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**Transcript of “Preserving Your Mental,
Emotional, Physical and Psychological
Health as a Caregiver”**

With Bill Hammond, Catherine Law and Jo Huey

Preserving Your Mental, Emotional, Physical and Psychological Health as a Caregiver

Bill: Hi, this is Bill Hammond. I'm here today with Catherine Law from Alzheimershope.com and 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: Jo, let me start right at the beginning. First of all, let's take a couple minutes and talk to me about what Alzheimer's disease is and some of the kinds of changes that occur in the brain as people go through this process.

Jo: Well, thank you Bill. I have a little scenario that I use to actually give people a very lay term but kind of a visual aspect of what happens with people with Alzheimer's, and I want to give you the basis of where I get this. I use the *DSM IV*, which is the *Diagnostic and Statistical Manual* for mental illness diagnosis. And that's where you get the little number that you will see on the bottom of the piece of paper that you have to hand in when you check out of the doctor's office so that they can put the diagnosis in the computer. So that's where that book is. In that book, it also has what is called Diagnostic Criteria. Now, a lot of times I like to kid with people that the reason we have all of these big terms and these big names is that there's a conspiracy theory out there. So, kid with you on that. It's just, you know, I don't know why it has to be so hard but sometimes it just has to be hard. So this diagnostic criteria is really the set of things that a physician uses when they're determining if a person has Alzheimer's disease and I take it right out of that book so that somebody could go and look at it. And what it says in that book is, in order to have dementia of the Alzheimer's type, a person has to have memory impairment and what that means in lay terms is the memory impairment is that they can't keep track of the most recent things and they can't retrieve those things if they do store them. So once again, I go back to my funny little conspiracy therapy because the area that we're talking about in the brain is called the hippocampus. Now, I quickly get off of that word because I don't know if we can ever remember it and it brings up all kinds of funny things in your mind, you know. Hippa somehow makes me think of something really big and it's a little part in your brain. So we just go into the storage center. So just think of the storage center. And then I

want to tell you that in our brains we have what I call a brain gizmo. And this little gizmo goes out there and picks up the information that is out there for us. Then that gizmo brings the information in and puts it in the storage center of the brain. Now, a person has either a gizmo that is multifaceted, which means it can work two ways, or you can have two gizmos if you would choose. But I want you to think of the gizmo because it's something that you're going to remember when you're dealing with the person with Alzheimer's. So the gizmo goes out and gets the information, puts it in the storage part of the brain and then the other side of your gizmo or your other gizmo, when you need that information, comes in and tries to pick that information up so that it can tell you what you had stored in there. Well, early on with the person, they have trouble with their gizmo. Their gizmo just malfunctions on occasion. It either doesn't store the information or it can't retrieve the information, but that gizmo has to get so broken that it adversely affects the person's ability to function in their everyday life. And that's what that memory impairment means. Now, that's not all. In addition, they have to have one of four of the following things at the time of diagnosis, and if they truly have Alzheimer's disease and go to the end states of the disease, they will ultimately have all four of these things. Now, they are just symptoms and, as you well know if you've ever had something as common as the flu, that symptoms come and symptoms go.

Bill: Sure.

Jo: So in these four things, the symptoms can come and the symptoms can go and they don't have to be there every day but you must have at least one of them. I'm just going to run through these four things because they're the things that people don't think about when they think about Alzheimer's.

Bill: Great.

Jo: The first one, once again, has the name apraxia. Now, it's back there like the hippocampus, so that just means the motor coordination. Well, the motor coordination, now we don't really have a motor. So I'm just going to talk about our ability to use our limbs, anything that has a muscle attached to it.

Bill: So arms, legs?

Jo: Yes. So arms, legs, even swallowing, and I want to get back to that.

Bill: Uh-huh. Okay.

Jo: So it might just be the difficulty in using your hands to open a bottle or button your jacket. Or it might be the way that you walk. Maybe you change how you take steps. It might be what you call your gait, which is also like walking, but you might get real rigid and kind of change the way

you stand and the way you move, and so you might be over to one side, over to the other side. You might walk in an s-shape. And then ultimately, if a person goes to the end stages of the disease, there can be a problem with swallowing. And again, this is the brain telling the body, all your muscle areas, what to do or what not to do. The second one is another funny word, and I spell this word because it's hard to say. It's agnosia. It's A-G-N-O-S-I-A.

Bill: Okay.

