

Transcript of “Understanding Alzheimer’s and the Progression of the Disease”

With Bill Hammond, Rick Law and Jo Huey



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Understanding Alzheimer's and the Progression of the Disease

Bill: Hello. This is Bill Hammond. I'm here today with elder law attorney Rick Law from Chicago and Alzheimer's caregiving expert Jo Huey. Jo has been working with persons with Alzheimer's disease in 24-hour care settings since 1986. She has a certificate in gerontology from the University of Denver and a Master of Social Science from the University of Colorado. Her master's thesis was Effectiveness of Training for Alzheimer's Caregivers. She is the author of *Alzheimer's Disease: Help and Hope* and her new book, *Don't Leave Mama Home with the Dog*. She founded the Alzheimer's Caregiver's Institute in 1999 and in 2007 she became a certified Alzheimer's educator. Welcome, Jo.

Jo: Thank you.

Bill: Now, let's get right down to it, Jo. What is Alzheimer's disease?

Jo: Well, Alzheimer's disease is many things to many people. It sometimes is just something that we are a little concerned about when we say things or we can't think of things that we want to say and we say, "Oh, dear. It must be my Alzheimer's," or it must be my memory or maybe it's a senior moment. Or a new phrase is intellectual interruption that you can use. However, Alzheimer's is truly and statistically one of the most dreaded diseases. And it's not just a disease of the elderly.

Bill: Right. Let me jump in here for a second. I'm guessing as I hear you talk that probably a lot of people are thinking to themselves, how do you really know whether we're talking about Alzheimer's or whether there's just some other kind of memory issue or something going on. What are some of the warning signs as you understand it from the National Institute of Health?

Jo: Well, a lot of those signs are things that you pick up in everyday conversation with people you care about; friends, loved ones. You might just find them telling the same story or asking the same question over and over again, maybe talking about some issues that they're having with things that they could always do and they might freely express, more than just I couldn't find my keys the other day, but I wasn't able to do something that I've been doing for a really long time. And sometimes, and this is usually a much more advanced kind of stage, that you're just noticing that their hygiene just isn't what it used to be and there are just things that really concern them.

Bill: So how do you counsel families then as to what they should be looking at with their loved one to start to be concerned that maybe there really is Alzheimer's disease involved?

Jo: Well, I think one of the most important things and one of the things that we're the most fearful of is going in and actually talking to a doctor about that because you really do need to have a good workup. We all should have our annual physicals and, as a part of your physical, it's recommended anytime that you're over the age of 50 you should be doing some other things that have to do with what's going on with your memory and gathering some historical data about what you're doing. Because it's also important, just like the person who maybe can't balance their checkbook, if they could never do their checkbook and they never did their checkbook, that's not a risk factor.

Bill: Right, so when you say gather historical data, I mean I don't know exactly what that means.

Jo: Well, what that would mean is to actually set up some time to talk to the doctor about we're really concerned about aging issues and we wonder if aren't there some things that they have out there like a clock draw and we're concerned that I'm doing more than just forgetting my keys. You know, the other day I couldn't even think of the name of something that was very familiar to me and I had to really struggle with that. So when those concerns are coming up in people's minds, that's the time to start looking at it and gathering that kind of information and often, particularly nowadays, and the best thing to do is to early diagnose. You want to start looking into that kind of stuff early on so that you can see if there's a pattern and what kind of change there is.

Bill: Do we start with the family doctor? How do we know when to go to a specialist, what kind of specialist would we even be talking about? Where do you begin?

Jo: Well, I think you should always begin with your annual physical and with the person that's the most familiar with you. However, with insurance and all the things that have changed in this day and age, that might not be the first person. It might not be somebody that you know, but it's a good place to start with the general area. Usually, if you express some things that are on that simple list that you get from the National Institute of Health, the doctor is going to want to refer you on for some other information. So, that's a good place to start and then you can kind of move on. Doctors that work with it are primarily neurologists and psychiatrists. Again...

Bill: Do you have a preference as far as...?

Jo: Well, there's a stigma with psychiatry and so a lot of times people are a lot happier going to a neurologist. So I think preference is important. Particularly, it's important to be comfortable to be able to really express what's going on, what your concerns are, what your fears are. So the

doctor is a good part of that. Now, there are some other less threatening things that can happen, particularly if you've got someone that's not bathing, the house is kind of a mess; you've got some serious concerns there. A lot of times you can talk to your doctor about maybe just having some kind of an evaluation done that's going to be done through an occupational therapist to just see what it is that they're capable of doing. Can they run that bath water? Bathing can be very complicated.

Bill: And is this part of that historical process you talked about? I mean is it important to kind of get like a baseline here and then maybe look at it six months later or 12 months down the road or something. Does that help the person to figure out whether or not things are progressing?

Jo: Well, if it's really Alzheimer's disease, and there are a lot of other things that cause brain degeneration, if it's really Alzheimer's disease it's probably not going to show in a short period of time. It doesn't really show on scans, but over a period of time, they call it kind of a sloping thing, as you look backwards it's very important to have the information initially.

