a little longer for them to get the message, understand it, process it, come back with an answer to your question. So you'd be surprised if you wait 20 to 30 seconds that these individuals are still able to have a conversation.

It just takes them a little longer to process, which a lot of times we think is confusion and disorientation, which it might be. But we find that if we do take the time to listen and you know, take that time with the individual, have that conversation, read their body language. 93% of our languages is through the body language, more so than the words... that's hard to do sometimes.

Amy Braun-Bostich: Yeah. That would be difficult. I think I read somewhere that also they may, their hearing may be fine, it's just that their brain isn't processing what they're hearing is that true?

Carrie Chiusano: You know, it's so individual individualized, Amy, it could be that their hearing's fine and their brain's not processing, or it could be that their brains processing and their battery's dead in their hearing aid.

You know, the docs will tell you first and foremost, make sure your hearing aids are working. That they're on a lot of times, you know, they fiddle with them and turn them off themselves and they can't hear you. And we think that they're confused simply because they can't hear us. And the other thing is vision... vision is huge. Make sure the glasses are clean and if they're living in a community make sure that their own glasses. A lot of times somebody will say, oh, I'm struggling, you know, see, and then they see a pair of glasses sitting on the table and they pick them up when it's actually their neighbors glasses and not their own.

Amy Braun-Bostich: It sounds, it sounds so like, it's very hard to make a differentiation between Alzheimer's and dementia from what you've just said, because it seems like the symptoms are, there are very similar.

Carrie Chiusano: Well... you know, dementia is an umbrella term and there's many different types of dementia that fall under that umbrella.

I like to use what I'm doing is some education opportunities in the community, I talk about flowers as being the umbrella term, and under that umbrella, we have roses and daisies and lilies and sunflowers, and black-eyed Susan's and all those great things. They look very different, but they're all flowers. We have dementia's, you know, the most common is Alzheimer's, the second most common is vascular. We have Lewy Body and Frontal Temporal.

Those are the ones that I think I said we see the most in, in our care communities. There were definitely the ones that we've seen the most knowing the different types is important because they're caused by different things.

There's better ways to treat once you know, what the real issue is. For example, Lewy body for many years was diagnosed as a Parkinson's disease. And the problem with that was, doc's we're treating for Parkinson's disease and the medications that they were prescribing were actually making the Lewy Body dementia worse.

So it's important to know the different types and, you know, before it was just senile dementia, right, that's what we knew 30, 40 years ago. That's what we called it to senile dementia, not knowing that there were so many different types.

Amy Braun-Bostich: Robin Williams had Lewy Body, right?

Carrie Chiusano: Robin Williams did have Lewy Body, correct, yes.

Amy Braun-Bostich: Yeah. I have not been really familiar with that at all until a client's father had it and she had mentioned it to me. And then shortly after that it was, you know, announced that Robin Williams had it. But other than that, I don't, I don't really hear it too much.

Carrie Chiusano: Well, we didn't hear it a lot for a long time. It wasn't until probably 10 years ago, we actually had our first individual that was diagnosed with Lewy Body at Woodside Place where I was the administrator. The one thing that I have to tell you, and I've asked as I go out teaching, I asked the groups that I'm spending the day with, I'll ask them... Have you ever had a woman diagnosed with Lewy Body? Now, I'm not saying it can't happen, but I've never had a resident that was diagnosed with Lewy Body and anybody else I've come in contact with. So, I'm going to have to do some research on that, Amy, to see what the difference is between men and women being diagnosed with Lewy Body.

Amy Braun-Bostich: Was Casey Kasim, Lewy Body, too? I seem to remember something about that.

Carrie Chiusano: Could be, I'm not sure to be honest, I'm not sure.

Amy Braun-Bostich: That's interesting.

Carrie Chiusano: It is the third most common dementia now. First Alzheimer's, and then vascular, which is, you know, vascular dementia used to be called multi-infarct dementia, but now it's vascular dementia.

It has to do with the lack of blood to the brain. You know, the flow of blood to the brain usually caused by heart attacks, strokes, and then Lewy Body and Frontal Temporal, those are the top four that we see.

Amy Braun-Bostich: Scary stuff. What are the early signs of dementia that you would look for?

Carrie Chiusano: Hmm, I like to go with the Alzheimer's association has a, a really nice list of, of early signs.

You know, starting with... I think about it, and I think about some of the things that I forget, like I had mentioned, I don't remember sometimes where I parked my car, but most everyone will experience some type of memory loss as they age. I mean, think about how many times you've not been able to come up with that word that you need or blanking on someone's name or losing track of a set of keys.

When the day that my husband found them in his keys, in the refrigerator, I was a little concerned, but we got over that quick.

Amy Braun-Bostich: This morning, I couldn't think of the word macaroon. I was like, Macarena. You know, I was like, oh gosh, am I losing it?