Jo: And that is the brain's ability to take in the information that it receives from the five senses. This can create huge problems in safety. For instance, many people in this day and age walk around carrying bottles, different colored things in them that they turn the lid and drink out of them and put the lid back. Well, if you'll look around your house someday or around the house of the person that maybe is being diagnosed with Alzheimer's, you'll see all kinds of bottles with lids on them with different colored liquids in them that wouldn't be good for them to drink out of.

Bill: Oh, yeah.

Jo: Their senses may not tell them what is in that. They may not get the right information. So it's a safety issue. It's also frustration because the phone can ring and they don't have to be hearing impaired but their senses aren't telling them that that's the phone and that they need to answer it. And so, that can be a lot of frustration if you're trying to keep track of them by the phone because they don't answer their phone and you think something has happened. You run over there and they just didn't understand what the phone was for. Or the first alarm. You know, they can put a pot on the stove, they can turn it on, they can forget they turned it on, it can start burning up, there can be smoke, the fire alarm goes off. They don't hear it. They don't know it, and so it causes problems. Another thing that it can cause problems with is television, the ability for them to be able to tell that something that happened on television didn't really happen in their house and so it's where they come up with some stories.

Bill: Right.

Jo: So that's just a few of the items in that but they're important ones for you to watch out for. The third one is aphasia. And that's a word that we kind of know about and we've heard of it and we think it's a speech thing. So if somebody is aphasic, they can't speak well, but that's only one side of it. Aphasia really is talking about the whole language. So there are those who speak very well and can almost play a tape in that they can have such good social skills and know all the right things to say, but just because they speak well doesn't mean they understand, which is the other side of the language. So there's expressive, speaking well, or there's receptive,

which is understanding what people say to you. So, even if somebody can speak well doesn't mean they understand and if somebody can't speak well, it doesn't mean that they don't understand.

Bill: So the speech going out or coming in.

Jo: Is two different ways and somebody can have problems with one and not the other. In fact, that's the most common occurrence.

Bill: Okay.

Jo: And last but not least of the four things is executive functioning, which for them is executive dysfunctioning, and I want to just narrow that down to the ability to plan. It takes a lot of planning for us to just get up and do the first basic things in the morning or to just go from your house or your car to drive to the place that you need to go. But even in little bitty things, it takes a lot of planning to be able to put your clothes on in the right order, and that's why you'll see things that are out of order.

Bill: Sure.

Jo: So backing up again to what to expect and what to look for and what Alzheimer's disease is, is it's really complicated. It's got to have this memory thing, and love for you to think of the gizmo again because, when people are having difficulty giving you information or keeping track of information, understand their gizmo is pretty broken and it's not working well. And then understand that they either have to have a problem with their motor system, their muscles and the way their body works or with their ability to understand from their five senses what's going on in their environment or something with their language, either expressing and/or understanding and their ability to plan. And, as they progress through the disease, they will ultimately have all these things and they will come and they will go. So once again, that just tells you why it's so complicated.

Catherine: So Jo, now that we have a good base of what Alzheimer's disease does to a patient, what is an Alzheimer's caregiver?

Jo: Well, thanks for asking that, Catherine. You know, Alzheimer's caregiver means a lot of things to a lot of people and, amazingly enough, the person that is probably the real caregiver is the one that doesn't think of themselves as the caregiver because they are the family member who sometimes self-assigns, sometimes just wins the lottery and gets to be the one that really is responsible for making all the choices and they don't think of themselves as a caregiver but they are. Now, other caregivers tend to be friends or family who spend a lot of time with them and who are helping them out with things. There are paid caregivers who might be somebody that's coming into the home just as the housekeeper, who is providing a whole lot of care and assistance or they can actually be people

in day centers. They can be people in assisted living, they can be people in long-term care who feel like they are paid and have a term called 'caregivers' and they have different terms for them. So an Alzheimer's caregiver is a lot of things to a lot of people and care is the important part in it. They are people who care and who are concerned and that's a really important thing for them to understand.

Bill: Would it be accurate to say, Jo, that depending upon where someone is in the progression of the disease, the amount of time that's needed for the caregiving functions could differ greatly?

Jo: It can differ greatly. And once again, it depends on that person who has self-assigned or feels like they have been assigned in some way that role. It can be, and as they progress through into the stages where their gizmo is so broken that they really need a lot of assistance, it can be an insurmountable amount of time.

Catherine: So at Alzheimershope.com, we try to provide a lot of good information for caregivers, but what would you say are the first few things that a caregiver should know?