Bill: Yeah, so let's dig into that a little bit. I mean I know from some of the readings that I've done, I mean you talk to people and they say, I don't know, my mother was in stage 5 of Alzheimer's and there's this thing I think they call a global deterioration scale and it's got 7 stages. And what I'd really like to do today is see if we can't figure out something that's going to be a little bit simpler for people to deal with and yet still give them some structure. So for starters, someone who is in the early stages, talk about that. What kinds of things are we looking at? What kinds of symptoms for someone who is early on in the process?

Jo: Well, I want to talk about that in kind of two ways. There's the standard that we've been doing for early stage and we primarily look at that usually with people that tend to be more aging, maybe somebody over 60, maybe over 70. I don't know. You know, that aging thing becomes relative as we all deal with it with our own aging process.

Bill: Sure. Boy, I can attest to that.

Jo: We used to deal with it just as the early stages and we really talked about the forgetfulness, many of the things that are actually on the list that you can easily look up from the National Institute of Health, but I want to step back just a little bit more and what I said earlier is that we really want to start looking at this a little bit younger because we have what they call early onset, which means acquiring the disease under the age of 65. And we also have early diagnosis, which means finding out that you have the disease early enough so that you can help participate in some of your own decision-making about how you're going to go through that disease. Now,

some of the things for that very early thing can be something as simple as falling, people that are falling a lot for no particular reason. There can be things again that they are noticing very early on. People are very aware that there's something going on with them. And they're a little afraid about it so they say it out loud to other people and we all offer this assurance. Like, "Oh, that just happens to everybody. It happens to me all the time." Then, as they progress a little bit farther, the fear really sets in because they know themselves that they've really got something wrong and so what they're likely to do is kind of start hiding all of that because they're uncomfortable.

Bill: Yeah, they're reluctant to face it, aren't they?

Jo: And so there's that person that we want to capture when they start saying those early on things. It's great to be reassuring to your friends, but it's also a really good time to go and start getting some information and to start setting that up.

Bill: So if someone was seeing these types of behaviors and whatnot, where they start to know that something's going on, if they haven't done the annual physical, which you talk about, which a lot of people just don't. I mean I know we all should but lots of times they just don't. That certainly would be the time at which then they ought to go to the family doctor and start to discuss some of these things, right?

Jo: They should do that. Let me share something. There is this clock draw that you do that talks about one form. It's not the entire Alzheimer's, but a pharmaceutical company actually came out with it sometime ago and I was doing some training for physicians on how to use this clock draw. It was a presentation that I did.

Bill: Yeah. Now, put a picture in my mind because I'm not sure what clock draw means.

Jo: It actually is a round circle and it's one of the testing mechanisms that you do use as a part of testing for Alzheimer's disease. And what you do is you instruct the person, they have a round circle that looks like a clock, you have them put the numbers on the clock starting with 12 at the top and you actually give them that instruction. Then you have them put something like 10 minutes after 11, which they need to draw in the hands so that you're putting in the hour hand and the second hand. I just want you to know that myself, when I started doing that, it took me a long time to draw that clock draw myself because of that underlying fear, even though I worked with it, even though I was a professional, because it will show things that you really have no control over.

Bill: Well, sure, and I'm sitting here, as soon as you say that, and you said 10 after 11 and I'm sitting here thinking, okay, can you do that, Bill? You know, because that's concerning and then wow, I felt good because I could do it mentally, so then I knew I could actually put it down on paper. So give me an indication, Jo, what happens for someone who is cognitively well, mentally well, they can probably sit down and draw that, but for the person who may be having Alzheimer's symptoms or these types, what will we see?

Jo: You'll see some things where they put the numbers too close together, much like a first grader when they're trying to put their name and you know how it runs clear off the end of the page and you can't, so it's spacial kinds of things is what it's measuring for. And so they'll put them all really close together or all really far apart or have trouble putting the hands in. Sometimes the hands will even appear outside of the clock draw. So there are some of those things that just can be a routine, nonthreatening thing if you did it with everybody at their say age 50 physical. Then, by the time they went on, they wouldn't be as fearful and wouldn't try as hard. So there are little things like that. But there also needs to be a part of are you forgetting things or is there something else going on? Falls, again, a fall often is a predictor that somebody is dealing with apraxia and they've got some muscle issues going on.

Bill: Dealing with and then you used a term.

Jo: I used the term 'apraxia.'

Bill: Yeah, tell me what that is.

Jo: Apraxia is the word that is used medically for the whole motor system, and that's very important because you will have people who have problems just maybe buttoning their shirt or you will see people who start walking differently. Sometimes it's a rigid type of walk. Sometimes it's little steps, sometimes it's large steps. Sometimes you will notice that people are walking all over to one side or all over to the other side. As the disease progresses, there will be people who will walk almost in an s-shape. So it's really the brain degeneration in an area where the brain is not giving the body the information that it needs.

