



**Transcript of "Caring
for and Communicating
with the Alzheimer's
Patient"**

**With Bill Hammond
and Jo Huey**

**Anthony B. Ferraro, Partner,
Robbins DiMonte - Attorneys at Law
216 Higgins Road
Park Ridge, IL, 60068
Phone: (847) 221-0154
AFerraro@robbinsdimonte.com**

Caring for and Communicating with the Alzheimer's Patient

Hi, this is Bill Hammond. I'm here with Jo Huey. Jo is a nationally known expert on Alzheimer's disease and caring for folks with Alzheimer's. Jo

has written books on Alzheimer's and it's a delight for me to have you here today, Jo.

Thank you. It's a delight to be here.

Thanks. What are the major challenges in communicating with and caring for someone with Alzheimer's disease?

Well, I think the major challenge is that they're not interpreting things the same way that we are and we have to get a lot of things done because life is busy and you have to do a lot of things. And so, there has to be a little bit of a mind shift for the caregiver to just understand that you are going to have to communicate in a different way. And it seems like just an initial burden early on, and so what I've done is I've kind of helped people understand what happens with the disease process and then figure out a way that you can communicate a little bit differently so that you can accomplish things but also so that you can enjoy your time together.

Yeah. So let's start there. What happens with the disease process? What's the Alzheimer's patient going through?

Well, they're going through a problem in keeping track of information, being able to store information, retrieve information, and they truly just can't remember some things that they have just done. There is this thing I refer to as a brain gizmo that just doesn't work in their brain anymore. And so it's supposed to store this information and it doesn't store it and it's supposed to retrieve information and it's not retrieving it. And so they're kind of in a world where they're really just in the here and now and sometimes that isn't even a few minutes ago. And then in another way, they can think way back in time because it's kind of the way the brain is degenerating is in reverse order. So it's from the time their brain gizmo isn't storing information and retrieving it on back. It's like if you took a big eraser and it just erased from a period of time backwards as time goes on. And so the majority of what's left in their brain is in a previous place in time. So that tends to be more where they're at and we're in today. and so, the natural inclination and communication is we try to bring them forward to what's going on today and they're not capable because their gizmo is broken, so they can't keep track of the most recent things and it's much easier if we can go back in time and deal with they're at and there are a lot of clues about where they're at based on what they're talking about.

Uh-huh. And I think that one of the things I understand from talking with you is that one of the things that we caregivers need to do is we need to simplify the daily tasks so that we can create positive interactions or whatnot, and I know that you have a series of, I think what you called, ten absolutes for caregivers. Almost, if you will, rules that make it easier for

the caregiver to care for the Alzheimer's patient. So Jo, let's start out. In no particular order, what's the first rule for caregivers?

Well, and it's interesting that you say rule. I learned a time back, when I was running the assisted living communities that I had helped create for people with Alzheimer's disease, my staff called them the ten rules and, you know, I learned, when you're just dealing with human nature, people don't like to follow rules. So I did a little rhyme game, I guess you could call it, and I changed those rules to tools because people will use tools. People don't want to use rules. So, I just might bring that up and it was so interesting.

I like that. Yeah, so what's the first tool?

Well, the first one is you should absolutely never argue. What you should do instead is agree. Now, there's a little history on how these got developed because I tend to be a pretty positive person and I'm saying absolutely never, which is really a negative way to start it out. Well, this happened. I had a lady with Alzheimer's disease who lived in my home with me, which is a whole other story that I won't get into, but I took care of her 12 hours a day, 7 days a week. Her family allowed me to hire someone to take care of her 12 hours a day, 7 days a week. And all of these years, she's still in the top 5 of the most difficult people I ever dealt with.

Wow!

In order to keep someone who would come that other 12 hours so that I could get out of the house, I would find myself writing lists and I would say, and don't do this and don't do this and don't do this and don't do this. And one of the wonderful caregivers who stayed with me 2 ½ of the 3 years I took care of this lady, said to me one day, "Jo, stop telling us what not to do. Would you tell us what to do instead?" And so that's how this tool was developed. And so you should absolutely never argue. And what you do instead, getting onto that positive side so that this is a useful tool, is you should agree.