Jo: I think the first thing that a caregiver needs to know is that they are going to have to figure out a way to take care of themselves, and that's the thing that usually comes last. And then the way that that comes to the caregiver is people say to them, now, are you taking care of yourself? Oh, I hope you're taking care of yourself. Well, I've heard that you should be taking care of yourself, which is very frustrating to the caregiver because how are they supposed to take care of themselves. You know, the book, which we kind of in the Alzheimer's caregiver arena refer to as the bible, was Nancy Mace's book, *The 36-Hour Day*. And the caregiver is trying to do, in 24-hours, what requires 36-hours, is why that book was so aptly named.

Bill: Yeah. And I know that, I mean for a lot of people, even if they jump into things and then the earlier stages, or however we want to term it, when not as much caregiving is needed, but as things progress doesn't it almost become a full-time job?

Jo: It becomes a full-time job and it becomes more than a full-time job. And then these caregivers, they tend to really be kind of superheroes. They still try to manage the rest of their life, like they've taken on this full-time job that shouldn't take their full time and that's what makes it so difficult and so taxing because they're trying to keep the structure around the person who is not able to do most of the things they've done before. And in addition, they're dealing with the loss of the person being able to do the things they did before and to hold the role, and I mean R-O-L-E, the role they had. So it's the spouse or it's the parent or it's the sibling. It's the person that they can't be who they used to be so the caregiver is taking on

those roles, which is a full-time job, still trying to be themselves and they're actually going into the grief process of that loss. And I think that's the most important thing for a caregiver to know. And then there's a lot of other things a caregiver has to know as well.

Catherine: Can we just jump back to where you talked about taking care of the caregiver and how they can take care of themselves? What are some specific examples of things that they can do to take the burden off?

Jo: Well, I think one of the easiest things for a caregiver, and it took us a long time to figure this out, but one of the easiest things for them to do is they need to understand that they have a responsibility. Caregivers are very responsible and that's why I'm using this term 'responsibility.' It's for you caregivers, that you have a responsibility to make sure that the person for whom you are caring still has quality in their life. Usually as caregivers, we try to make sure that all the things are taken care of but we do it more around their physical well-being. I mean of course, you have to take care of making sure they eat. You have to take care of making sure they're clean, making sure they're dressed, making sure they get to appointments on time. And so one of the things that's the most important is you have to figure out how they can have peers and so that means that you need to search out some things like a day center that they can go to.

Bill: Now, Jo, it's obvious to me, after spending time with you, that you have an incredible passion for Alzheimer's caregiving and I know there must be a personal story behind that. It would be wonderful if you could share that with us.

Jo: Well, thank you. I actually have two personal stories. I have one that is the reason that I got into Alzheimer's care and that was based on a very significant person in my life from the time I was a small child, and it was an elderly couple who were my best friends. And so that's how I got into it and was so interested in making sure that there was care available for people when their family members couldn't take care of them anymore and that the caregivers, care providers, institutions like day care or in 24-hour care, that those people knew how to deal with a person with Alzheimer's disease because it takes some training and it takes some shift in how you think of things. And so I focused on that. Little did I know that ultimately I was being prepared to take care of my own mother.

Bill: Wow.

Jo: And so you would have thought just being able to do it would have been enough, but sometimes we get special blessings in this life. And in retrospect, I truly do think it was a special blessing that I was able to take care of my mother.

Bill: I can just imagine how difficult that must have been at first and yet the nice thing was, at least in your situation, you got almost immediate visual feedback that it really was the right place for her. So that's pretty neat. But let's say that we've got someone who doesn't need to be in day services or senior services center at that time but they're still at home. How do you go about making the home safe for them?

Jo: Well, I think it's very important to use kind of a child analogy because we talked about if they have agnosia and you don't know if it's going to come or go and that's when their senses may have them, as I said, the drinking out of the wrong bottle. So what we kind of do is we tell people early on to think of an 18-month-old that's really tall and that kind of helps you figure out how to make sure that you have safety as far as just things that people can drink out of and cleansers and things like that, medicines around that they might take or forget, or making sure that their medicines are in med minders. Some little things like that that are just little visual assistance things that help keep them a lot safer. If they seem to do a lot of cooking, sometimes you might want to really think about how safe that is and there's ways that you can get evaluations done with an occupational therapist through the doctor to see if they're really safe to cook and do some things like that because what you might want to do is maybe disable the stove and have them only use microwave or something like that. So, there are things and you need to tailor it to different people for different things. But I want to go back to something that you said earlier on, and the reason that I took my mother in as a volunteer is once your gizmo is broken enough for you to get a diagnosis, then that is the time when it's not too early to get them involved with other people. The natural tendency, as they sense their own decline, is for them to withdraw from people. And so it's very important that you do find some kind of a center where they can go initially for them to volunteer and all centers are very capable of doing that. And then ultimately they will just fit into the program as a participant. And so this is an important thing for people to think of early on. Now, you're doing two things here. You're providing this for the person so that they have peer people to be with. It gives them a sense of purpose and well-being because they go somewhere on a regular basis. It also keeps their days and nights from getting mixed up and will actually allow them to be able to stay in their own environment. A lot of these places actually have pick-up and delivery service and that works very well because you don't have to get into that mix early on as far as taking them or telling them that they have to go somewhere. And the people that pick them up, even the bus drivers, often know how to just invite and they just say, "Where's your coat? I'm here to pick you up." And so it actually worked out really well and will prevent a lot of the other symptoms that you will classically see when they spend too much time alone and are scared and forgetful.

