

Female Speaker: Good afternoon and welcome to the third and final webinar in Alzheimer's disease and related dementia's three-part webinar series. We are pleased that so many of you have joined us for today's live presentation of webinar #3 Understanding and Responding to Behavior. Please note that this webinar is being recorded and we will share the link with you as soon as it becomes available after today. Today's webinar presentation features Dr. J.T. Hunter, The Family Services Coordinator for the Alzheimer's Association West Virginia Chapter, he directly supports Alzheimer's support group leaders and conducts community workshops and training throughout the Charleston West Virginia region. JT is an experienced community presenter and is heavily involved with supporting Alzheimer's family through the association's helpline. He has also been involved with Alzheimer's Association West Virginia chapter since 2009.

Due to the high volume of participants we will keep all lines muted throughout today's webinar and many of you are likely listening through your computer speakers as well. Finally, so that you have an opportunity to ask questions and share your input toward the end of today's presentation, we ask that you submit your questions through the chat box feature which is located on the right side of your WebEx player. We will get to as many as time allows after JT concludes the presentation, again thank you for joining us today and without further ado it's my pleasure to introduce JT Hunter.

JT Hunter: Hello and welcome to Alzheimer's Association West Virginia Chapter presentation of understanding and responding to behaviors. Before I get started, I would like to mention our toll free 24-hour helpline phone number, this is an opportunity in a way for people to anyone, caregivers, care partners, professionals and families to always get in touch and speak with a live care consultant with the Alzheimer's Association, that person can answer any and all question you may have regarding Alzheimer's disease or related dementia and also we have these moments or new thing pops up what do we do, how should I proceed, you can call 1800-272-3900 and only speak to a live care consultant, this is one thing I want to pass on to everyone before we even get started. The other thing I want to mention you may notice on my opening slide is the website alz.org has great information for caregivers for family members, also there are online chartrooms through our website, so once again I want to put those tools out there and in your minds before I even move forward, you can always reach someone at the Alzheimer's Association.

So my name is JT Hunter, I am a family services coordinator for the West Virginia Chapter for the Alzheimer's Association, and I will be your presenter today. Now, you can see on the screen, the learning objectives for today. Upon completion of this workshop today a citizen should be able to define behaviors and identify triggers, Identify the meaning of behaviors and discuss examples common to persons with Alzheimer's disease; also Identify possible causes related to challenging behaviors, as well as identifying discuss effective techniques for managing challenging behaviors and maintaining the independence of the person with dementia and the last objective better understanding comfort and pain in persons with Alzheimer's or related dementia. I want to quickly talk about what I call the traditional practice, as professionals especially as nurses, caregivers, professional caregivers we are trying to do what we call traditional practice. I wanted to share this with you because we are going to talk about this and you may notice in my presentation today I am going to take a slightly different angle of what I call the traditional

practice, so when you look at the traditional practice here this is usually what we think of, that practice focuses on managing behaviors, particularly those what we call difficult behaviors and then caregiving, under that you can see we focus on maintaining control and then at the very bottom what also happens is there will be losses incurred by the person with dementia through this traditional practice.

So today I hope to take you what I call on a journey, on a journey through Alzheimer's disease but also as journey through the mind of a person with Alzheimer's disease and related dementia. We are also going to learn how to understand and respond appropriately instead of managing that behavior, I am also going to talk to you and show you how to see caregiving no longer is caregiving but what I call care partnering whether you are professional or family member, we are now partners in the care, so I call it now no longer caregivers, care partners.

I also want to address maintaining control, hopefully on this journey today we can re-look at that phrase, maintaining control and look at it through a different way, because what happens in this traditional practice is as losses start to happens, so the person who has Alzheimer's disease and related dementia going through many changes and incurring these losses and naturally as humans when we think of change we usually associate that with taking things away, so hopefully today we will talk about how to add things that can enhance the quality of life for a person with Alzheimer's disease and related dementia. I wanted to share what I call some common behavioral events, these are things that can commonly occur with someone with Alzheimer's or related dementia but they may not occur for every single person with Alzheimer's disease and related dementia. So as you can see on your screen, I have quite a few examples common behaviors that can occur, I want to point out and talk about just a few of those today, the first one I want to mention is shattering.