Bill: Uh-huh. And I'm guessing that, as I'm sitting here thinking about this, for instance I know that something that's very common among folks who have Parkinson's is falling; very frequently falling straight backwards. And so I think that someone listening to this recording, probably what they really need to do is take the first piece of advice that you gave and that is these types of behaviors should be a reason for them to go to a physician. In other words, we're not diagnosing here. We're not saying because someone is walking in an s-shape or we're not saying because

someone falls that this is Alzheimer's disease. We're saying that the motor skills, the use of the hands and the legs and whatnot, that this may be an indication that something is going on and that they need to get it checked out. Is that a good way to put it?

Jo: That's a very good way to put it. and again, to keep it from being this fear factor thing, I think so often people, and again we were talking about early onset and/or early diagnosis, so often people think that it's just based on the memory and the disease is a whole lot more than that and that's why we're talking about some other things that are early that need to be checked out. The other important thing and the reason that you always want to go in when you have something that's unusual in whatever is going on with your body as it's attached to your mind, you can't separate the two out even though it's kind of done with stigmas sometimes, is that it's really important to be sure that you're looking for things that you can do something about. And so that's the real reason to go in and get things checked out and see what they are and that helps alleviate the fear because stress and fear can create some of the other symptoms like the not being able to remember things.

Bill: Right. Okay. Now, in a few minutes I'm going to bring in Rick Law to talk about the legal side of things, but before I do that I did want to mention Rick has talked in the past about I think what he calls the Alzheimer's journey, the Alzheimer's caregiver journey. As we progress through this journey, whatever it looks like, I mean you've talked about some of the things that one group of experts would term to be the early stages and then you've kind of given us a good framework on how to look at that. For lack of a better term, as someone progresses into what I as a layman might think of as the middle stages, what are we seeing in those instances and how should we be looking at that?

Jo: Well, I think when you get into the middle stages, those are those symptoms that we talked about where you're dealing with forgetfulness, difficulty concentrating. You'll still have people that are early enough that are still trying to work or are having work issues. Driving becomes a really big thing then; do they have the capability for driving? And you'll have some other things like depression. They're not really themselves anymore. They withdraw. They don't want to do things that other people are doing. So there's a lot of real definite signs more in the middle stages than in the early stage and that's when the family members start saying to the person, "You know, I think there's something wrong and you probably need to go to the doctor."

Bill: Yeah. Now, you just gave me a bunch of nuggets there, so let me go back for a second. First of all, I know driving is a huge issue. So we're into this part of the journey were perhaps maybe it's okay to drive or maybe it's not okay to drive, and particularly in our culture with men frequently,

their identity is tied up with the ability to drive. I mean I know, I grew up in upstate New York and, when I turned 16 and could get a restricted license and I could drive on my own, what a huge day that was. And I know for a lot of men it's a very huge issue, for women, too. And so how do we get to the point where we can make an assessment as to whether or not someone really can drive, whether they're safe not only for themselves but everybody else on the road? I mean how do you even begin to go about figuring that out?

Jo: This is huge and it is difficult and I think as much as identity, the other thing that the driving allows the person to have is independency and freedom, which is one of our inalienable rights.

Bill: Uh-huh. Absolutely. That's right.

Jo: And that's why it's so difficult for families to think, oh my gosh, am I the one that has to even broach the subject of how am I going to take away your ability to have independence? Your ability to have freedom? It's really difficult. I believe that the best thing to do is to have somebody take a driving test and they are provided. They're usually at any kind of a hospital setting that has an occupational therapy department. Driving tests are available and maybe all of us should take them, but what they do is they will actually say whether a person is safe to drive based on what they do in this driving test.

Bill: Sure. Well, and then I'll give you a little story. In my practice I had a family that came in and they had taken their loved one down to one of the memory clinics in the area just a couple of days prior to when they saw me and their car had a big dent in the door. And they came up and we sat down and we talked and they told me that, when they went down to the driving clinic, they pulled into the parking lot and just as they pulled in somebody came racing out of the parking space driving as quickly as they could in reverse and ran right into them. And then the woman who was in the car that hit them got out and said, "Please don't be angry at my husband. He has Alzheimer's disease." And the family was like, yeah but so does my loved one probably and yet he's not driving. We drove him down there. And I just thought that showed just such a beautiful example of what a difficult thing this is because I know with a lot of people who have Alzheimer's, they might even get to the point where if you go and have a driving test, they might decide they're going to drive anyhow.

Jo: Well, and they're not even going to decide that they're going to drive anyhow. They will forget that they had the driving test.

Bill: Yeah, so what do you do?

Jo: And they will truly forget it. They truly don't remember it and, if you try to bring it up to them it causes an argument. My point was this is what the family needs to make the decision about broaching the subject about the safety of it. And then there are all kinds of things that you have to do right down to disabling the car, actually taking the car away. Now, I have a wonderful story of five children whom I worked with for a long time based on their mother, a very independent, very active, tennis-playing woman.