Carrie Chiusano: Right. You know? And then the older you get, the more you think, oh my gosh, is that a sign?

Yeah. So like I said, I like to use the signs from the Alzheimer's association because they, I think they fit nicely with the experiences that we've had a Presbyterian Senior Care Network. First and foremost is memory loss, but more importantly, memory loss that disrupts daily life. So, you know, forgetting recently learned information.

You know, forgetting important dates, asking the same question over and over again, increasingly needing to rely on reminder notes. You use your outlook, your, you know, your electronic calendar to make sure that, that you have everybody's birthday in there and, and everything that you need to remember for the day, or simply asking family members for things that you used to handle yourself.

So, that's a big one, you know, sometimes forgetting a name or appointments, but remembering them later, like that's, that's common stuff. My husband and I have a deal that when somebody is walking at us, we have to say their name. Hi Jim. Hi Sarah. Just in case the

other one forgets because, and we're only mid-fifties, what's gonna, you know, I'm like...holy smokes!

There's also challenges in planning or problem solving and, you know, some folks living with dementia, they experienced changes in the ability to develop and follow a plan at work. You know, some of the things that they used to do, I think of a resident, oh gosh, she was... talk about always dressed to the nines her hair was perfect.

Her makeup, just such a beautiful lady. Her husband was a physician, and she would host and entertain everybody all the time. And she, even, when she moved into Woodside Place our personal care community, she did, she would plan all the parties and she was, she had a bowl of, of fruit loops the one day., and she said, these, these put these on the list. She thought I worked for her, put these on the list. We will have these as, as the hors d'oeuvre for Saturday night. And of course, guess what we did. We had hors d'oeuvre's later that evening that, and then they were, everybody got an individual bowl of fruit loops because that's what she wanted.

But there's difficulty trying to keep, you know, following familiar recipes or keeping track of monthly bills. A lot of times this is when family members will pick up the phone and they'll give us a call because they've received something about mom or dad's account from the bank, the bills weren't paid.

Maybe they were paid twice. For the first time ever. They've, you know, they've had an overdraft fee, all those different types of things. Those are one of the big ones that, that we get calls from family members. Then there's folks that are living with dementia, they find it hard to complete routine tasks.

Sometimes they have trouble remembering getting to church when they've been going to that same church forever and ever or organizing the grocery list. The one that breaks my heart all the time is when you know, the husband or the wife will call and they they'll say things like, you know, we've been in the same bridge club with the same people for, for 40 years and now we don't get invited on Friday nights anymore because my spouse doesn't remember how to play. So it it's, it's hard. And then so in, instead of, you know, people, friends for decades, right? Instead of friends for decades, a lot of times they just don't get the invite. Now, a lot of times we have the stories where the friends have really rallied around the spouse or the person living with dementia and they'll say, well, hey, if we have to go to go fish, it's about being together. It's about spending time with friends that have become family and that just warms my heart.

Amy Braun-Bostich: That's, that's a definition of a true friend there.

Carrie Chiusano: That's right. Confusion with time or place and this is different than what people think of.

Say if you're on vacation or you're recently retired and you're like, holy smokes is today, Tuesday or Thursday. Like, I don't remember, but, but losing track of the dates, the seasons, you know, the passage of time you know, we, we have people really working hard trying to remember the day of the week. But you know what, for somebody living with dementia, it really doesn't matter what the day of the week it is.

So if they think that it's Saturday, it's Saturday, I have a retired friend now, he just recently retired and he said every day, Saturday for me, Carrie, and I just, I'm a little jealous that he's retired at the age he's retired at, but nonetheless for him, you know, there's no job to get up to. He gets up, he does what he wants to do.

He keeps himself busy. The one suggestion that we do have that we share with family members quite often is. If, the person living with dementia has say a doctor's appointment, their granddaughter's getting married in a month or so. If there's a big event, if there's a party you know, whatever the case may be, whatever that appointment, whatever that event is, don't tell them too far in advance because they will really, they will really focus on that and they will get anxious about it.

They don't want to miss it. It's very important to them. So we suggest waiting until much closer to the date. Sometimes we don't tell people they have a doctor's appointment until an hour before when we have to get ready and we'll just say, oh, well, they just called and they have a, you know, an opening.

So they'd like to see you now instead of next week when your appointment was scheduled for. That way, they don't perseverate on it and get themselves all worked up. So that's, that has been a very successful suggestion for a lot of family members.

Amy Braun-Bostich: Yeah, that's a really good tip. Not, not something that you would really think about yourself, but it makes total sense.

Carrie Chiusano: Yeah.

Putting things on the calendar for the person living with dementia can be a very good thing to help them stay involved, to help them remain independent. But sometimes when they're not able to understand the calendar anymore, it actually is more of a frustration for them. So again, going back to knowing the individual, there's a saying out there, it says when you've met one person living with dementia, you've met one person living with dementia because everybody is so different.