So, shattering, what you may notice if you caring for someone with Alzheimer's disease especially if you are what you call the primary care partner with one doing the most for that person, you may notice that they don't want you out of their sight, or if you are gone they may ask that person where you are, you almost become what I call a rock of comfort to that person with Alzheimer's disease so even though you may not hear from that person that they love you or you are doing a great job, what you may see is they follow you around and don't want you out of your sight. once again you are that person and you have experienced that shattering let me tell you this that means you are doing a good job, because in order for that person to shatter and wants you around you have conveyed more about your body language and tone of voice that you are there to help, that you are there to take care of them, so it's a strange dichotomy that shattering will occur to those doing their job and doing it right, so it's very common that can occur..

The other one I want to mention is swearing and cursing especially for our family members and I am a caregiver myself for a love done, this can be very difficult especially with grandma always worked at a church, taught Sunday school and raised us to never curse, the person I knew, well now because of this disease, she curses like a sailor, she swears up and down and most of her language is filled with four letter words, that is very common and that can happen with people with Alzheimer's, it's not the cause at this point in their life, they decided to day, you know what? It doesn't matter, what's really going on is we have something in the brain called the filter,

that filter tells you that's not an appropriate words, that's a cuss word. My filter also tells me, hey, JT it's not appropriate to say that, as you have that filter, but what happens with Alzheimer's disease is that it can take away that filter. So, what happens now are those things that maybe free flowing, there is nothing saying that's not an appropriate word, that's not appropriate to do now. So it's very common with Alzheimer's disease, you may notice this can occur.

The other thing I want to mention that is very common is resisting care, that can happen, it usually does happen to all of us at some point, it can make daily caregiving very difficult for us to perform, so I will address some of these common behavioral events let me say this about behaviors. So first of all, all behavior has a reason and for a person with Alzheimer's disease or related dementia, that behavior is a form of communication. Let me actually share the definition of communication with you. The definition of communication is a behavior that sends a message, so when we remember that behavior is a form of communication, we know that it's we can see the world through the eyes of the person with Alzheimer's disease, and if we experienced what they experience then the way we do that behavior would make perfect sense.

So let me explain why these things happen. Let's take a few minutes to review Alzheimer's disease and related dementias, Alzheimer's disease is one disease process, but has dementia, dementia itself is not a disease but a term, it's a word that describes the wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce the person's ability labor perform every day activities, it could be caused by many different things, some dementia could be caused by infections, dehydration, drug side effects, or maybe even diabetes complications, dementia causes once pinpointed and caught somewhat correctible or reversible with proper treatment. So when you think of the word dementia I say it's an umbrella term. It's kind of like the word food, it's a very broad term. Alzheimer's disease is a specific type of dementia, just like pizza is a specific type of food. Alzheimer's disease is a common form of dementia, it's also the most commonly diagnosed form of dementia and unfortunately with Alzheimer's disease it is not reversible, and as you can see on my slide, I have listed some other dementias as well. For example, frontotemporal lobe dementias, can look very similar to that of Alzheimer's disease. Lewy Body dementia is another common dementia that can sometimes occur along with Parkinson's disease. Vascular dementia usually caused by cardiovascular issues, very high blood pressure, clogged arteries, even what they call mini strokes that can occur that we may not be even aware we had ourselves, those are what they call vascular dementia, those dementia can often mimic and almost look like that of Alzheimer's disease.

I love sharing this slide because as we go through this journey and before we really dive into this journey I need to talk about this. This is very important, this kind of sets the tone for the way we look at Alzheimer's disease, so you can see here on your slide the same sentence slightly written differently, so let's talk about this, it's very easy to put dementia before the person, blaming it on the dementia. My grandmother says there are people outside of her home that are trying to get in because she has dementia, that's natural and easy to do. However, the problem is not the person with dementia, the problem is the disease. We can't change this disease, but we can change how we read or interpret and how we respond to this disease so this is a person, this is a person who has disease. The person is always, always a person first, and the person should always be bigger than the dementia. So let's separate the person from the disease, and focus on the quality of life of that person. Now I want to look at some of those causes that's going on inside the body and

inside the mind of a person with Alzheimer's disease that can cause those refusals and resistance to the care we are trying to provide.