Catherine: And of course, we know that, as they have time away, the caregiver can also get things done that they need to do during the day, whether that's going to work or just doing the daily things, doing laundry, taking a long bath, doing things to take care of themselves. How can the caregiver, who maybe can't take mom or dad to a day center, what sort of activities would you have in mind for the Alzheimer's patient to do at home to help them, like you said, have a sense of purpose or well-being?

Jo: Well, there are even the hours that they are there in the evening, so no matter what this is a very important thing for all caregivers. To make sure that they have something to do that makes them feel useful. Initially, you just want to let them help you do things. And helping you do things works out really pretty well, but then sometimes, as they progress on, they can't do things that are helpful. I have a little story that I often tell about my mom and I, she really, really wanted to help me in the kitchen. And I'm a really independent person and my life had changed a lot with my mom coming to live with me and at the end of the day I really just wanted to get dinner because that's what we needed to do and I had kind of stopped getting dinner, so this was kind of going back to doing something I wasn't exactly excited about doing, which is what happens with caregivers as you're providing care. So I just wanted to get dinner and get it over with because it's what we had to do. And my mom wanted to help. So if I would just back up, there she would be right there beside me. And she wasn't able to help anymore and I figured that out one day when I gave her the tomato to slice and I looked at the tomato and she had sliced it the wrong direction and it just kind of all mushed and fell apart. Now, I didn't know there was direction on slicing tomatoes until then. And so it was like oh, what do I do? And I didn't want her to feel like she wasn't doing things right because that doesn't feel useful or purposeful and I really did care about her and she really wanted to help. And so I decided that she could wash the lettuce. And so, I bought iceberg lettuce and we actually ate romaine, and you know these are little clues to tell you that you can make things different. And I would let her take the lettuce apart and wash the lettuce and she would happily wash the lettuce. I gave her a colander. She would be there at the water. This solved two things. It gave her something to do that made her feel useful and purposeful and it kept her busy so I could do everything else in the kitchen and set our dinner on the table. And then, when we would sit down to dinner, as I would go in to clean up, I would quickly put the lettuce in a bag, put it in the refrigerator and we would get to use it the next day. And so that was a way that I figured out how she could be useful and I could get what I needed and we could enjoy dinner together and we weren't on cross purposes as far as what we were doing. So that's just one little story of how you can adapt and adjust with just a little bit of thought. There are a lot of other things that people can do. Just simply having them clip coupons, and even if you don't use the coupons, you can give them scissors and just have them cut out the things that we're going to buy at the store and put them in an

envelope. So there are just little tiny things that are just around the house. A load of laundry is a wonderful thing. You know, you pull it out of the dryer and you throw it on the table and you can even visit while you're doing it and talk about, well, you know, this is nice. If you don't happen to have laundry every day, a wonderful thing that grandmas in particular like is you can have a bunch of stockings that you picked up at the thrift store and there'll be all different sizes. Baby stockings and big person stockings and you can throw that in the dryer, take it out, it's nice and warm, put it on the table and then, while they're folding them, you can talk about all the wonderful reminiscing things like oh, when Jason was a baby he had little boots just like those. You can talk about all the things that are wonderful. So there are a lot of nice, little, easy things you can do while you're doing other things that just help you enjoy your time together instead of just focusing on all the tasks that need to be done or aren't getting done. So it helps both of you take care of yourselves.

Bill: Yeah. Do you have to watch out, Jo, for frustration or agitation? I mean what would be signs that maybe we have either taken an activity too far or it's too difficult?