Bill: Yeah, please tell us.

Jo: She couldn't drive anymore. She couldn't do a lot of things and she was independent. She was not going to let go. So her son took the car and said, "Mom, we're just not going to let you have a car anymore." Well, she knew how to call a taxi and she called the taxi and the taxi took her to the local Cadillac dealership, where she had been known for years. She walked in and said that she had given her car to her son and she wanted to buy a new car for herself. She had the means. She bought the car and she drove the car home. So, you're going to deal with a whole lot of issues when you're dealing with this and it's not going to be a one size fits all and it's not going to be a one time is going to take care of it. It's like a season of what you can deal with.

Bill: Wow! And I think that's a real good microcosm and it kind of sums up the American culture and all those issues and the independence all at once. Continuing on with the journey, so to speak, what happens later as the disease progresses? I mean whether we call it late states or whatever. And once again, I fully understand that people are going to progress differently. At the same time, I think it's helpful to have a model of what things we might be looking for. Give us some information on that.

Jo: I think the model really does help and I think people kind of like to have stages again to help them make these decisions. The decisions of whether it's bad enough yet for us to intervene, whether they can still stay in their home, whether they really need assistance, all of those things because as times goes on they are less able to manage safely. We'll just talk about safety as an issue. Once again, you have to have something that families can hang onto that help them make decisions because they're in a role reversal now, which is difficult and painful.

Bill: Sure.

Jo: So to put them in that, what you want to do is you want to offer them some tools and the staging is one tool. Now, that staging can work as a reverse tool because then, if their parent isn't exhibiting some of these things, let's just say for example they gave up driving easily. It just didn't seem to be that important to them or maybe they didn't have the confidence to drive

anymore, but they're doing fine living alone and nothing has really happened. So then they can say, "Well, they're not that bad yet because they're still very reasonable and they're still okay and they can do this." So you do want that framework. You do want to remember that each individual is individual. And so a lot of things happen in the middle stages. But then as you get on to the later stages, you're keenly aware. Usually something happens and you will hear statements like this: "Well, I think mom's still okay to be home alone because she really likes to be home and she's only gotten out at night once."

Bill: Once again, I guess that's one of those things where it's really hard to know exactly where you draw the line and I think one of the things that I understand with Alzheimer's patients I think is that sometime the behaviors can change almost on an hourly basis. I mean I've seen people, and maybe this is in the middle stages, where at one point they're doing quite well and then a couple of hours later they don't know what they did. They don't know you. They repeat questions over and over again. How do you know when it's the right time to say, "Mom really can't stay home alone," or whatever the issue is that you're facing?

Jo: And once again, that's why I suggested early on that a really important part of the evaluation and getting it early on, having some history, makes it a little easier because you can go in to evaluate again to see where you're at. And this is a tool that's much more for the caregiver than actually for the person because it helps you feel like you've got some backup and some support for this decision because, as the caregiver, you're really concerned with the fact that you don't want to do something too early. You don't want to take away that independence. You don't want to rob them of a life they could have and they definitely will have the good days early on, even middle stages they can have good weeks. They can totally agree that they shouldn't drive anymore and assure you that they're not going to drive anymore and that yes, they know the doctor said and even they don't have their driver's license anymore and then the next day drive straight up to your house. And you say, "Well, but I thought you promised," and they truly don't remember what they had promised. That's how that goes, which makes it hard for the caregivers. However, to be able to do things consistently, you want to evaluate their capability safety-wise and occupational therapists can do that. They do some very simple tests. They have them prepare a cup of tea.

Bill: Okay.

Jo: They have them prepare a bath. So what they do is they go in and just have them get ready to take your bath. Select the clothes, select whatever you're going to need to go through the entire bath process. And there's many steps to that and in the middle stages it's very hard to do those kind of steps in order, and so you can see that one of the reasons they thought

they took the bath and that's clearly a middle stage thing, is that they did go through some of the steps and then they absolutely forgot. That becomes very evident. Well, if you can't do the steps to take a bath and you can't manage a cup of tea, then you're probably not going to be safe to be by yourself for 24-hours because you can't handle emergency processes.

Bill: Sure. And you know, one of the things that I've heard people talk about in the past is this term called 'activities of daily living' and I mean it's just a fancy term for things like getting dressed and eating and bathing and going to the toilet and those types of things. What happens with these activities as the person who has Alzheimer's as the disease progresses?

Jo: They actually forget whether they've done them or not.

Bill: Uh-huh.