So give me an example.

Well, I'll actually give you two examples on this one, Bill, because they're classics. There are two things that Alzheimer's people, particularly on the middle stages, when they're requiring a lot of care and a lot of things where you need tools for, is there are two things that they do. And the number one thing is they tend to look for somebody who is deceased. And that's really a difficult one for family members in particular to deal with because, you know, it's really hard to know what to say. I mean they're looking for somebody that's dead. And that's where that little analogy I used earlier

that says, that little eraser, well, in their mind that person is dead because the majority of what's in their mind is in a previous place in time.

█ Sure.

█ And you think well, and social workers will tell you, well they have a right to know they're dead. Well, they do but most of us that have experienced that when you say, "Well, they died." They will say, "They died. Somebody should have told me. Well, I didn't even get to go to the funeral." And we, in response to that because we think oh, my gosh, now what have I done. And we say, "But you did go to the funeral and you wore your blue dress and we had pie and coffee at the church afterwards and Uncle Tom came." And we're going through this whole scenario and before we finish it, they come back because they're gizmo is broken and they're not keeping track of the most recent things, and they will make the same statement they said at the beginning of the conversation. Well, I can't eat dinner until Tom gets here and Tom was the husband who has recently died. And so you're both so frustrated. So what do you do? Well, what you do is you say a sentence that is the truth because they really understand the truth and they know if you're saying something that isn't true, and so you tell them the truth.

█ So, as an example, you said, you know, we've got a situation, a husband and wife. The wife has Alzheimer's. Tom is the husband and Tom recently passed away. And the wife says to someone, "I can't eat dinner until my husband, Tom, gets here." Tom has passed away. What do you say?

█ And this is the classic answer that you say. You say, "Well, I haven't seen him today." Because, you see, that is the truth if he's dead.

█ Correct. Yeah.

█ And then you change the subject to a better subject and say, "So how about if we just start with this and go into what you're doing." And they may give you the opportunity to go through that same scenario all over again. And how do you get better at things? I'm asking you.

█ Practice.

█ You practice.

█ Yeah, practice. Of course.

█ So you might get the opportunity to say it again but it's a much better scenario than going through the he died scenario and both of you getting upset. And so, a good answer when somebody is looking for somebody that is deceased is to honestly say, "I haven't seen them today." Now, another example, I said that there were two.

Right, two.

The other example is when they say, "I want to go..."

Home.

And see. We hadn't practiced this at all and you knew the answer to that.

Sure, of course.

It's such a common phrase that in almost everybody's book that's written about Alzheimer's, including mine, there's a chapter about, "I want to go home."

You bet.

And I have the answer for that one. It's the only thing that I tell people that they should memorize but I make it really easy for caregivers. And that memorization requires only three words, five easy letters. And when they say, "I want to go home." The answer for them is, "So do I." Now, we believe that home is them looking for a better place in time. And if, as a caregiver, you've ever dealt with this I want to go home issue, you know that it's really the truth that you want to go home too if you're going to go through this downward spiral of when they decide they want to go home. Because once again, based on what's in their mind, you can have spouses who are in a house that they've lived in for 45 years and the spouse with Alzheimer's is saying I want to go home. And the clue to the person who is with them, although it hurts and is painful for a spouse, is that the majority of what's in their brain is previous to that 45 years in time. Now, when you say, "I want to go home," and the reason I put it under agreement, what that is doing is it's putting you on the same page, which is a term that we talk about.

Sure, so do I. Right, great. So do I.

And so you're in agreement. When you're in agreement, you can manage almost anything together. If you start the disagreement, such as the classic answer, by saying, well, you are home. If they would have thought they were home, they wouldn't have said it in the first place and thus, you have created an argument even though you aren't trying to argue.

Yeah, that's a great tool. The second one, I think you said, was reason.

You should absolutely never reason. Now, I give a lot of reasons of why you shouldn't reason and it's just a takeoff on that same arguing thing.

Uh-huh.

If their gizmo is broken and they can't keep track of the most recent things, then all the reasons you are giving them to do something they don't want to do is just kind of getting in their face.

It doesn't do any good.