Let me talk about what's going on in the brain. On your slide here you can see two slightly different pictures of the human brain, the one on the left is the brain of a healthy aging person, the brain on the right is the brain of a person with Alzheimer's disease, so our brains shrink as we age. No one ever told me this and I did notice this recently but it was also good to know that that's normal. All our brains are going to shrink, as normal healthy aging our brains shrink. Now healthy aging those brains that are healthy they are going to shrink approximately 7 to 8% of their size as we age, that's normal healthy aging, it can happen to all of us. Now, the Alzheimer's brain could be approximately 20% of its size, so here you can see the comparison of the healthy brain to that of a person with Alzheimer's disease. So, as the brain is shrinking we have what I call switches, switches in our body that are sending all these messages to our brain and the brain then makes that action happen, so for example, I have a switch right now that is telling me, I don't need to go to the bathroom, I have a switch telling me I am not hungry, I also have a switch that's telling me to look at the screen and talk at the same time, so basically what I am saying is our bodies are constantly sending messages, that's the way we are able to perform and do these things that we do and it's easy to forget that that's a process, that there are messages being sent that will allow us to do these things. So a brain of a person with Alzheimer's disease that switch all of those switches can start to be twisted and tangled, and eventually as the disease progresses far enough, those switches could break off. So what you may see early on with this disease is what I call a misfire, a misfire for example instead of saying the word watch, I may say hand clock. That's close to a watch, maybe close enough that you can figure out what I was talking about, that's an early misfire what I call. Now as the disease progresses I may not be able to find the word association, maybe a word just comes up, maybe the word is cupcake and I am talking about a watch or a wallet, that can happen, so as the disease progresses more and more twisted and tangled and eventually break off, so that's how I describe the shrinking of the brain, these switches are being affected and how a major effect on how that person reacts to situations and what they may say or do.

This next slide I just wanted to share with you, also Alzheimer's disease brain, those ventricles enlarge and the cortex shrivels. Especially near the hippocampus, as you can see below those enlarged ventricles and the cortex shriveling up, now you heard me mention especially the word hippocampus. The hippocampus is where short term memory is stored, that is typically where the disease may start. We know a hallmark for Alzheimer's disease is short term memory loss. So that also is why you may ask your loved one what they had for lunch and they can't tell you but they may clearly be able to tell you something that happened 20-30 years ago just like it happened yesterday.

So, why do these things happen? Well, I hope this slide helps straighten this point, that everything is affected in the brain, from thoughts, words reused, actions redisplayed and feelings redisplayed. Alzheimer's disease is also a progressive disease, so it's constantly moving through the brain, so more brain cells die over time and different parts can get hit, and it's constantly changing, it's also variable, it can be moment to moment, morning to night, day to day, and person to person. So for example, my loved one may have a good moment and then in the very next minute, seem very confused and upset, it can go what I call in and out very quickly, you don't know moments

of clarity are going to occur. We also may notice with your loved one or the person you care for, maybe you notice at certain times of the day they seem to be a little clear a little vivid, that can fluctuate from one person to person so my loved one maybe better as the day progresses to the early afternoon. Your loved one or person may seem to do better in the morning, so it can vary person to person, it's saying to you that it is very important to remember if you met one person with Alzheimer's disease you have met one person with Alzheimer's disease. And also dementia is predictable. What I mean by that is Alzheimer's affects specific brain parts and if someone has a typical spread and also some parts, for instance, long term memory maybe preserved or preserved longer in some than others. So what is happening?