Jo: Everybody says, well, they stopped eating and they did because they thought they already ate or you can get the opposite side of the spectrum. We're all humans; we go from one side to the other. Or you can get the people who are gaining weight because they forgot that they ate so they eat again and then they eat again and then they eat again. So it really has to do with their memory that they can't do the activities of daily living. And so they need some assistance with that and when they need assistance with that, once again, they clearly can't stay at home. They can't take care of themselves. They need those kinds of things even though they're able to do it with some cues, then you have a responsibility again as a caregiver, as someone who cares about them, to make sure that they have someone assist them with those cues. So if staying home is what you're focusing on, that doesn't have to go away, but they can't stay home without some assistance and without some help and without some emergency kinds of things.

Bill: In a cue. So tell me what that is.

Jo: A cue is a hint or a piece of information that they need. So for instance, you know what mealtimes are and you have breakfast and call it breakfast and then you have lunch and call it lunch and then you have dinner and call it dinner. So you're providing the cue or the hint or the reminder to get someone to have at least three meals a day so that they can get the proper nutrition.

Bill: So would that mean, for instance, if lunchtime in the house was 11:30 or 12:00, that the caregiver would then make a hint or give a hint to the individual, "Are you getting hungry? Would you like something to eat?" Is that an example of a cue?

Jo: That would be an example of a cue and just reminders, again, of just little things. So it's morning, let's get a shower, let's put on our clothes. It looks like it's a nice day. Maybe we're going to work in the garden but we'll have a little bit to eat before we start our daily work. So all of those things just kind of to develop the routine is definitely what I'm talking about.

Bill: Okay. Would it be accurate to say, Jo, that as the journey progresses that, if someone got into the very late stages of the disease, sometimes they might lose the ability to speak, to eat, even to swallow food? Is that something that happens?

Jo: It is something that happens. Now, there isn't a high percentage that go actually into the late stage of the disease because, even though it is a debilitating and it is a terminal illness, it doesn't necessarily go to the late stage. I believe the most recent statistics on that is only about 6% go to the end stage of the disease because there are other factors, again based on what happens with the disease, that creates their death before that. But if someone goes to what we call true end stage of the disease, then one of the issues you almost always have to deal with is their inability to swallow. That goes back to that term I used, apraxia, motor coordination. One of the apraxia things or the motor coordination things is that people can't swallow any longer and that means that even with their own saliva in their mouth, if you can't swallow appropriately, what will happen is, as they try to swallow that, it will go into their lungs and create what they call an aspiration pneumonia, which just means liquid got into the lungs and you can't cough it out. And so even that can happen but you need to look at more medical things to deal with that and that's all of our issues that deal with the legalities and the term that most often comes up with swallowing is do you use a food tube or don't you.

Bill: Uh-huh. And that's I think a perfect way to transition into some of the legal issues. And, as I mentioned earlier, we have elder law attorney Rick Law from Chicago here to talk about that. Rick, as you've heard Jo take us through the process of the disease and how we look at it, one thing that becomes pretty clear to me is, with someone who may be facing memory loss which may be Alzheimer's and some of the other things we've talked about, early treatment from a legal perspective also would be really important. So, kind of take us through, if you would, a little bit of what you as an elder law attorney would be advising families who have a loved one facing Alzheimer's disease. Where do they start? What are the first steps?

Rick: Well, our focus in our practice really is very different than most attorneys in that the primary beneficiary of our work is the client themselves and we perceive the client usually to be the afflicted individual who has a diagnosis. But the secondary beneficiaries of the work that we do are the

families themselves. And so when we're dealing with these kind of issues, we're really trying to evaluate how best to help the client as well as the family. And one of the problems that we do have in life as human beings as I've listened to Jo is people tend to be in denial and, just as Jo recommended people seeing a physician early, we would recommend that in the ideal world, when one had a diagnosis of any sort of long-term illness that one of the thoughts that would come to mind is we also need to see an attorney that's focused in the area of disability and the issues of what we call the frail senior. And of course, and sometimes the person is not a senior but someone who has a diagnosis. One of the reasons that we have to do that is because we have capacity issues and, as an attorney, when I have a person in front of me I have to be evaluating whether or not the human being that's in front of me has sufficient mental capability to understand the legal consequences of the documents that I'm putting in front of them. So, as we've just heard Jo go through this trajectory of decline of a person's memory abilities, we would ideally want to have the family with the affected individual meet with us and go through a decision-making about who can make decisions for them when they no longer are able to make decisions for themselves.

Bill: Let me stop you right there for a second, because one of the things that kind of jumped out at me was you talked about when someone has a diagnosis that they absolutely ought to be talking with an attorney. And I know that's true. I also think, I'm not sure of this, but I think that a lot of people simply won't get a diagnosis because they're afraid of what it might say. And Jo talked about her reluctance. She is one of the experts in the country but was almost reluctant to draw the clock herself, do that clock test, because it might show something that was going to be frightening and lead to all kinds of consequences. So if we have a situation where people are going to be reluctant to perhaps get a diagnosis, would it be, maybe another way to state it is that if someone begins to have even the slightest concern that something is going on, those very, very early things that Jo was talking about, they really ought to talk to an attorney. Is that a good way to put it?