Jo: I think that you really do have to be very aware of what's going on. Often you can prevent frustration and agitation just based on their body language. The other thing that most people aren't aware of, and I want to be so careful when I talk about this because what we don't want to do is get into the blame game of blaming the caregiver, but if you really go through the stages, people with Alzheimer's disease, there really is no aggressive, combative, frustrated stage of the disease. What really is happening is they are only reacting to what is going on in their environment that they don't understand. So I want to back up just a minute to the scenario that would lead to frustration with my mom, and this happened many times. So maybe for a second I'll be confessions of the dutiful daughter. When she wanted to help me in the early days, I would say, "Mom, if you really want to help me could you just go sit down and let me fix dinner." And her first response, because she was a sweet, caring person would be, "Well, don't get mad at me." To which my response would be, "Mom, I'm not mad at you. I'm sorry. I'm just tired." Now, did you hear, I didn't sound very sorry. I did sound tired.

Bill: Right.

Jo: So she picks up on that because their feelings are not impaired. That's not the part of their brain that was impaired. You know, when I talked about all that brain gizmo stuff, I didn't talk about their feelings. So what she's picking up is my frustration. Well, it's normal human behavior when somebody is approaching you frustrated and with frustrated body language, they're very capable of reading that, the natural response is that they come back at you a little frustrated, too. So they will say, well, I'm

capable of doing a few things around here, to which it's like well then why don't you try to do them? Now, you can see the road I'm going down.

Bill: Sure.

Jo: And so what happens is they are reacting to what they don't understand that's going on in the environment. But back to not blaming the caregivers, we as caregivers can only do so much and so that's when it's time to say oh, what are we doing anyway. This doesn't matter. Let's go out to dinner. And these are the kind of tools, and I'm calling the word right, tools. These are the kinds of things that you need to do to just decide how important is it anyway and, as a caregiver, that probably should be a little mantra or a little sign that you need to put up how important is it anyway because you will learn as a caregiver of a person with Alzheimer's disease, because they will eventually train you, that you can get into a downward spiral and it will just keep going and going and going and you're the one that's going to have to make it stop. And that's why people get aggressive and combative. It's a response to what's going on in the environment and you can prevent this by just throwing up your arms and giving up early and eventually people will tell you and share with you in support groups that that's what they finally learned, is how important is this anyway? I'm not going to win this battle.

Bill: Yeah, and it's interesting to me, Jo, you talked about, I think your expression was how important is this? Why don't we just go out to dinner? And I think mealtime is a big deal for a lot of families who have a loved one with Alzheimer's and I recently read a study that said that when they did tests they found that if you presented the food on a colored plate to someone with Alzheimer's they ate, I forget the exact amount, but 32% more I think. If you gave them their liquid in a colored cup or a colored glass, they drank 84% more. Now, the numbers are up for dispute but the point being that this was a strategy, a tool that was found to be very effective. I know mealtime is a big deal. You talked about, you know, your mother washing the lettuce while you prepared the meal and then you and she would sit down to dinner. What are some of the strategies that folks should use to make sure that their loved one with Alzheimer's eats enough and drinks enough?

Jo: I think one of the strategies is that someone needs to be there because they forget whether they've eaten or not. But another thing is they may forget how to eat. And so it's very important not only the colors but that those colors be solid colors. Often they, again back to that ability to determine what is there. If you have a plate with flowers on it, then they can't necessarily determine what is the food and what are the flowers. Very often they will forget how to use utensils. And so a picture is truly worth a thousand words. If you want them to eat, sit across from them rather than sitting beside them and get them to where they can go into rote.

There's rote, R-O-T-E memory. If they aren't eating, instead of trying to feed them, pick up the fork, put it in their hand, sit across from them. Often they will watch you. But what you can do is get them to the point where they can start moving themselves or turn anything into a finger food. The way that you can have a nice, healthy finger food is you can cut the crust off of nice whole wheat bread and put something in it and roll it like a little roll up, whatever you have. You don't have to go change all your menus and cook differently because that's a lot of extra stress for the caregiver. You can just put it in a little roll up and hand it to them and very often people can eat with their fingers and you can turn anything into a finger food. And so that encourages their eating. So again, by seeing what you're doing, that's a picture's worth a thousand words, and then my adapting whatever they have. Both, as you said, with the colors and with the ability for them to be able to continue to feed themselves because it promotes their independence and their self worth and that's all really important.

Catherine: And Jo, speaking from a standpoint of self-worth, from an emotional and social point of view, you talked about how sometimes it's easier to do something for your loved one instead of letting them have the independence and do it themselves. Can you talk a little bit more about that?