Exactly. And what you need to do is just change the subject and just tend to move a little bit forward. Now, I use my instead as the word 'divert' there, which is just a nice, easy word that means change the subject to a better subject.

Sure, yeah. Good. Okay. The third tool.

The third one is you should absolutely never shame. Probably a more common word that we use now is the word 'embarrass.' So if you'd like to substitute that word, they are interchangeable there. And that's really important to be aware that the person that is impaired, it's not their feelings that are impaired and that's so important for you to know. So they are easily embarrassed and they don't even know what they've just said, even though a lot of times they say things that are inappropriate or maybe not even actually true, or embarrassing. And the only way that they know that they have said something wrong is by the look on our face or our reaction or what we say to them and that can really hurt their feelings.

Yeah. What's the fourth tool, Jo?

Well, the fourth tool is you should absolutely never lecture. Now, the shame and lecture go together here. And the reason that I say you should never lecture is because we're kind of an I-told-you-so society. And when somebody is having trouble keeping track of the most recent things and retrieving what you've just promised and all of that, we tend to kind of get in their face. It's really important for us to understand that by the time these tools are going to be effective with people, when we're having serious problems communicating, they probably are far enough in their disease process to have frontal lobe damage. Now, the frontal lobes are where, and I use very lay terms, are where I say that the manners are stored.

Ah!

And so, what happens with people, is they will just say whatever comes into their mind. Now, the reason I carry this back into number three too is often they will say things that are very embarrassing. And so then we say, "Ah, why did you say that?" So we become accusatory and then we follow-up when they're naturally going to say, "Well, I never said that. I would never say such a thing." And then there's another thing that's located in that frontal lobe and that's the impulse control. And so when we get in their face and we start lecturing them and accusing, they very often might think that they would just like to smack us or shut us up or get us to get out of

their face and, if they've lost their ability to control their impulses, this is where the aggressive combative stage of the disease kicks in and they might be aggressive or combative with us.

So if we don't lecture them, Jo, what do we do instead?

Well, what you do instead is you offer assurance. You know, they say, "Well, I would never do anything like that." You know, it's okay for us to learn to apologize, apologize, apologize even if we haven't done anything wrong. Again, you can be real honest and you can say, "Well, I just don't know what got into me. I'm so sorry this happened. Will you ever forgive me?" And just go right into a next thing of going back to changing the subject.

Okay. We're on a roll. What's the next one, number five.

Well, the next one is you need to take the word 'remember' out of your vocabulary.

Ah, makes sense.

You know, we don't ask people that have gone blind with macular degeneration if they can read and turn on the lights and say, "Well, if you tried you could just read a little better." But even the questions on the tests that we use to establish, the Mini Mental Exam, are direct questions. Do you know, I don't think anybody likes a direct question. You know? Don't you always know that somebody is going to ask you the one question you don't have the answer to?

Right.

Well, that's where they live all the time.

Yeah, and this Mini Mental Exam that you mentioned, that's a tool that sometimes physicians use to help at least to begin to diagnose memory problems.

It is. Yeah, it is. And it's just a small exam. You can get a score of 30 on it and most people have heard it. They also use it when you're coming out of surgery. They ask you if you know little things like what's your name, who is the President of the United States, those kinds of things. So yeah, it's a standardly used tool. So it's real important that when you're talking with someone that you don't put them on the spot. Nobody likes direct questions. They live most of the time in knowing that they don't know the answers to questions. It's why even yes/no questions don't work very well.

Right.

You know, don't ask yes/no questions if no isn't an acceptable answer, but have another little thought about that. If someone doesn't know what you're saying to them, no is honestly the only safe answer. And so that's why you get a lot of no. Now, I want to go to...

So if we don't say 'remember,' then what do we do? What's the instead?