There is lot of things going on and I use this slide to illustrate some of those things that can occur, so let me start with memory. So when the memory is damaged that person can't learn new things. They may actually use old memories just like new, they may not be able to identify themselves or others correctly. Confabulate, I know that's a big word, that's my word of the day, it's always good to use a new word and use it correctly, so let me tell you, confabulate means fabricating or imagining and experience and compensation for memory loss. So once again what that means is there are strange stories you may here or 'someone stole that from me, I didn't do it,' that can commonly happen but also that person with Alzheimer's disease as the memory is affected, maybe still able to follow those visual cues. So if we put a sign or a picture of a normal common looking toilet, on the bathroom door that may trigger that's where you can go to use the bathroom, that may help them able to keep that independence a little bit longer, they can also seek out the familiar, so there is old routines, there is old habits, I am going to revert to the way I have always done it's, that's going to occur as well. And also they can get stuck on what I call an old emotional memory effect, so also what can happen as the memory is being affected is that tragic event maybe either be a war, we have all tragic life experiences that have happened to us, that happened in the past very well likely that they could reappear, that person may kind of relive that experience, so that's very important to know as this disease is progressing those things that can happen.

Let me talk a little bit about language damage. First let me tell you this person with Alzheimer's disease they still have a very concrete understanding of words but look what happens, when trying to speak they may miss one out of four words or when we are telling them something very important, they may not catch every word I say. So, for example, the famous one out of four words and I say 'don't go there today' One of the most important word in that sentence is 'don't' and that's the word the missed, so it's better to keeping it very simple, shorter simple language because I like I mentioned earlier they may also have problem finding those words, that can read into what I call word salad problems, just jumbled words, sentence may not make sense, it's just words, that can happen. A person with Alzheimer's that has experienced language damage can also possibly follow your cues. So as I hold my finger up to my teeth and do a brushing motion that may still trigger brushing the teeth, that's the way we can still communicate as the language is damaged. So let me explain this inside the mind of the brain, inside the mind of a person with Alzheimer's disease and what's going on in the brain. The destruction of brain cells caused by Alzheimer's disease is a systematically moving throughout the brain, it's damaging sections that control memory and language first. And then begins to destroy the hippocampus which is a part of the temporal lobe, as the disease progresses it continues to destroy neurons and regions of the brain that control other functions as well. Multiple regions can be affected simultaneously.

As Alzheimer's progresses, individuals may also experience changes in personality and behavior and may have trouble recognizing friends and family members, then moves onto judgment and movement which is all in the frontal lobe as well as visual processing which is in the frontal lobe and movement, orientation and recognition and perception of stimuli and then advanced Alzheimer's disease most of the cerebral cortex is seriously damaged, individuals may lose their ability to communicate to recognize loved ones and to care for themselves, so these two slides once again illustrate these things that are going to happen and areas that can be affected early on in the disease process.

So once again let me just point out a few on the second slide under impulse control problems. We talked about swearing and why that occurs, using cuss words and racial slurs when stressed, once again no filter, nothing telling me that's not appropriate or not the right words to say, and remember some of these things are things that we heard long time, all of our life and we knew when the filter was working, but with that filter gone it may seem that they act impulsively, they can't hold back on their thoughts and actions, that's natural with this disease with impulse control, filters are affected and also can lead to performance problems. It maybe very well likely that the person thinks they can do a lot better than they actually can, which can cause safety concerns but depending on the person maybe that person has always done under pressure, maybe not, depends on the person, and attempts to perform or do something maybe dangerous or fatal depending on the issues they think they can do better than they actually can and it's very likely to happen and also our families especially they over or under limit activities, it's very natural to say, well, grandma has Alzheimer's disease she really can't do those things she enjoyed before. So maybe she can't fold the laundry the way she used to but can she still pick up the clothes and do it her way which maybe different from our way? But that could do a lot for that person to feel needed, useful and in this new world that we are in. it's an activity.