Rick: Well, that would be wonderful, but in the real world people would much rather see their physician than see an attorney. No one's heart fills with delight at the idea of seeing an attorney, so there's also that particular barrier as well.

Bill: So let's say that in the real world they're probably not going to run to the attorney at that time, but at some point they might realize enough of an issue here that they will go to an attorney. What kinds of things would you be talking with them about?

Rick: Well, once again, if a person does recognize that they have a diagnosis or some sort of long-term care issue, that causes them and motivates them to

actually call our office because for the majority of the persons who come to my office, it's because either the family or the individual themselves has identified that there is an issue that they're willing to embrace. So if we look at that, then we're dealing with really a new style of estate planning. Because in the past, estate planning has typically been what we now consider to be death planning.

Bill: Sure.

Rick: Today, the bigger issue, truly the bigger issue is how are we going to be providing the best estate protection and the best care for the individual, as well as their family, during their lifetime.

Bill: So in the olden days, I'm thinking of my parents, my mom and dad did a will way back in the, I don't know, '60s let's say, and the will just said at the death of my wife everything to my husband and vice versa and then at the second death it goes on down to the kids and it was all really about when they were both gone passing property on down to us kids. But now you're saying that there are health-related issues that are a bigger part of that, or at least as important.

Rick: Well, there really are. And if we go back to the 1960s, the 1960s was really the beginning of a term that we don't use in this country much, but it was the beginning of our socialized medicine because we began medicare and medicaid in the mid '60s. But if we go back to the life expectancy of human beings, North American human beings in the mid-60s, most of us men died before 65 and most women died before the age of 70. Now, as we scroll forward to today, we have seen millions of US citizens who will be living into their late 80s and because of that they are going to have the new issue of how do they stretch their financial resources through periods of long-term disability and long-term care because we actually have a reaction pushing back from the other side, which is our federal government is actually working to restrict the ability of individuals to qualify for some healthcare services. And one of the ways that they're creating a barrier is that they often say that if somebody does any sort of estate protection type work it needs to be five years before they would really need nursing home care or, in many cases, assisted living care. But when people have a diagnosis of Alzheimer's or Parkinson's or many other long-term care diseases, they have more than five years of trajectory and that's one of the reasons why they need to be seeing an attorney to be working on powers of attorney for healthcare, powers of attorney for property, perhaps using trusts and certainly modifying their wills to make sure that they do what they're supposed to do in light of their long-term illness.

Bill: Yeah, so let's start there. You said a couple of different types of powers of attorney. One I think you said for healthcare and one for property. So

let's start with a healthcare power of attorney. What is that and why is it important and when should I do it?

Rick: Well, we believe that a person at the age of 18 should do a power of attorney for healthcare, and one name that stands out to us is the name of Terri Schiavo, because Terri Schiavo was a very famous case where we have a major conflict over a human being on whether or not they could have a feeding tube removed, and the husband said that he knew Terri Schiavo very well as his wife and she would never have wanted to live in this state of her life being maintained. Meanwhile, her parents said, well we know Terry very well and we raised her and, based on her beliefs, she would not want to have her life terminated. And so this led to basically an international conflict even over whether or not Terry had the right, so to speak, to have a feeding tube removed, which eventually did happen and her life came to an end. The power of attorney for healthcare would have solved that problem without any international and national consequences because Terry would have indicated during her life in writing, you know, if I ever have a situation where I've been diagnosed as being terminally ill, I allow you my beloved agent to make healthcare decisions for me and I indicate that I do or do not want to have life prolonging treatment such as a ventilator or nutrition or hydration, water, being provided.

Bill: So she might have said, if I have an incurable injury or disease or illness or whatever where I can't say what I want, then I'm appointing my husband or my child or my mother or father to make that decision for me.

Rick: Yes. That would actually be a power of attorney because you're appointing an agent. Another common tool that's used in almost every state is a concept called a Living Will, which is quite a misnamed document really because it's not a will at all. But it is about end of life issues and, if you have a living will, you're actually indicating to a healthcare provider what your options should be in the event that you have been given a terminal diagnosis and now the decision is whether or not you're going to be receiving life-prolonging treatments such as a ventilator or nutrition or...

Bill: Sure. So hopefully you're sitting down and preparing these documents at a time when you can make the decision when you have, as I think you mentioned earlier, capacity, the ability to make the decisions.