Well, what you do instead is you reminisce and you're like well, now how can I reminisce without saying 'remember' because it just clicks in. And you just say, "Well, do you remember when?" Well, what you do is you start in the middle of the sentence, which in effect let's them be the smart guy. So if you're looking at picture books, and picture books are a great tool for reminiscing because they are pictures that are taken of things in the past, because they're already in picture form. So instead of saying, "Who is this in the picture?" Which is asking a question, you can say, "This looks like..." and if they don't know and they don't care, they don't know and they don't care. But if they do, they can be the smart guy and they can say, "It looks like Tom. That's not Tom. That's me and I'm standing in front of my 1930 car." And, you know, it really is a wonderful reminiscent tool. So what you do is you go back and you can just start a sentence and say, "Well, that one time when we went to the park down in Colorado Springs," and they will just chime right in. And so that's how you use that reminiscent tool.

Yeah. Good. Okay. We're halfway home. That's the first five: don't argue, don't reason, don't shame, don't lecture, don't say 'remember.' What's the next one?

Well, the next one is when you kind of get to that point as a caregiver, and often I demonstrate this one by standing up and punching my fists and kind of gritting my teeth. But I think I can emphasize it here a little bit. When you start saying, "I just told you. How many times do I have to tell you?"

Right.

You know, with repetitive behaviors and hearing the same thing over and over and trying to deal with it, you know, as a caregiver you can get pretty stressed out. It also is a sign, this is a sign to you caregivers that you're trying to do too much. It's time to accept some help.

Yeah.

But the immediate tool is you need to regroup. And the one you need to regroup is you. You need a sense of humor. And do you know...?

And that's the instead, the regrouping is the instead.

The regrouping is the instead. And do you know, you can just go out and come back in again. Now, that sounds a little silly, but you know, sometimes just that change in posture or change in positioning, change in room can make a huge difference. Take a deep breath. Count to ten. We all know those things when we're kind of losing control and we just have to bring them back in.

That's great. What's the next one, Jo?

Well, the next one is you need to stop saying, "You can't." You know, you will say, "You can't say that. You can't take that. You can't do that. You can't go to the bank, it's midnight. You can't go outside, it's raining. You can't, you can't, you can't."

Yeah. So what do we do?

Well, you know, they're painfully aware of how many things they can't do. So once again, I always challenge caregivers because they're responsible people or they wouldn't be caregivers, that we have a responsibility to find out what they can do and we need to provide the things that they can do so that they have meaning and purpose in their life. Life is too long, that's why they call it the long journey, for them to just sit around being essentially cared for and having nothing to look forward to except the end of their life.

Uh-huh. That makes a lot of sense. The next one - command.

Command and demand. You know, when you're busy and you have to get things done and you need to get them done on schedule, you get very commanding and demanding and they don't respond very well to that. Nobody likes to be pushed around and so we commend and we demand and we try to make them do things. And they have different disease processes that are coming in, like just things like sitting down on the chair, getting into the car, trying to eat. Sometimes their body doesn't do what we want them to do. And so what you need to do instead is you need to step back again, this is about you. It's your tool. And remember that a picture is worth a thousand words. So if you want someone to eat, sit across from them and show them how to eat. Or provide them with the ability to get to a place where they can go into their rote or what we refer to as automatic pilot. Or, if you want somebody to just sit down, sometimes they have trouble, they'll just stand and can't sit, then get them to look at you and you go through the motions. A picture is worth a thousand words. And instead of trying to tell them what to do, you can show them what to do.

Good. What's the ninth one, Jo?

Well, the ninth one is never condescend. Don't talk about them in front of them like they're not even there.

Don't talk down to them.

And you know, one of the places that this comes in often is like when you go to the doctor's office. You take them on an appointment, so you're not really trying to talk about them in front of them but let me draw a little scenario for you here. You're in the doctor's office, you've been waiting and waiting isn't one of the things that they do very well because they are kind of antsy, and so you're sitting on one side and they're sitting on the other side. The doctor walks in and looks at them, which is appropriate, and says, "And how are you today? What can I do?" And they say, "I'm just fine." And the doctor thinks, well good. I was running behind anyway and starts out the door and you just up and run over to the door and say, "Well, but we need to talk about this and this and this." We're talking about them in front of them like they're not even there. So what works better is when the doctor comes in, you get up and walk over and be with them. It's a change in positioning. And when they say to the doctor, "I'm just fine." Because that would be the normal response; it's good social graces. You say, "Well, doctor. They're just fine but we've made a list of things that we were going to talk to you about today," and the two of you together talk to the doctor and the doctor answers the two of you and then it's with them and not about them and you're all more receptive.