Jo: I sure can, and thanks Catherine for bringing that up because it's really an important and valuable thing. We are kind of in a society where we think that we should do everything in a hurry and, you know, we just have to get it done, get it done, get it done. And they aren't oriented to time. Now, that's a social work perspective when you say somebody is oriented. What you just really mean is time doesn't really matter to them. They're in the here. They're in the now. They're not aware of time, which is kind of wonderful when you can just let yourself stop being aware of time and just enjoy the little things together. So it's important for them to still be able to put on their shoes and socks and it's important for them to still be able to pick out their own clothing and it's important for them to, as it was with my mom, to feel like they're helping in the kitchen. And so what you need to do is back to that same thing I said, how important is it when somebody is picking out their own clothing, does it really matter if it doesn't match? Maybe it's their favorite thing and if it's not really going to hurt anything, does it really matter if it's not outside appropriate? Are you really going outside? If you are, you can always bring up another sweater and give it to them. I mean if they decide to wear gloves today and it's hot outside, I have a wonderful little story about this with my mom. And this was one of the things that was my tipping point, when I just would kind of lose it. We lived in Louisiana and my mom hadn't lived in Louisiana before, so this was new for her. She always figured that when you went outside you needed your coat. Now, that was a good mother thing and in that particular role I was her daughter. I wasn't the

caregiver. So every time we would go out to walk the dog in the evening, we'd get ready to go and we had this big 125 pound bull mastiff that was on the leash. Oh, good, we're going for a walk. Mother would disappear and the dog's jumping. I'm like, "Mom, what are you doing?" She would go to the closet to get our sweaters and bring them to us. I'd say, "Mom, I don't need a sweater. It's 97° outside." Now, six days out of the week I could just lay the sweater down as we were going out and she wouldn't notice, but there would be that one day when I would say, "I just told you it's 97° out. I don't want to wear a sweater." And of course, she'd say, "Well, don't yell at me." And then in motherly fashion she would say, "And now put on your coat." And so the second time I'd usually get it and I would put on my coat and then we would go out and I would throw it back in on the floor and pick it up when we came back in. But it's really important to understand that they should be able to do things and you should be able to do things and you need to have a sense of humor as a caregiver. You've got to be able to laugh at yourself. You've got to be able to relax. And you can laugh with them. You can say, well, we're sure warm enough today. Do you want me to maybe put those coats back in? The important thing is accepting what's going on, understanding that it's a part of their disease and just not worrying about how important all of this is. Let them be who they are and you be who you are and you can truly enjoy a lot of your time together if you'll just relax a little.

Bill: Yeah. And another way to say that, I guess, is if you've got a situation where, oh, I don't know, like you said, it's hot outside but they're inside in the air conditioning. If they put their winter gloves on, as long as it's not harmful to them, it's quite all right. It makes no difference. And so rather than getting into a fight over no, the gloves are to be worn in the wintertime or whatever, it's accepting the behavior as long as it's not something that's dangerous. Is that a good way to put it?

Jo: That's really a good way of summing it up, is as long as it's not dangerous, what difference does it make? And maybe you think well, the people that you're going to encounter out there are going to notice they have their gloves on. You know, how important is that?

Bill: Right. So who cares? Well, let me do this. We have spent quite a bit of time, and rightfully so, focusing on what's going on with the Alzheimer's patient him or herself. I want to squarely stop right now on a dime and I want to focus on the caregiver for a few minutes. Jo, how do I as a caregiver take care of myself? We've talked about all the wonderful strategies for caring for your loved one with Alzheimer's. I want to be selfish right now. How do I take care of myself if I'm the caregiver?

Jo: Well, I think as the caregiver it isn't selfish to take care of yourself and I like to help people think of new ways to think of things because those are the kind of things that will help you make a change in your life. Your

person that has Alzheimer's is going to be less and less able to take care of themselves and is going to need you more and more, not necessarily to give the bath or to even prepare the meal or to do the basic things that you can hire done, but to be around and alive and available to help make decisions for them when they can't make decisions for themselves. And the only way that you are going to be around is if you take care of yourself, because we all know that stress, and particularly caregiver stress, is going to be extremely, extremely detrimental to your health if you don't take care of yourself.

Bill: Yeah, so how do I do it?