Rick: It's absolutely critical that you have capacity because, if you don't have capacity, we then have to deal with going to court and creating a guardianship, which is really one of the worst situations that we can have. The only person that gains from that is the attorney who gets to charge fees to go to court because what we are really doing is suing your loved one to take away their rights as a citizen to make their own decisions. And so you are faced with either the very simple task of creating a written

understanding of what your desires are at the end of life versus having the state become the decision-maker for you and appointing someone to be your guardian. So one of the things that we have to deal with as an elder law attorney is because we're typically looking across the table at someone who is either the caregiver of a loved one with Alzheimer's or we're looking at someone who has been diagnosed and they're at an early stage or perhaps mid stage, and we really have to look at them in a new way and ask them to think about the reality that their life trajectory does include what Jo earlier talked about; not being able to swallow, not being able to eat. And do they have the capacity to make the decision and even the courage to make the decision to communicate to their family what is the family supposed to do when that happens. Are they supposed to force the person to have water? Are they supposed to force the person to have nutrition? And I have had very painful, tearful conversations in my office over this issue, and yet when those conversations are over, people are actually so relieved that they have now made a decision one way or the other and communicated that to their beloved family, which now allows that caregiving family to be relieved of the guilt of which way this is supposed to go because they have been given instructions by the person who is affected.

Bill: Yeah, that's amazing. It's a gift from them.

Rick: It is a major gift, and that's one of the things that we try to express to our clients, is that please give your family the gift of knowing what you want so that they are not tormented by indecision or even conflict among children or other loved ones over what's supposed to be the right decision. You tell us and we will incorporate it into your power of attorney for healthcare.

Bill: Otherwise, the family might carry the guilt and the conflict for years, decades even.

Rick: Well, the guilt can actually fracture families completely because I recently had a situation where one of my clients said, "My daughter is a nurse but I will absolutely not allow her to be my power of attorney for healthcare because she will keep me alive forever." And he said, "So I am going to appoint my sons who are here and I'm sorry but this is the way that it is." And so he was specifically choosing who among his children would be the decision-makers and yet he was articulating it for me as his attorney, I was articulating in writing these sentiments so that it was his burden that he was taking. She wouldn't be able to say to the boys, "You killed dad."

Bill: That's right. Yeah. Well, that deals with the healthcare side of things. Then earlier you mentioned, I think you said a property power of attorney or something?

- Rick: Yes. And many people don't recognize that there are distinct differences between the two, and the property power of attorney is something that one needs to take great care with because obviously, when you're doing a property power of attorney you're choosing an agent to make decisions about finances for you. So for us, who work with families, we're always looking for that honest and reliable decision-maker and when you have a spouse of many years who has capacity, that's obviously the first choice. But then again, you're looking to who might follow that spouse as far as an honest and reliable child or other loved one that could assist you in making financial decisions when you are no longer able to do that.
- Bill: Okay. Now, obviously I read the papers. I see ads all the time for these seminars that talk about wills and trusts and that type of thing. I mean how do I know, where does that tie into the type of planning we're talking about?
- Rick: Well, Jo and I have worked together for a number of years and she can address that from the medical side, and I'm happy to say that she believes that really people need to get their legal affairs in order at the beginning of being concerned about their healthcare issues. As I touched on earlier, our legal, the healthcare benefits that are provided by the government are actually in somewhat of a fractured manner. And that is we have medicare and medicare provides healthcare services for the over 65, the blind and the disabled and there's no financial limits on that; however, medicaid is really, in this country, pays for 50% of nursing home and assisted living facilities because that's the only governmental healthcare provider that does so. And Medicaid has a five-year barrier that you cannot have done any sort of, typically you cannot have done estate protection work with wills and trusts within five years of needing to apply for medicaid services. Now, of course there are many exceptions to that, just as there are to the tax rules, but typically when someone comes to see us we're looking at both the public benefits issues, as well as death issues, as well as healthcare issues. And so someone really needs to be seeking someone who has expertise not only in the end of life issues but also the long-term care issues.
- Bill: Uh-huh. And I also know that, along with these recordings, that you have something called the Alzheimer's Legal Survival Guide, which I think takes people through the issues of powers of attorney and, while we don't have time to cover it today, this whole issue of medicaid qualification, division of assets and how to get help paying for the cost of care through the VA and through the state and all those types of things. So that advice is out there if people will go through the materials they have received.
- Rick: Yes, as you mentioned, we've just recently updated that to take into consideration the most recent changes in rules.

Bill: Now, Rick, you mentioned earlier that you have worked with Jo for some time now and we had an earlier discussion about capacity. Are there some things that she has taught you that have been valuable in your practice in helping the families that come to see you?

Rick: I'm glad you asked that. One of the most interesting things that she has shown me that I think would be helpful really to anyone as they're having discussions with their own family members is this, and she can add to this. She taught me, and I believe it's about a 15 minute cycle. And she says that many times people have developed their way of masking their incapacity by appearing to be very well for about 15 minutes. And this has helped me to change my interviewing process and I have really actually observed this. That I can be having a discussion with an individual across the table and they really seem to be getting it and they really seem to be with it, and I'm saying to myself, you know what, they're doing just fine. I don't know why anyone would think that they have a problem. And then, after about 15 minutes, they kind of start over. Is that about what...?