That's wonderful. What's the last one?

The last but certainly not the least is you should absolutely never force. When a person is forced to do something, whether it's get into a car, take a bath—that's a big one that comes up really often—when you are trying to force someone, and sometimes you get help. I can remember one time when somebody told me that it took five people to get their mother to take a bath. It's a scary thought, but when you use force, there is a psychological response that kicks in and it's called 'fight or flight.'

Oh, yeah.

Or I'm sure that you've heard of the adrenaline response when a little lady can pick up a car to get her son out from under it. And when they get into this fight or flight or adrenaline response, somebody is going to get hurt and there's a secondary thing that you don't want to happen with somebody getting hurt, is it puts a label on them that they're a danger to themselves or others and sometimes that can keep you from having care on down the road. This is truly where the aggressive combative stage of the disease comes. So if they need something to be done, you need to find skills and techniques and sometimes you need to back off and just wait for a better time so that you can reinforce the positive things you want to happen and don't force somebody into doing something that can create a whole new set of problems for everybody involved.

Yeah, that's really helpful. That's ten tools. I love that and I know our listeners will want to go back over and listen to that again and again. I'm going to real quickly run down through them. Basically never argue but instead agree. Never reason, instead divert. Never shame, instead distract. Never lecture them, instead reassure them. Never say remember, instead reminisce with them. Never say, "I told you," instead repeat or regroup. Never say, "You can't," instead tell them what they can do. Never command them or demand that they do something, instead ask them or model behavior. Never condescend, instead encourage them or praise them. And never force them to do something, instead reinforce. And I think those are great tools. Now, obviously, Jo, there are certain situations or challenges that are going to demand some special, I don't know, skills or interventions or whatnot. And let's just go down through some of them rather quickly because I know these are things that people face. So bath time. We've talked about it a couple times. What do you do at bath time?

Well, bath time is a really special one. And people say to me, why is the bath such a problem. And I say back to people, and I'm going to do it here, how could the bath not be a problem. You know, taking off all of your clothes and having your body washed is a really private thing.

Right.

So I ask you and every listener, who is it in your life that you would like to remove all of your clothing and give you a bath because they determine that that was something you need? Is it your spouse? Your parent? Your child? Your grandchild? Your sister? Your brother? The next door neighbor? Some stranger? You see, when I put it that way, you realize that hmm, you probably don't really want any of those people doing that. So it's going to need to be someone who has rapport with you and there's one other thing. You know, you don't have to take a shower or a bath to get clean. Sometimes you can just do it in peace and part. And so what I like to do in developing rapport is let's just talk about the same thing but a little bit differently. Now, who is it out here who wouldn't like a day at the spa? Now, think about that. You know, you get this relaxing robe that you can put on.

You can get pampered, sure.

They put a hot towel around your neck, you know. You can put your feet in a foot soak and that's nice warm water and sometimes it kind of moves. Do you see how I'm drawing a whole different picture?

Uh-huh. Oh, yeah. Yeah, absolutely.

And so what you do is you might start out just helping somebody wash their feet. You might start out with just a nice warm washcloth. You know,

sometimes it's pampering. You can go out for barbecue or something and somebody will hand you a nice warm washcloth and you can wipe your hands with it. So you know, and then you can kind of just motion. They'll often follow you. A picture is worth a thousand words and they'll rub it on their own arms or around their neck or around their head. And then you can say, "Oh, your shirt got a little bit wet. Here, let me help you take this off." I think I'm drawing a picture of how you can develop a rapport and you can work into this just by approaching it a little bit differently instead of coming up and saying, "Okay, it's time for your bath and now we're going to take a bath whether you like it or not." You know, it's kind of a human natural response and it makes a huge difference.

Wow, that's really helpful information. A real difficult situation for a lot of folks, Jo, is when someone becomes incontinent. Talk about that. What do you do as a caregiver?