I want to share this with you all, I am not a psychology major so I won't tell you the whole history of Dr. Maslow but I want to share Maslow's Hierarchy of Needs. This is a theory in psychology, first proposed by Dr. Abraham Maslow in his 1943 article titled A Theory of Human Motivation, so, Maslow's theory stated there are certain psychological needs that every person has. So you maybe asking what are those psychological needs that every person has. Let me list them for you. The psychological needs that all of us have as humans are love, comfort, attachment, identity, occupation, and inclusion, these needs are way at the heart of supporting the person with Alzheimer's disease and related dementia in understanding his or her behavior. Every person has these core psychological needs, people with Alzheimer's disease and related dementia are often unable to self assert in order to have their needs met. So I want to pose this question to you, in your desk or at your office or at your home wherever you are listening to this, I would like to just to think or write down your top four things that you just cannot live without. That could be seeing somebody every day, that could be your coffee or your diet coke, that could actually be what you do for living. Those things make up who we are and never goes away, so even if I have late stage Alzheimer's or mid to late Alzheimer's in my late of my abilities communicate and tell you how I am feeling diminished, what I am supplying with you know is to let you know that as care partners these core psychological needs never go away, it doesn't

matter if that person is late stage Alzheimer's they still have these core psychological needs, it does not go away now that you have Alzheimer's disease or related dementia.

So, in order to understand and respond accordingly I need to share these six pieces of the puzzle, these six pieces are where we need to start in order to understand and respond accordingly.

Personal history and preferences: Very key to responding accordingly with a person with Alzheimer's disease. Let me give you an example of this very quickly, I got a call one day and a facility was having an issue with a gentleman and what was happening with this gentleman when it was time for activity or whenever he was going to the dining room this gentleman would walk in the corner, go straight to this pot of plant and proceed to urinate. Well, the facility didn't know why he was doing that and it was disturbing to the other residents and so we got a call to help figure out to do what we could do accommodate that person, so I went to personal history and preferences, I asked one question where did he grow up and the answer was this gentleman was raised on a farm, being a male myself, I also knew that lot of time as males we are taught wherever you when you need to go you go. So, what we found out with this gentleman that pot of plant to this man who lived on a farm when urine struck him that plant looks like the appropriate place, scratch, outside, so once we moved that pot of plant we did not have that issue anymore, so we had to know a little bit about his personal history.

Type and level of dementia: It is very important, so I don't mean that you need to go and look at the seven stages and pinpoint exactly which number stage they are, I want to take a slightly different angle, what we need to know is are they early, middle or late stage because that level of dementia can affect their perception of the events that are going on around them, it's also going to determine their level of communication, and also lack of ability that may not have any longer, it helps to know that level and type of dementia that you are dealing with before we can respond appropriately.

Other conditions and sensory losses: Do they have hearing loss, do they have vision issues, if so those devices need to be accessible and used every day for that person because that's going to affect that person with dementia as well. One other thing about other conditions, pain, lot of times when there is a pain, you can see new strange behavior that occurs, you need to do a pain assessment, the #1 reason for agitation is pain, so when a new behavior occurs we need to respond appropriately to that behavior a pain assessment should always be included.

Environmental conditions: Is it too loud? Are there other distractions going on especially in a facility? As much as we can control those other environmental distractions it's very important to do so, in a nursing home, we could consider a small separate dining room for people with Alzheimer's disease but they need more assistance, maybe we can break down to a small group of 4 to 6 people on the same level, this may help.

Care partner approach and behaviors, which is very crucial and very important, when we are talking about understanding and responding to behaviors, the actions and reactions of caregivers are the two most important factors and determining whether or not that person with Alzheimer's disease exhibits behavioral challenges. Care partners can trigger problems and make them worse or they can minimize and make them better. I want to share a quick story with you. So, a nurse

in a facility was helping a lady in a wheelchair, she was wheeling her down the hall to the activities room, as they are going to the activities room this conversation starts, the lady asked the nurse or said to the nurse, I should say 'I never had breakfast today, no one came to give me my breakfast.' The nurse who was standing behind the lady in the wheelchair says, 'yes you did, I brought breakfast to you myself, I know you had it this morning.' The lady says, 'no, I didn't, I know I did not have breakfast this morning, you did not bring me breakfast.' The nurse still says standing behind the lady 'yes, you did, I brought to you yourself, I am not talking about this anymore' and walks away from the wheelchair leaving her in the hallway. That lady then says 'I know I did not have breakfast, you all think I am crazy, I am not crazy'. So I hope I illustrated that story well enough to place this question. Did we just set this lady up for behavior issue? I would let you think for a moment.