One of the things that are very similar... something that's very similar is visual images, spatial relationships and I know Amy, you and I have talked about this in the past about vision problems are a sure sign of dementia, judging distance, determining color or contrast. Colors are a big deal with somebody living with dementia and there's studies...

There's so many studies out there. Should you have yellow walls to brighten the day? Do persons living with dementia, eat better if they're eating off of a red plate and I'm not gonna dispute any of those any of those papers or any of that research, but in our experience it's about the contrast.

So I like to have people close their eyes and think about, say Thanksgiving, dinner, think about turkey, mashed potatoes, cauliflower, gravy over everything and put it on a white plate. And if you have any of the aging eyes already, so you've got your aging eyes and you've got your cheaters that you need to wear.

Let's talk about glaucoma macular degeneration. I mean, there's so many different, so many different... cataracts vision issues that happen with the aging eye. And oh, by the way, we're going to add dementia on top of that. So when you think about the turkey, all that white on a white plate, it kind of all blends together.

So people thought, okay, we're going to use red plates, which is great because there's that contrast. But then we think about what if we're having pasta with red sauce, it's the same problem. It's not so much about the red plate for us. It's about the contrast of the food to the plate. We also think about, you know, all of our Woodside Communities have multiple colored plates just for that reason.

So if we're having spaghetti today, we use the white plate. You know, if we're having, you know, salads, you know, Turkey or chicken salads or steak salads, we don't use the green plate, we'll use a different colored plate.

Amy Braun-Bostich: That's really interesting. And that's not something that you would even think about either.

That's really interesting that, you know, just using a different plate might be able to entice them to eat a little bit better.

Carrie Chiusano: And we have seen that too. The other thing is, when the person living with dementia is walking, if it's a red and white checker, if it's a black and white checker floor, a lot of times you see those and, you know, in the, in the little delis or some of the restaurants have them, some bathrooms in restaurants have those and the black, the black squares they see as holes.

So we, we won't, you know, we really have to work hard at holding their hands, walking in front of them trying to get them to, you know, they'll just try and step on the white squares. The other thing is when you walk into say a target or a grocery store, they have those rugs, as soon as you walk through the door, so you can wipe your feet off... again, white floor with a black carpet, brown, dark brown carpet.

You know, you try and dry your feet off and they see that as a hole. They're very concerned about stepping on that carpet because in their mind, they're seeing just a hole in the ground.

Amy Braun-Bostich: Now, does this happen early in the dementia, or is this an affect from, you know, after you've been had dementia for a while?

Carrie Chiusano: No, I've seen it all through an individual's journey. You know, especially when our... we have an adult day adult day center and when they come to our adult day center, they're pretty high functioning, they're still living at home. You know, most often their families will bring them for socialization to be engaged, you know, just really to be safe.

All of those different types of things, just to get acclimated in case they're thinking about transitioning them or moving them in when, when they're no longer safe at home and we will take them on outings and we see it pretty high functioning all the way through until the end of their journey, you could do a whole full day workshop on color contrast and individuals living with dementia.

I just get so excited when I start talking about it.

Amy Braun-Bostich: Well, it's probably because it's also one thing that you can do to manage care that is helpful and it's not intrusive and it's not expensive.

Carrie Chiusano: Right. We had one lady that wouldn't come out of a room. She was new to the community, and she was, they would get her up and get her ready for the day and she would just climb back into bed. And I had just gone to a seminar and learned about the color black and how dementia, how it affects individuals living with dementia. And I shared it with the team, and we were in a huddle, and I was like, hey guys, where do you hear about some of this color stuff?

She had the idea to take a comforter, a black comforter. She went to the store and got black comforter, started covering up her bed while she was in the bathroom in the morning. The resident didn't see the bed. When she came out, after she had gotten ready for the day, brushed her teeth. She started going to breakfast in the dining room simply because there was no bed to crawl back into, if you would have told me that I would have thought, okay, we'll give it a try.

But when I saw it happening and they, they did it for a few months and then the one day, for some reason, somebody just forgot, but it had been long enough that her routine was different. She went down to breakfast, and they never had to do it again. But what creative thinking for this this team member to just really come up with something like that.

Amy Braun-Bostich: So that's pretty awesome. That's fantastic.

Carrie Chiusano: Well, one of the other warning signs is that people living with dementia may have trouble following or joining a conversation. They might stop in the middle. They might not know where or how to continue. They might repeat themselves. If they're in the earlier stages, they might really be afraid to join the conversation because like I said, they were, you know, they're aware of their deficits. They don't want to be embarrassed. My suggestion for

that is get to know their new language. For example, the lady with the pink stuff, you know, I need the pink stuff instead of saying, would you like some sweet and low in your coffee this morning?

I would just hand it to her and say, here's your pink stuff for your coffee. Once you know this new, quote unquote, language of the person that you're caring for. You know, I highly recommend that you share it with the other people that are caring for her, you know, family members, friends, it's kind of a big deal

Amy Braun-Bostich: And it probably reduces the anxiety level for them, right?