It's really tough and it is the time when people often decide they just can't do it anymore. They have made a wonderful new thing and they're called pull ups. They're made by different companies. And for me there are actually products that can be used that are more in the front for incontinence. So one of the things to do is to use that kind of as a preventive. And so, you know, you want to start using those. I know little ladies who even wash out their pull ups so they can seem like normal underwear. And that will help a lot with that. And start showing people the bathroom. Often they just don't remember how to go. So they don't have to be incontinent if you can just say, "Come with me. Oh, look. There it is. I bet you needed that." And often they just need, again, from rote to get to the point to where they can see it. So a lot of this can be very preventive. And then when it is beyond that, then a lot of times you really need to get some assistance to take care of that.

Okay. I think one of the real challenges for Alzheimer's caregivers is the caregivers don't get enough sleep and I've heard so many people say this, when their spouse has sleeping problems or when the spouse is wandering then the caregiver never really gets a good nights' sleep and then the cycle begins over and over again to where they become exhausted and it starts this whole downward spiral. So those two are kind of related. What do we do with sleep issues and particularly what do we do with wandering where it occurs at night. I mean how do you handle those as a caregiver?

Well, the first thing that you need to do is you need to look at the daytime. Usually what's happening is they've got their days and nights turned around. And so in the daytime they're snoozing a lot in their chair and you're so tired you're just grateful that they're doing it and you don't want to do anything about it. So, there are some things you need to find ways to keep them busy. And you know what, when I say 'you' I'm talking about the caregiver. If you can't send them out to some kind of a program, then

there are people that you can hire to come in to spend time with them so that you can go catch that nap that you need and so that you can get their days and nights turned around. Or sometimes you might need to hire somebody to come in for a night or two or have them stay someplace for a night or two until you can both get things back on track.

That's great. Let me go through some of the questions that I know people frequently have. And let's just kind of go down through these. Jo, what are the most common behavioral outbursts and how do you deal with them?

Well, the most common behavioral outbursts really tend to be a reaction to something that the caregiver has said. You know, it sounds like I'm picking on the caregiver here and I'm really not. It's like anything else in life, the only thing that you can change, the only thing you have any control over is yourself. And so that's why I like to provide tools. So, they'll really usually only outburst back to you or something that consistently makes them very angry. And so you need to try to set up things so that that doesn't happen; so that they don't have anything to respond to and that they're not getting upset about things. So let's say they always look for their wallet and they feel like their wallet has been stolen. You want to provide. It's okay to get several wallets that look alike because they're going to hide their own wallets. So get you a bag of wallets. You can get them at the thrift shop. Get you a bag of wallets and every time they're looking for their wallet just provide it to them. Do some preventive things because you can clearly state what their outbursts are about. You know them because you've been practicing them.

Yeah. So you go through and you figure out what particular things set your loved one off and then you...

And you do some preventive measures.

Wonderful. What if my loved one is out of control? I mean if it's gotten to the point where, for whatever reason, they are really acting out, how do I calm them?

The very best thing to do is apologize, apologize, apologize, even if you haven't done anything wrong. You can be sincere and say, "I don't know how we got to this. I am so sorry this happened." They will hear the sincerity, so you have to be sorry and you are sorry that it's gotten to this, whether you were responsible or not. And ask if there's anything we can do to change it or forgive it. Ask for their help and very often that's just enough to change that. It's almost like magic. It really works almost every time.

Do you see where people sometimes have UTI, urinary tract infections, and it causes outbursts and they can't really vocalize what's going on?

Very definitely. A key equation that I use, and I write it up all the time, and it's called 'dramatic change in behavior equals illness.' So, when they sleep particularly late, they stop eating when they've always been eating, if they're particularly grumpy, acting out, maybe want to strike at you, if those are things that aren't their norm, then they're definitely ill and those are the signs for that and you need to get some medical attention right away. The disease process itself is very slow moving. So it's not just the disease when you have a dramatic change and that's so important for all caregivers to know.

Good. Does bribery work? And if so, how do I do it?

Bribery absolutely works.

Give me an example.