The last piece of the puzzle is very important, when there is a behavioral episode we need to go back and document what happened, that includes the full day and all the players involved, but it's very crucial piece because once again just like I mentioned for these slides, lot of times it has something to do with our approach and maybe what we conveyed nonverbally or unintentionally had an affect negatively on this person with Alzheimer's disease and related dementia.

So if you ask me what's the overall goal of today's presentation, I would share this with you. To reduce the reliance of use medication s with negative side effects to manage behaviors and instead care provider skills and knowledge for use of problem solving strategies and intervention techniques that work. People with Alzheimer's disease are very vulnerable to other medication, and to reaction from combination of drugs and other side effects. Lot of times, that medication we may use to manage a behavior may actually make it worse in the long run, it may actually have opposite effect on the person with Alzheimer's and dementia than what it is intended to, so when we give that medication to the lady who just screamed 'help me, help me' and is disturbing everybody when we give her the Haldol? Maybe she immediately goes to sleep, or is quieted or sedated by the medication but then when she gets up maybe that behavior is actually worse and I want to point out one other thing, there is no medication used to treat anxiety, and aggression or just behaviors in person with Alzheimer's disease and related dementia that have been approved for persons with Alzheimer's or dementia. So we need to consider what is that very best medicine to treat those behaviors? It maybe the best medications to treat the symptoms of Alzheimer's disease could includes those ones heard of such as Aricept, Exelon, Razadyne and Namenda that I propose this spot, similarly to manage a difficult behavior the most effective treatment maybe you.

So what can we do? Well, by making simple changes in tasks, demands, and environments based on individual background and preferences can positively impact outcomes, at this point we need to look at tasks and demands that person with dementia seems to be resistant to or refusing to participate in, even if it's something they always love to do, and again to modify and adjust to their new needs for simplification and segmentation of tasks and introduction of environmental cues and safety. So the goal is not to make all things too simple or eliminate all use, so not to take away but to add to the routine environment ina way that will enhance their ability to perform new things that will improve their quality of life and at the same time lowering the stress.

A quick story here, a gentleman in a facility refused to come to the activities and the activity director was trying the hardest to get him out to do an activity so they could do their job. Well, the big activity was Bingo, this man had no interest in Bingo and was not coming outside his room for Bingo, so we had to go in, I used that first piece of the puzzle, where did you live? Where did you grow up and what did you do for a living? We found out this gentleman grew up on a farm, this family raised quarter horses, so we got to get creative and think outside the box, so using that first piece of the puzzle, we found out that riding horses and caring for horses was a huge part of this man's life. So our activity director went to a flea market and bought a fowl, and the next day we went to the gentleman and said, we are just not going to be able to get the horse's saddle today, we really need to polish the saddle' and we had a bowl of water and that gentleman because of who he was and his identity was more than willing to help, took that bottle and shined and shined and actually came out to the activity that he was working on a saddle. That's maybe how we can make a simple change and demands based on his background and preferences.

Also it's very important here, you need to accept the fact that the behavior they are exhibiting is because they have an unmet psychological or physical need, maybe they feel out of place or out of touch. I mean just imagine how you would feel if you were in an unfamiliar place with unfamiliar folks or maybe there is a physical reason that we as care partners must sort through that possibility that we are truly going to manage that behavior, and remember we use the term care partner now, don't just give him care, we need to partner with them on their care, so we are not calling ourselves caregivers but we are care partners, essentially that person with Alzheimer's disease or related dementia needs to be involved in the process as well, so let's focus on the new abilities, not what they lost, so we need to restate and reframe behavior that we experience as unmet needs, distress or discomfort or may be attempts at self expression.