Jo: The very first thing is you're going to have to learn to accept assistance and it's okay if that assistance isn't as good as you could do it yourself. In fact, other people probably can't do it like you do it but you need to accept assistance. So the first thing I think is a tiny little tool to just help all folks is to write down your favorite things. Make a list. And then look at that list of your favorite things. Now, your favorite thing might be eating ice cream. It might be taking a bath, as I think Catherine mentioned earlier. It might be going for a walk unaccompanied. You know, it might be reading a book. It might be going to a movie. But list at least ten things that are your favorite things. And then look at that list of those ten things and write down the last time you did one of those things. And I think you're going to be surprised as a caregiver that you probably haven't done any of them recently. And then start little. You don't have to get big on this. Say, let's just use I would like to go to a movie. Figure out what movie you want to go to and find a way, whether it's a friend, a neighbor, a church member, a family member, somebody who could stay with the person you're caring for for let's say three hours, a half hour to get there, two hours at the movie, half hour to get home and start small and give that to yourself once a week. Now, you maybe don't want to see a movie once a week, so the next time it could be something else that you enjoy doing and if three hours was too much to start with, start with something smaller. Start with something like having somebody come in so you can go take a bath uninterrupted. You know, these are little things but it's very little steps and then you and that person will get used to you doing something different.

Bill: Yeah. And I know my uncle had Alzheimer's when I was growing up and my aunt was very famous, as a lot of people are, for putting on her happy face. And someone would call and they would say, you know, "Can I come over and help? How are things?" And she says, "Just fine." And then she'd hang up the phone and then the house would be in chaos because she had to care for him so much. And I think what you're saying is it's okay not to have a happy face. It's okay, in fact it's imperative that when someone calls you and says, "Can I help?" the answer is yes.

Jo: And that's exactly right, Bill. And the reason that I started with that saying, you know, you have a responsibility to take care of yourself because, once again, caregivers will be responsible. And if they can shift that to taking care of themselves as being their responsibility to staying around through this whole disease process, then they're more likely to do it. And that's my message to you the caregivers. And you know how I learned this? I learned this from taking care of my own mom. Now, I was a professional caregiver. I was the one who taught caregivers how to take care of people and then I had my own mom. So of course, I could do it better than anyone else. But I didn't listen to my own advice and my health started declining and I had already had some interventions from my own children who really loved their grandmother but they loved their mom, too. And my health was showing. I gained a bunch of weight. I went from low blood pressure to high blood pressure. I wasn't getting adequate sleep at night. I wasn't doing very well, but I thought I could do everything for my mom. And that's where the story, the book, my second book, *Don't Leave Mama Home with the Dog*. Is that I felt like I was the only one that could do anything for her and I wasn't, although I had all kinds of resources available because I was a resource guru and I worked in the field. So I knew care providers who were trained to stay with her. I wouldn't let people help me with her because I didn't want to admit that I needed help. And so that wasn't good for my health. But it also wasn't good for her because she needed care all the time and one day I hadn't arranged for anything. I needed to leave and I was feeling really badly about it because I was going to have to leave her alone and I had a doctor tell me that she should not be left alone anymore and they had just told me that and I needed to leave. So I said to my mom as I was getting all these things ready to leave her, I said, "Mom, I'm really worried about you." And she said, "Honey, I can tell you're really worried. What are you so worried about?" And I just wanted to be a daughter for that moment and I said to her, "Well, mom I'm going to have to leave you alone for a few minutes until Louise can get here and I know that I shouldn't leave you alone." And she said, "Honey, honey, stop." Just for that moment she was my mom again. And she said, "You're not leaving me alone. You're leaving me here with a perfectly good dog to take care of me." And as I drove out, I thought to myself, I am leaving her alone with the dog and I should report myself to Elderly Protective Services. Now, that was a wakeup call for me but, you know, as those dedicated caregivers, we're even capable of putting somebody in harm's way because we want to do it all and we need to practice in little steps taking care of ourself but getting them used to other people taking care of them because we can't be there all the time for everything.

Bill: Yeah. And you know, when someone passes away, you go through a grieving process and it seems to me like one of the challenges with Alzheimer's caregiving, I mean someone called Alzheimer's disease the long goodbye. And I think the reason is because there's no defined

endpoint until the person passes away and yet you constantly see them slipping away and so you're never able to fully grieve. What are the stages of the grieving process, Jo, and how do I get to the point where I'm okay with all this, where I can accept it?