Carrie Chiusano: No, absolutely. And a lot of times when pink stuff, I need the pink stuff. If somebody, we have dedicated team members that are, they work with the same residents every day. They get to know their routines, the residents then get to know the team members, which is great. So there's a relationship that's built there.

Well, when somebody maybe is on vacation for a few days, and we have new people. Covering the house and they might not know every little detail and they're saying the pink stuff, they just start.... Do you want cranberry juice? Do you want that? And they will just start kind of firing things at them and then the housekeeper will come in or somebody from dining services or another resident.

And they're all trying to help her by guessing what the pink stuff is. And that just frustrates her and gets her angry. And she'll just toss her cup and go the other way. But knowing the individual is it's very important also knowing where a person's special hiding place is a big deal because someone living with dementia really put, they put some items in unusual places. They might lose things... They're not really able to go back and retrace their steps to find them again. And, as this happens and as the disease progresses, the person really might accuse others, family members, friends as the disease progresses of stealing some of that stuff.

So knowing where some of the hiding places are, and then sharing them again with the family so that they aren't the person being accused of stealing. Some of our go-to hiding places are tissue boxes, pillowcases, the back of the toilet and, I finally found out a long time ago when people were in the depression... They would take things and keep them cold in the back of the toilet or try and keep the kids from eating them. You know, if there was a lot of something and they could use it for two meals, they would put it in the back of the toilet. They would wrap it in plastic, tape it up and that way they would have enough for two meals, and I flat out asked the residents one day, why do you do that?

Then they told me, well, that's where, that's where you keep things cold or that's where you hide things. So kind of crazy... underwear drawers and in folded socks. So we've also found dentures in a bush. So that could all go right out the window too. So you never know.

Decreased in poor judgment, this changes a lot. They might be paying less attention to their grooming, keeping themselves clean. And when you think about poor judgment, putting

things on the stove and forgetting that they're there. We have family members that come home from the holidays. And again, that's when we get the majority of our phone calls, I think something's wrong with mom and I really need to talk to somebody.

I came home, all the pots and pans are gone. Well, she's early enough in her dementia journey that she knows that she's burned them all. It's going to be a red flag for people, so she gets rid of them. Or, you know, she will just not care about her appearance. And she'll tell you, I had a shower.

When she hasn't had a shower in two weeks. In her mind, she just had one this morning. And how dare you tell me that I stink. So, that's a big one, the decrease in poor judgment, and then withdrawing from work or social functions. That's another big one. Somebody that used to be the social butterfly and now they're, I think about that person that doesn't get invited to bridge any longer. And for me, the earliest stage is the hardest, because they're so aware of their own deficits and they just, and they stopped saying people's names. It's not only that they don't remember the rules to gin anymore, but they don't remember the names of their friends.

And you hear more words like, oh, there she is. Oh, she's my friend or, oh my gosh, did you see that play he made? Or, you know, if you ask a question to them and they're not able to answer it though, they'll say, oh, you know, or what do you, what did you order at brunch today? Oh, the regular. So there's no detail anymore.

You get a lot more pronouns. They're really trying to cover. And all of this all comes together and it's hard on them. It gives them, it changes their mood. It changes their personality. Cause they're really working hard. Number one, to do what they know they're supposed to be doing and two, a lot of them are trying to cover it up because they don't want other people to know.

So they get upset easily. They get upset at home, at work with friends. And you know, my suggestion is to be sympathetic. I think every single person caring for somebody living with dementia needs to look at photo of a healthy brain compared to a brain that has advanced Alzheimer's or dementia, any type of dementia, really so that they can see the difference of what's happening in that brain.

And it's hard and they're doing the best they can. They're not doing it on purpose. I hear that a lot. I know she's doing this on purpose. She's really not just take, just take a couple minutes, be sympathetic, be helpful, and don't do it for them. You know, use it or lose it. I tell people all the time, if they use it, if they don't use it, they're going to lose it.

And then you're really going to have to do all the work.

Amy Braun-Bostich: I can certainly see where having an understanding of the science is important, not just, you know, for the individual that may be experiencing them, but also other people witnessing them. And those that they care about. Now, suppose a person or someone in their family has been diagnosed with dementia.

What are the first things they should do?

Carrie Chiusano: Recognize first and foremost that you and your family are going through a variety of emotions. I mean, a news of a diagnosis and changes that it's going to bring really give you a variety of feelings. There's people that get angry and they deny it, or they're embarrassed by it.

They're frustrated. They're scared. There's just so much happening. And I tell people, please, you're important too, is that as the person carrying, everything's on you. So if your feelings become overwhelming and they don't go away after a short period of time, please talk to somebody, go see your doctor.