Now let's talk about developing a plan to implement routines and promote independence for a person with Alzheimer's disease or related dementia, this is very key. First we need to know the person, knowing that person may include some history about the person, what are their values and beliefs, are they religious? What religion do they associate themselves with? Habits and routines, are they a night person? Did they start their day at 11:30 at night because their job started at midnight? Did they eat breakfast at 7 a.m.? Did they take a shower or a bath? These are very important, and who that person is, they always gotten up at 11:30 at night because they have midnight job, is it realistic to say now they are going to have to get up at 7 a.m. of breakfast because they are in another place now, we need to consider that.

Personality and stress behaviors. Let me put this thought because we are who we are, may be sometimes that person is displaying a long term habit, maybe that person always threw things when they got upset or what if that person is claustrophobic and we put them in certain situations and their reaction to that environment is what we call a dangerous behavior, it may or may not but we did know the personality and stress behaviors of that person. Work and family history, this is very important because I guarantee you at some point you may hear from that loved one or that person, they need to go to work or they need to find someone that's very important to them, if we know a little bit about work and family history maybe we can supply the proper answer. If I know Mr. Jones worked on a construction site, that day he tells me he needs go to work, what would be a real honest realistic reason why a construction worker wouldn't have to go to work I

need to have that in my plan and ready to provide to him when he tells me he needs to work, I cannot say you don't go to work anymore, you are retired. That's not going to work. He is actually going to get probably get more frustrated and determined to prove me wrong, so I kind of set him up there.

Leisure and spiritual history, once again very important, what did they do for fun? What brings them comfort. That leads me into the last one, hot buttons and comforts. Once again where are those hot buttons, what are those things that make that person tick, if we can know any of that, it's going to be very helpful and also help us try to eliminate those hot buttons and also what's comforting to them, does that person have a warm glass of milk every night before they went to bed? Do they use a night light? Are there favorite songs that bring them comfort that they just love? We need to know these things, so if we know the person maybe we can find 10 or 15 things that bring them pleasure, could it be cookies, music, stroking their arm, or puppy or foot massage, then we implant those and use those appropriately when needed, and it's going to help us provide the best quality care for that person with Alzheimer's or related dementia.

Then once we have done that, got to know the person, we can replace first of all replace client with the word person because remember they are always a person and then we can implement those daily routines in person centered programming, so remember and consider their old habits and routines, what are those patterns during the day, is there a place in your facility if you work in a facility that at anytime if the person gets frustrated or getting up at night or they are anxious and upset is there a quiet place where we can do something together, do we have that structure in place? Even if you are at home think of that, when they get up at night, most confusing time, do we have something in place, a calm area, where we can take them, a soothing comfort that we know of, we could plan together now, but also with the plan we need a time to rest, time to work, time to play and a time to socialize, those are all very important things and for a person with Alzheimer's especially routine is very important.

So once again consider these things, did they eat breakfast, are they a night person, do they like being around people, all these things are going to help you come up with a daily plan, but also think of this. Think about your retirement plans, think about I need to think at my age at 35 what am I going to do when I am retired, kind of dream that we all have, I would pose this question to you. Any of you thought about your retirement plans did any of you include in those plans I am going to get a terminal disease, I have to move in with a loved one or a child and they are going to have to take care of me or I plan on retiring and moving into a strange new place, possibly having a stranger as a roommate, I am sure none of those plans are there, the only reason I brought that up as well and it's good to remember that, this is not in their plans either, this is not what they envisioned for their life. Sometimes putting yourself in their shoes, how would I like to be treated, you come up with some great answers and things we can use to enhance the quality of life for a person with Alzheimer's disease.

So we also need to consider health and illness, let me give you some examples, are they right handed or left handed? This is interesting but it's a great thing to know because God forbid what if the person ever gets lost or wanders, what we know is a person with Alzheimer's disease or related dementia they tend to follow the dominant hand when wandering, so once again you need to get that information now, God forbid what if. Like I said earlier pain is the number one reason

for agitation, so have a thorough pain assessment. Remember do they need glasses or hearing aids, if they have glasses or hearing aids they need them always because not having them will affect their perception and their reaction. Also we consider once again what other illnesses or aches or maybe underlying conditions does that person have. They can very well have Alzheimer's disease and another underlying condition, diabetes, many many other issues, it's all going to have an affect so we need to know, this all makes a difference, it's very important information.