It's one of the quick change things. You need to know what their favorite things are and you need to use it. Now, you know, intellectually we all know that bribery works. Usually their feelings have gotten hurt, they've been embarrassed, something's happened. They may not even remember what it is but that feeling is sticking there and the best way to change somebody's status—now, let's just go back to our normal human beings because that's a good frame of reference for us to start with. Let's suppose that you did something wrong or you were just accused of doing something wrong and it really hurt a dear friend. And it's important to you that that friend isn't mad at you anymore. An apology might help, but you know what, if you come in with flowers or with chocolate or with something that you know especially they love, you know, they're going to accept your apology a little more quickly. So it works.

And then you get that quick change for the positive.

Yes, indeed. And it works with them as well. So, know what their favorite things are, keep those favorite things around and use them. When things get out of control, bribery works.

Yeah. We touched on this earlier but I want to go back because I think it's so important. I think so many people who have Alzheimer's, you hear from them I want to go home.

And I truly believe and many professionals believe that at that particular moment they're tired, they're bored, their fatigued. They may even be getting ill. They're just looking for a better place in time and the word for that is 'home.' And so the best answer for that is three little words, five easy letters, "So do I." And that puts the two of you in this issue together and, when you do something together, you can solve anything.

Is there a simple gesture, Jo, that I can use to change my loved one's disposition quickly?

Very often there is. They tend to be much more willing to touch. Now again, if somebody has space problems, they're all individuals. You don't walk into something. If somebody is shaking their fists, don't try to touch. And it's important to say that because sometimes people misread that. But often, if you will just open your arms or just sit down or use a posture that's basically saying, oh, dear. How did we get here? I'm so sorry. How can we fix this? Let me give you a hug. That kind of thing. That will almost always break something, particularly if it's coming genuinely from your heart. They will pick up on that. They really read you very well.

Uh-huh. The advice that you've given people, the tools here are literally things that it would take years and years of caregiving experience to know and understand and you've short-cutted this for so many people and it's such a gift. I would be remiss if I didn't let our listeners know the full story of Hurricane Huey, as we call you sometimes. You have the most amazing story and everybody is familiar with Hurricane Katrina. What they don't know, of course, is how that affected your lives and the lives of the ones you were caring with and I would feel honored if you would take a few minutes and tell us what happened during Katrina and how it started a whole new odyssey for you.

Well, once again, we just never know what life is going to hand us. I had practices. I had actually practiced hurricane evacuation. I moved to Louisiana 12 years ago and one of the things that we knew there, and people do agree with that, although that isn't necessarily what's reported on the news, is that the city of New Orleans will never be safe if you get a full blown, over category 3, using their terminology, the hurricane terminology, is never going to be safe because even if the levies hold, between the lake and the Mississippi River and being below sea level New Orleans is in a bowl. And so what can happen is the storm surge after the storm can come over and fill up the bowl. And so, because we know that we're not safe there, the plan, particularly for responsible people, and I was responsible for people with Alzheimer's disease, is that you have to evacuate.

And when you say you were responsible for people with Alzheimer's, what were you doing?

I ran 24-hour care homes that I had been recruited to New Orleans to start based on a model I had created.

So nursing homes.

They are actually small assisted living group homes.

Assisted living facilities. Okay. So you had folks with Alzheimer's who were living in these group homes.

Yes.

And they were your responsibility.

And they were my responsibility and you had to have an evacuation plan and I had just moved my mom into those homes. We had a capacity for 30. Don't tell the state, but we actually had 32 people then because we were over capacity and 26 of them went on the evacuation with us.

Wow.

Now, we knew how...

So I'm picturing myself sitting in Kansas City watching the news and we're seeing that there's going to be this Hurricane Katrina that's probably going to hit New Orleans. And so I'm looking at this and feeling for everybody but I have to tell you that it's the kind of feeling that we all have when we see something going on in some part of the world that does not affect us, and yet you are in New Orleans with Alzheimer's patients who are totally reliant upon you. The news media is telling us what's happening. Pick up the story. What's going on?

Well, we had to evacuate. And we had practiced a lot, so we were good. The caravans that we had ordered from Hertz, who is number one, you know, they want to get their cars out, too, so the caravans we had ordered, I don't know, something just didn't work out and we ended up with Ford Expeditions. But you know, the good news was that it was harder for people to get out of those. So we got our cars and we headed out on gridlock and, you know, we were only going a two hour drive but it took ten and that was okay because we had learned how to manage all of that.