Jo: Well, the stages of the grieving process are classic stages. There's denial, anger, bargaining, depression and acceptance. And now, unless you've really studied the grieving process and sometimes when you read the classic book *On Death and Dying*, by Elizabeth Kubler-Ross, where I got these five stages, even in that book it doesn't specifically say that these stages don't have to be in order. Now, I know that with my own mom, I was in denial all the way through. There were days in her last days when my thought was I still was going to take her and have her with me all the time because that's what I really wanted. And so because of that, I changed the word 'denial' to 'eternal hopefulness.' There's just that hopefulness that one day you're going to wake up and it's all going to be a bad dream, maybe a nightmare, and everything will have gone away. And I think that stays with us all the way through. Anger. The anger is right there on the surface and, since they pick up on our environment and what we're doing, like I stressed before, when you get angry at them they'll get angry back, that anger is really there. And a lot of times we take out that anger on our family and our friends and we won't accept help but we say, "Oh, they won't give us any help or when they do help they don't do it right." And that's a lot of the anger. The bargaining goes back to that eternal hopefulness where you're just hoping that if you just work hard this one day, next week will be better. And then there's the depression. The depression is there early on because you are visibly participating in and watching this person change before your very eyes. It is a long goodbye and they're fading away. The point I'm making is that you, as a caregiver of a person with Alzheimer's disease, are going through all of these. You're going through them all every day all the time, which is just another reason that you need to take care of yourself. It's another reason that you need to go to the doctor and you need to mention. You know, my doctor was very concerned about my weight gain and I said to her, well you know, I'm taking care of my mom and I'm not exercising anymore and there's a lot of things I'm not doing. Do you know, she never once asked me if I was depressed? Now, I'm not doing the blame game, but I think that's a common thing that happens, is I might have been able to get on an antidepressant and that might have helped a whole lot of things and I didn't do it in retrospect.

Catherine: Now, Jo, I know depression is another serious health risk for the caregiver and I recently read that health issues for caregivers can go as late as three years beyond the caregiving journey, after the end of the caregiving journey. And it's a real serious issue, the health of the caregiver. Can you give us some specific examples of what a caregiver may be facing?

Jo: Well, Catherine, I'm glad you said that. You know, I mentioned that I had gained a lot of weight and my mom's been gone for a year and a half now, so I'm glad that I still have a year and a half to lose that weight. But with all joking aside, I did read once some years ago that 32% of the primary caregivers die before the person that they're taking care of and that's an alarming statistic. It's probably increased by now. You are at risk and it is really difficult on the caregiver. Stress is a big factor and a lot of people do end up with cancer and a lot of other things that they're dealing with while they're taking care of the person as a caregiver. So that definitely is something that you have to take into effect. And the last thing on that is acceptance, which is one of the stages of grief. The acceptance often comes afterwards and that's the last stage that you get to work on.

Bill: But how do you do it? I mean I knew a woman who had Alzheimer's and she actually went around all day long just whistling and I was in the house for, I don't know maybe 45 minutes and it was constant. It was three or four words and then whistling and then three or four words. After awhile I wondered, how does the daughter do this? How do you handle the situation where the mother has asked the son the same question eight times in a row and on the ninth time you just can't stand it and you just want to go crazy? What do you do?

Jo: Well, now there's a new thing that we've been using recently for the noise, the whistling and that kind of thing. And it's called an iPod. You can actually put some of your own music in and it sounds like of like I'm kidding, but I'm kind of laughing because it's comic relief that you can do it. I have a friend who the one, two, three strikes you're out on the repetitive questioning. And so they would answer it three times and then the fourth one they would absolutely change the subject to an entirely different subject. So if she was saying, "When are we going to go?" He would say, "The cat jumped out the window." Or something entirely different. Now, they may not have even had a cat, but just changing it. So he called it three strikes you're out. And he would just change the subject, and a lot of times that's a great diversionary tactic.

Catherine: Jo, you also talk about being able to laugh at yourself and being able to find light in the situation. What sort of blessings can we be looking for as caregivers of an Alzheimer's patient?

Jo: I think that there really are a lot of blessings. I don't want to minimize the devastation of the disease, but I think it's very important for people to understand that their feelings aren't impaired, but many times people who never were demonstrative, never were able to hug and do things like that are very open to that so that you can get a lot of hugs. And for me, my own special blessing and now again it's in retrospect, how many people have the opportunity to spend that much time with a parent in the last years of their life. Sometimes you see your parent maybe once or twice a

month. If you're out of state, maybe once or twice a year. I got to see my mom every day for three years and there are some wonderful blessings in that time together that I can look at now. And I think that too in the grief process is called acceptance.

Bill: Well, and your sharing your knowledge and your strategies and your tools and the warmth and advice has been a real blessing to us today. Thank you so much.

Jo: And thank you for those kind words, Bill.