They're going to know things to help you, not only with the person that you're caring for, but also for you learn all you can about the disease. You know, it just find out about how it can affect the person, what changes you can expect, how you can provide some help and support, find out what else is out there.

There are, not just the Alzheimer's association, but they are so many things online right now. You know, online webinars, the one thing that has come out of all this COVID is... so much is virtual that anybody can hop on and learn. And don't be afraid, when your friends and your family and your coworkers say to you, how can I help.

Find something they can do for you, even if it's just to visit with him. So, you know, your husband's so that you can take the dog for a walk in peace, just time for you to have a breath, have a moment for you. You know, it affects every person's abilities. It will affect how they function day to day, how they learn about the disease will help the person that's caring for them. And what the realistic expectations are.

Your husband did all the plumbing before. If he's going into a moderate stage of dementia, I'm thinking I don't want him working on the plumbing or in the electrical box anymore. It's not safe for anybody.

Amy Braun-Bostich: Yeah, that's true.

Carrie Chiusano: And don't lose sight of the person no matter how the disease affects this individual, it is important. So, I can't stress this enough, how important it is to treat them with dignity and respect. You know, some of their abilities are going to be lost. Their emotions and feelings are going to remain. Like I said, 93% of communication is through body language. Allow them to remain as independent as possible. I think about the quote from Maria Montessori that I was taught years and years ago.

“What you do for me, you take from me”. So if it's taken me too long to brush my teeth, tie my shoe button, my shirt, and if it's taking me too long and somebody comes along here, just let me know. I'm not going to want to do it anymore. First of all, I'm embarrassed. Second of all, what's the purpose if I feel like I'm not doing it right.

And explore treatment options, it's out there, you know, talk about, you know, there's no cure, but there are medications that can help some people with the symptoms, discuss the risks of those. Talk about the benefits, talk about it with your doctor, find out what they are. There's so many research opportunities that people can hop into and see if a drug.

So that's not for some people, but some people it is, and recognize that caregiving can take its toll. So seek out some help. We recently started a program a couple years ago. It was a three-year project that we started, we got a nice sized grant for the Presbyterian Senior Care Network.

And we just believe how it's so vitally important, especially if the goal is to care for the family member, living at home, that the family caregiver has direct personal support from professionals that are really gonna connect with them and point them in the right direction and make those connections.

We have a program called dementia 360. It connects the caregiver with dedicated professionals. So you get yourself a care coordinator and they are yours for as long as you're in our program we have a registered nurse, a therapist, a dietician, direct care expert, and then all the rest of us on the team at Presbyterian Senior Care Network.

So if there's a question about physical therapy, occupational therapy, speech, we reach out to them too. We all come together, and we put together what we call a roadmap. So, you know, if you think about suddenly being put, so you get this diagnosis, you're, a caregiver and your spouse gets this diagnosis of dementia.

And you really kind of don't know what it's all about. And, you know, imagine suddenly being put in the pilot's seat of an airplane and you're responsible to land it safely with your family member on board. It can feel quite harrowing, and having that voice over the radio, that expert guiding you through it all is so important.

And that's the way we think of our role of our dementia, 360 care coordinators. They're all certified dementia practitioners, and they've been doing this a long time. They have the connections in the community to help and, you know, first thing they do is they come to your home, they visit, they learn everything they can about you, about the individual living with dementia.

What are your goals? It's about you? How are we going to help you? Do you want to keep this person in home? Or, you know, are you thinking possibly of moving into a care community? We look about safety. We look at comfort. We look at lifestyles and from all this input, the whole team gets together... has a conversation to create a roadmap to guide through caring for the person living with dementia, but also for you.

So this is more of a program for the caregiver to help improve the life of the person living with dementia.

Amy Braun-Bostich: I'm sorry. I was just what I was thinking about everything you were saying, and I could just see where, you know, the caregiver really needs to have a developed skillset in order to handle and to be able to manage somebody and to keep them happy right.

Carrie Chiusano: Absolutely. Some of the hardest things, Amy or for people to understand communication techniques. Thinking about the words, think about telling your husband on a daily basis. No, don't can't no, Jimmy don't open the door. You can't go outside. Oh, if it's anything like my husband, he'd say, hold my beer, watch this.

But trying to teach the family, caregivers, communication tips, different ways to approach all these things. You know, the goal for us for every dementia 360 client is that they have more good days than bad days. And that they know despite the challenging diagnosis, there are still joyful moments there they're ahead of them.

They're not alone. And we're with them every step of the way. So developing a support network, and that's not just a place like dementia 360 or Presbyterian Senior Care Network. That's your friends. That's your family support groups are huge. Support groups are huge... hearing other people talk about the same things that you're going through.