Jo: That's exactly right. And it is an assessment tool that I've been using for a long time and advise people on it. And I actually call it, amazingly enough, the 15 minute test. And I instruct people to look at your watch because 15 minutes is a lot longer than you think it is, so just look at your watch when you start talking to this person. They are so good and it really is about small talk and the way we're socialized and the things we say. And there's kind of a standard thing that we say that some people even refer to it as nonsense talk because it helps them figure that out a little bit on their 15 minute test, and this is more the clinicians, that helps them; not as much a legal person. But what you do is you look at your watch, you have the conversation with them. Now, it'll get up, some people that are really good will go 12, 13; 13 minutes is as long as I've ever worked with anyone in over 25 years that could manage. About the 14th or the 15th minute, they will actually start all over again as if they're playing a tape. And they're still so good and so articulate that you will actually look around, look at your watch and wonder yourself if somebody else has come in or if you're perhaps just missing something because they start it all over as a tape and you don't expect that. And then, if you will let them continue, they will continue on. And if you really weren't paying attention and didn't use your watch, it seems so normal that you'll actually sit there and listen to it all again before it finally dawns on you that oh my goodness, there really is something wrong here.

Rick: And that is actually very important to understand when you go to a physician to have that diagnosis, because I went and spoke to a couple of different physicians about what would you do as a physician if I told you that this particular person had some early issues or they were vulnerable due to their memory issues, and they kind of looked at me somewhat

askance. Number one, one physician said, well you know there's no medicare reimbursement code for vulnerable and there's no test for vulnerable, so I wouldn't be able to test for vulnerability, which really many family members would be very, very aware that their loved one is vulnerable to being manipulated by individuals; they've lost that. The other thing is when you go to an HMO or even your preferred provider that your insurance company gives you, these days these physicians are not supposed to even be with you for 15 minutes, much less listen to a specific conversation for 15 minutes to see if it repeats. So they are not even looking or testing for this. So the family needs to use this test that Jo has taught me as a professional attorney working in this area. The family needs to use this test themselves to be able to see this repeat.

Bill: That's really helpful, thank you. Now, let me ask you this. Let's say we've got a situation where I have a loved one, my mother for instance, and let's say that I look at this, we go through the 15 minute test. We've done the clock drawing or whatever and I absolutely, I know something is wrong. Now, I'm not a doctor. I'm not here to diagnose her but I know something is wrong and she insists there's nothing wrong. No matter what, I might go to her with proof, I might say you couldn't draw the clock hands. I might say, mom I sat and I tracked you for an hour and we went through the 15 minute test four times and this is what happens, and she looks at me and she says, "There's nothing wrong with me." And she's adamant that there's nothing wrong with her and that she won't go to the doctor and she won't cooperate and I don't know what to do. Where do I go with that?

Jo: That's a very difficult situation and in my experience it's actually one of the most common ones. And sometimes there's this one little piece that helps us with that denial that we have of our own, which I have renamed eternal hopefulness, particularly for the caregivers. Even for the person that has them themselves, we just don't want to get this diagnosis. We don't want to have this diagnosis because it's the most feared thing that there is.

Bill: Sure.

Jo: So with that in mind, you're probably not going to be the person that's going to take them because you are the threatening person. You are the person that now has the power to take away from them the things that they hold dear, their independence, their freedom. These are really important to us. So we start saying, well, this is what's wrong with you and this is what you need to do and you need to do this because. It's very helpful to have been a parent of a teenager and this is where I learned my skills in helping people with this. You know, you can think that you're going to make a teenager do something unless you've actually had one and if you had one that is really rebellious and really creative and has all of those

things that are going to make him a success, then you realize that, you know, you've got to really work with this. Now, I'm going into this, I'm laboring this a little bit because there are people who work really well at influencing them and they're called peers. So what you want to do is you want to find their best friend or one of their peers. Now, be careful because peers will not necessarily align with you, the authority figure, against the other one but there's probably a peer that's concerned let's say about riding with your mother because she always picks up. she now is hanging on to the fact that she can drive, so she's going to drive more often, and they are not real excited about riding with her anymore because they're seeing that something is wrong. So what you can do is see if you can talk to a peer who is concerned about something or just talk about that annual physical. A lot of times people are very good about doing their annual physical and on their annual physical, even though there are HIPAA laws and things like this, very often as a concerned person you can get her peer to go along with her so that she can help her with it or you can send a note to the doctor and ask if they will check some of these things that you have some concern. And there's a problem with that because it feels just a little bit sneaky, and so we say, well, I don't really feel like I have the right to do that. And so then you want to come back around and use some of the things like safety and some of the things, well, do you have a right to do that? But what would happen to your mom, to her life, to you if she kept driving, she was really impaired, you knew it, you didn't do something about it and she was one of those that you read about in the paper that ran into a bunch of children or ran over a neighbor kid? So there's a part of where you need to do this and one of the best ways again is to get some work done with a peer or intercede with her doctor.

Bill: That's terrific. This has been so helpful. I want to thank both of you for sharing your expertise with us today.

Jo: Well, thank you, Bill, it was my pleasure.

Rick: Yeah, it was a joy to be here. Thank you.