How many cars did we have in this caravan?

We had six rental cars and we had a pickup truck because we were taking along a lot of stuff that we needed and I had my own car and then we had another car that was being driven by two family members. So I was trying to run a caravan of 11 vehicles in gridlock with contra flow, which means sometimes they'll send one car one way and one car the other way because they're changing the direction. Everything is going out instead of coming in.

Sure, sure.

But we had gotten good. We had walkie-talkies. We had done this drill before. So, we did a good job. We got evacuated. We got everybody all

fed and settled after our lengthy ten-hour drive to go a two-hour distance. And then this time it was different. I equate it to a fire drill. How many times have you done fire drills, whether you were small children or adults in an office building and how many times did the building burn? Well, that's kind of how we were. We had done evacuation drills but this time we saw our city and our lives fill up with water, never to be the same again.

So you didn't have any place to take them back to.

We couldn't go home.

Yeah, so what happened?

Well, one of the plans was what do you do when there is no way to go back home? And I hadn't actually figured out that plan but I'm a pretty resourceful lady, so I found a new place. It had just opened up. It was an assisted living community about 20 miles from where we had evacuated to supposedly temporarily. And so it took us a little bit of time but we had gotten over there and we got pretty well settled in and we had three cane fields, sugar cane fields and it was harvest time. It was early September now and one 65-mile-an-hour highway and no secure doors and I had very wandering people.

Oh, yeah.

So there were a lot of things we had to do. We had good success. I had a lot of staff, 12 people who had gone with me. We were all settled in and thought we could stay there until I don't know when, until we could figure out how to go back home.

Sure.

But only three weeks had passed and then there was this other storm and they called it Hurricane Rita.

Uh-huh.

And they had a mandatory evacuation because they had learned in New Orleans if you didn't have a mandatory evacuation everybody didn't have to leave.

Right. No one was leaving, sure.

And so I had a mandatory evacuation but I had turned my rental cars back in. So I guess I don't even want to put on tape all the things I did, but it involved getting a bus that didn't belong to me and a whole lot of other things, but I got my people out and I got them safely in nursing homes in Arkansas and, because of FEMA and Medicare and a whole bunch of

consortiums that I probably won't even like the name of again, I had them settled and they weren't my responsibility anymore because I wasn't licensed to work in Arkansas and they had rules. And so I took my mom, who was one of those people. I didn't admit her to the nursing home, and my dog, who was along with us, and mom and I and the dog headed up the road and, after I called all the family members and told them where their loved ones were and they were safe, I also told them that I had decided I was going to retire from 24-hour care.

So Hurricane Jo Huey was actually chased across country by two different hurricanes.

Two hurricanes the same year, lost everything.

Taking a caravan of Alzheimer's patients. And the reason, Jo, why I wanted to make sure people understood that is because as a layperson I can only imagine the incredible caregiving skills that it must have taken to move folks with Alzheimer's under those kinds of conditions and all the tools that you had to make sure that they were all delivered safely, and you did that. And so folks who are listening to this will be well served to go back and listen to your tools and techniques over and over again because, as difficult as they might have it in their own household, it's probably not a whole lot more difficult than being chased across the country by two different tropical storms with a whole group of people who could not fend for themselves and whose responsibility was yours and you did it using the very tools and techniques that have been taught on this program.

Yes, I did. And also I might add that I had 12 well-trained staff who used these tools, at this stage, sometimes better than I did because remember I had my own mom with me and she really wanted to go home. She asked me repeatedly what I did to get us kicked out of our house and when we could go back.

Final advice to caregivers.

You know, spend time thinking about what is important. Do those hugs. Eat that ice cream. Take that walk. Do the things together that matter and, you know what, if everybody isn't perfectly clean and the house isn't in order, you know, none of that stuff really matters. The time we have together to enjoy together, that's what really matters and try to focus on that and the rest will just take care of itself.

Thank you. It's been a great gift for us. Thank you so much.

Thank you.

Anthony B. Ferraro, Partner,
Robbins DiMonte – Attorneys at Law

216 Higgins Road
Park Ridge, IL, 60068
Phone: (847) 221-0154