And then making connections afterwards, we have two physicians that are in our support group that after support group, they go out and they get a couple beers and they talk about, they just talk about what life is at home and they share techniques and they, and they share ideas. And I don't think they've ever needed a DD yet, but sometimes I bet those conversations get long and then pant plan for the future, which I'm sure you could speak to much better than I, but really making sure you know, all the ideas, all the decision-making is made as soon as possible, just to create something that is accepted by the person living with dementia, the caregiver, the family's all on board, you know, not just, not just about financial and healthcare decisions, but, you know, In your mind having that peace of mind? It's a lot.

Amy Braun-Bostich: Oh yeah, definitely. That's all really incredibly helpful. It kind of leads to my next question. How prevalent is dementia?

Carrie Chiusano: Well, when I knew we were doing this, I looked up some statistics, Amy and an estimated 6.2 million Americans aged 65 and older were living with some form of dementia in 2021, 6.2 million! Of that number, 1 in 9 age 65 to 75 is living with dementia.

17% of age, 75 to 84 and 32% of people aged 85 and older living with dementia. So as you can see, it's quite prevalent. Now that people are living longer, those numbers are just going to get larger and larger.

Amy Braun-Bostich: Well, hopefully with some lifestyle changes we can, for younger generations, we can push some of that off so that it doesn't happen as early.

Carrie Chiusano: For sure.

Amy Braun-Bostich: You have some educational programs that you subscribe to for a few members.

Carrie Chiusano: We do so Presbyterian Senior Care Network, we have several education programs to raise awareness, both with our team, as well as in the community at large, for our own team, we have what it's a four-hour program it's required upon hire.

Everybody, It doesn't matter what role they're in. They have this training and they become certified through a company called Healthcare Interactive, which really has some, some great trainings attached to it. We've been working with them for quite a few years, but it gives a basic overview and it's really been something that makes people feel a little more confident before they step into their roles in caring for individuals with dementia.

I have to tell you a lot of people don't know, 80% of the population in long-term care living, and that can be anything from independent living, assisted living, personal care, skilled nursing. 80% of that population does have some form of a dementia. We also provide sensitivity training so there's something called Dementia Live.

And it's part of our onboarding now. It's where we put on gloves and headphones and glasses. You really simulates person living with dementia and what they go through on a day-to-day basis. So they hear what they hear. They see what they see. And they're trying to with these gloves, cause we talked about fine motor skills not being what they used to. That's been very positive in helping people to understand about those that they care for. Very powerful, very powerful training.

Amy Braun-Bostich: That would be sort of a fantastic experience for anybody, but most certainly for a caregiver to really understand through their own, you know, touch and feel and site, what is actually going on with the people they're caring about. That's got to be very powerful.

Carrie Chiusano: It's so powerful. And then we do kind of a debrief discussion afterwards, the actual, you know, process that they do, it only takes seven minutes. They have seven minutes to complete five tasks. Most people don't get to the third one. It's just so much coming at them at once. I've had people actually take off the headphones and literally sit on the floor and sob, you know, I cared for my mother, I had no idea. This is what she was feeling, something like this.

It's so powerful. We do a lot of that. We've incorporated into what we call our Woodside workshop. That's how we start our day. And then we do eight hours hands-on training and, you know, we just, we just talk about the different types of dementia.

And, you know, we talk about the family piece of it. We talk about distressed reactions. When somebody gets frustrated and upset how we approach them, you know, how to help them get ready for the day that's best for them. We talk about all different types of things. We also

have over 150 certified dementia coordinators, which is very in depth education opportunity that, that we do.

So 150 people that really have taken that deeper dive in dementia and how they want to care for our residents living with dementia has been pretty awesome that, you know, nobody's told you have to do this. This is people that have come forward and said, hey, I think I could do a better job if I had this.

So that's kind of great. Some of the other things that we do is out in the community at large, we've gone to the hospitals, we've gone and spoke to the EMT, the firefighters, the police, I was at a search and rescue. They do 13 counties search and rescue. And I go every other every other year. And I teach that group.

What a great group. It's from Erie to Washington, PA... we do, we do quite a few of those.

Amy Braun-Bostich: I could see how that, you know, just having somebody maybe not follow your directions if you're a police officer or a firefighter and getting terribly frustrated, because you're not recognizing that they don't understand or that they have dementia.

I could see how that would be really, really a good experience for the community first responders.

Carrie Chiusano: It was kind of fun. The, the craziest opportunity I've ever had is when the Pennsylvania park and recreation group reached out to me and said, so we have this new project where, you know, get the family out, get outdoors, everything was, get outdoors, get outdoors.

This was a few years ago, but they took grandma and grandpa camping. And in the middle of the night, grandma and grandpa would get up and get out of the tent and go to the bathroom and then they couldn't get back. So they had to call the park Rangers and the park Rangers didn't know how to communicate with them, or, I mean, some of them were really great, but after I talked to a room full of park Rangers, they said, oh my gosh, this was great information to have.

I wish I would have had that. I wish I would have had that a while ago, but you just don't know what you don't know and same with search and rescue. If you're taking big dogs and they're barking, it's very scary to somebody living with dementia. They're gonna, you know, and what they told me was they hide under a tree because they're scared of the dog.

They don't yell. I'm here, I'm here. They hide better because they're afraid of the dog that's barking.

Amy Braun-Bostich: So I would never even think of that.

Carrie Chiusano: Right. Our newest thing that we're doing is it's called dementia friendly businesses. What it is it's a free one hour training session for team members of businesses in the community, hairdressers, you know, we've hairdressers have them one that have really done a lot.

Banks, if you think about banks and especially with fraud happening now, The bank called us the one day and said, you know, I'm a little concerned, the same young man he's in his early twenties. He keeps bringing grandpa every week and they withdraw and the money that the amount of money keeps getting more and more.

Well, they found out that the grandson was coming and getting grandpa who was living with dementia, and he was taking his money to support a drug habit and you know, how great of that bank teller to recognize that and say, you know, what do I do? What do I do? I said, well, first thing, call 9 1 1. And then let's talk about getting the rest of the tellers, educated on what to do.

Amy Braun-Bostich: We had that happen with a client. It wasn't a grownup firm. It was a, a caregiver that was, you know, going to the bank and having them pull money out. And so the bank did get the department of aging involved and they got, you know, they got to taken care of, but I think it was 10 or \$15,000.

Carrie Chiusano: Oh my! Well, you know, and the, the businesses that we've gone to have been really, really accepting. And it's kinda cool too, because then, you know, the goal is for their team members to get educated and recognize the signs and symptoms of dementia, but to feel confident in better communicating with the individual living with dementia, but most importantly, ensuring the interactions with the person living with dementia is a pleasant experience, not just for the person living with dementia, but the person providing the service too.

Like sometimes it, you know, they... they're just nervous because they keep asking the same questions over and over again. And the person providing the service just kind of doesn't know what to do. So having that information now and knowing how to handle and at the end of the session, it's only an hour.

The business receives resources, different resources for different things that they can offer to the customers that are coming in a certificate of attendance. And then they get a window cling to proclaim that their business is a dementia friendly business. And then we send that out to all of our dementia, 360 clients, anybody who takes, you know, anybody in our communities within the network.

You know, we share that with people, you know... hey, my mom really loves to get her hair done, is there any place that you can recommend, as a matter of fact, I can. And so it's been something really nice that we're able to do. You know, we want to make a dementia friendly community, wherever we can.

Amy Braun-Bostich: That is such a great program. That's fantastic. What are the biggest challenges to caring with the person living with dementia at home?

Carrie Chiusano: One of our most important goals is to minimize ER visits and hospital stays. Even short hospital stays can escalate dementia symptoms and lead to sudden deterioration.

We've actually found that one of the key benefits of our dementia 360 clients is they have had fewer and shorter hospitalizations. People don't realize what going to a scary, strange place is. And you know, many people living with dementia also have other health conditions, diabetes, cardiac, respiratory disease, weakened immune systems, and believe it or not, another big one is poor kidney function.

So many of these conditions, if not carefully managed can lead to sudden health crisis requiring an emergency hospitals, a stay, maybe just a visit to the ER. And if we are able, as the care coordinators to take those visits and take those emergency visits away, and we can walk them through the things that they need, sometimes it's just because they're not taking their medication properly or they've run out of their medication.

And, you know, they need to find a way to get that. They don't know that some of the Walgreens actually deliver some of the other things that they do send in... we'll connect them with an in-home help so that they could come and make sure that their medication is laid out for them and do what they have to do.

Okay. You just take this every morning. Here it is lined up in a pill box, but getting them to get the pill box filled, they're not able to do that. So again, infuriating for them but helping them remain independent, but giving them the tools to do whatever it is that they need to do.

Amy Braun-Bostich: I remember setting up alarms on one of my client's phones because they kept forgetting to take blood sugar measurements.

So I said, hey, let's just set it up on your phone. But that was sort of one of the beginning stages of realizing that, you know, they weren't functioning properly.

Carrie Chiusano: And those little things... for example, we were talking this morning, we were talking about a client this morning that he's afraid. He's caring for his wife. She is healthy, healthy, healthy is all healthy can be. He cognitively is much better, but he has a lot of trouble with gait. He falls quite a bit. So they did some research and it's amazing to me, like you said, the phone setting up the phone for her to take her medication.

The phone can recognize if you fall, it will call you to make sure you're okay. If you don't answer, it calls a designated person, whoever you designated. I'm thinking, holy smokes, you can have it on your apple watch too so, you see all these 85 year old's wearing apple watches, just as a helping them in case that they have a fall.

Amy Braun-Bostich: I actually bought one for my mom a few years back just in case, you know, she would fall. She's still really good and she's living on her own, but it's always just such a fear that they would fall and not be able to get back up.

Carrie Chiusano: Right. It's peace of mind, right Amy?

Amy Braun-Bostich: Yeah, definitely. I had a client one time fall, and she was living alone, and she couldn't get up and she laid there for like a day and a half and that it was just, just so sad. You know, it really, really stuck with me as it would.

Okay. Maybe now you can let us know. So, you know, everybody wants to stay at home and the family really doesn't want somebody to go into a facility. But there's a certain point, I guess, where it just, it's not feasible to take care of somebody at home.

So how does a family know when it's time to consider a care community?

Carrie Chiusano: Well, from my standpoint, in what I suggest to a lot of people that I interact with is first and foremost, I state that dementia is a progressive and terminal disease. You don't get better when you're living with dementia. Medications and therapies, they can alleviate some of the symptoms and slow the progression down, but there's no cure.

And the goal for many family members is to keep the person, like you said, staying at home, caring for them at home until the very end, but other families aren't able to do that, whether it be you know, the person that's the caregiver, isn't healthy enough to make that happen.

It's just not an option. There's so many reasons why it can't be an option. And day by day, week by week, it starts to be something that, that really breaks a person down and you have to worry about your own health too. Regardless of the family's goal, sometimes it's just really important.

It's very important to have a plan in place before it becomes a crisis. Our dementia 360 clients have preferred status within our Woodside place communities as well as the rest of our network. But when somebody is no longer safe at home and that's not just the person living with dementia, but like I said, the family that's around them, caring for them.

That's when I really push and say... hey, if we can't keep people safe, that's when I really recommend... and for us at Presbyterian Senior Care Network, you can put in an application. That doesn't mean that they have to come in, you've already made all the decisions.

You've already submitted everything that you have to. So when a crisis happens, we have everything you need. I'm sure you preach that quite a bit, don't you?

Amy Braun-Bostich: Yeah, yeah. To have a plan in place. And I just see, you know, I see a couple of things happening either, you know? So they, the spouse tries to take care of the other spouse, but they're both roughly the same age.

And sometimes, you know, the spouse has some, you know, disease processes going on, but they get help. And then when, you know, they have to start looking at round the clock help, or the help gets too expensive, you know, then they're like, you know, they feel guilty, but they have to do something about it. So it becomes a financial issue.

But they've probably pushed that beyond where it should have been pushed. It's just that running out of money now has, you know, caused them to, to think about other options.

Carrie Chiusano: A lot of people will bring in the 24 hour care so that they can keep their family member at home, but that is so expensive. And then, like you said, when it comes time, when they're ready to move in, they may not have the funds that they used to. They've exhausted. So many of those with the 24 hour care.

Amy Braun-Bostich: I think I had a cup of clients spending on, you know, probably 200,000 a year on, you know, around the clock care. So even really wealthy people, you know, that's, you know, a few years of that can really take a toll

Carrie Chiusano: Personal preference, right?

Amy Braun-Bostich: Yeah. So the community, you said you're Woodside communities... are there multiples throughout the Pittsburgh area?

Carrie Chiusano: Well, there is. So Presbyterian Senior Care Network is, you know, we have communities from Erie to Washington PA. We did open our first Woodside place, personal care community on our Oakmont campus in 1991. So we're celebrating our 32nd year.

That's just crazy thinking about that. But the Woodside philosophy was really introduced in a different way to think about dementia care. It's so different from the institutional setting that was common for dementia care at that time. So the Woodside Place model was based upon the merits of residential living.

We use visual cues that encourage mobility and comfort with a secure atmosphere. It's more of a social model rather than a medical model. I like to tell that to people because they think of a hospital like community, but it's not like that at all. It's not a hospital setting. It's very residential.

And today the Woodside program model is evident across our entire network. There's three freestanding Woodside communities, two of which are personal care. That's the Oakmont one and the one in Erie. And then we recently opened in February of 2020. Woodside Place of Washington and that one is licensed as assisted living all are designed specifically for individuals living with dementia and our Woodside program and philosophy the live in the moment.

You know, we really focus on living in the moment. It's really integrated into our eight skilled nursing communities, all of our personal care, you know, and now we have dementia 360 to

add to that. It's been a great journey for me. I've been there since 1984. And, and to just watch it grow and evolve has been such a blessing.

I just feel so honored to be a part of it. So I hope that this has been helpful for your listeners Amy.

Amy Braun-Bostich: What great information you've shared, and I thank you so much. And if, if people listening want more information on Alzheimer's or other forms of dementia, where should they start?

Carrie Chiusano: Oh, well, of course you can call me or any of our care coordinators at dementia 360. My direct number is 412.826.6065 that's 412.826.6065. And you can get to the dementia coordinators. That dementia 360 line is 412.435.8950.

Amy Braun-Bostich: Thank you so much. You've been incredibly generous with your time and you're such a wealth of knowledge. I really appreciate it!

Carrie Chiusano: Oh, it's my pleasure. Thank you. You take care.

Amy Braun-Bostich: You too.