I want to talk about the approach, the approach of us as care partners, the attitude and manner of the care staff are extremely important, people with cognitive impairment are extremely sensitive to nonverbal cues and mirror the effective behavior of those around them, so a patient calm and gentle manner, and has a positive effect, is also important to be aware that body language indicates a feeling of tension, frustration or anger, it may contradict those words that are being used.

Caregivers are involved in providing very personal and crucial sometimes hands on care to individuals with Alzheimer's disease. This often triggers behavioral challenges, so I want to share this with you all. When working with a person with Alzheimer's disease or related dementia it's 93% non verbal, 7% verbal, so it's not always the words we are using, what we are saying, it's what I am expressing, what I am conveying by my tone of voice, by my facial expression and think about how the situation feels to the person with Alzheimer's disease which usually his or her behavioral reaction.

Talk about some key helping behaviors. These are for us as care partners, these helping behaviors we need to use every time in reacting with someone with Alzheimer's disease, so positive physical approach, never approach that person from behind, never, approach that person from the front and get down to their eye level and it's also important to use short effective verbal cues, for example rest, read, one step at a time, and I would say at this point no longer asking 'do you want to take a bath?' 'Would you like to have dinner' but replace it with let's or we. Minimal and familiar tactile cues, let's match that sensation if they are rubbing their hands or fiddling with buttons, what can we give them that would match that sensation, sometimes just maybe a stuffed animal or just activity board where they can play with buttons that will occupy their hands and give them that sensation but remember use what you know about that person, their preferences, likes and dislikes, religious beliefs, all make a difference, and then we can change the environment to help, so remember reducing environmental distractions, these are things that we can bring to the table, and usually these helping behaviors will help understand and respond appropriately.

I just want to share this with you all. It's relationship that's most critical not the outcome of the encounter, none of us exist independent of relationships with others, relationships must be genuine and trustworthy and also provide a sense of security and comfort. Here are some ways we can connect with that person with Alzheimer's disease, since they are the one with the disease, the person with dementia cannot always be expected to express their needs, instead we must try to enter their world and connect with that person that they are. So once again always approach the person from the front and get to their eye level and always introduce yourself and any others that are there, please note what that person likes or prefers to be called, they may not

like the words 'baby' 'honey' and 'sweetie' so note that language is appropriate, a slight touch or hug when appropriate can do wonders. Let's focus on the emotions behind the words, focus on the feelings not the acts, then you can respond appropriately and once again please remember any religious beliefs.

Encourage engagement, here are some tips to help with encouraging that engagement. Let's ask the person to try or could you please help me, let's get simple positive directions, one step at a time, a person with Alzheimer's disease could take up 90 seconds for them to perfect that first sentence or that first statement that we told them, so give him time to respond. You can use props or objects as well, that can be very helpful. Gesture once again, my example of my finger demonstrating teeth brushing. Those gestures can help, it's okay to demonstrate, maybe if you started, they can then pick up and do it as well. They can also mimic you so remember that, they need help with guidance at times, you don't want it do it for them but you can help guide them and then you may at times need to distract, and this activity real quickly when we talk about distract, so they may tell you I need to go home, I need to see mom or dad, what they need to know is that person knows where they are and it's okay for them to be there and then maybe we can say as soon as we get this done I just really need your help to do this right now and then you are able to redirect

Intervention and programming, hopefully when thinking about activities it encompasses all of these areas, so when an activity is introduced first of all activity that we are doing, person with dementia can be engaged in meaningful action, research findings are disrupted behaviors in psychiatric symptoms, once that behavior is escalated activities may be less effective and actually worsen the behavior, so it leads to worsening concentration and more frustration, so reflect back to that information we discussed, when we were talking about the behaviors and changes that are occurring, because we are saying the same holds true as we look at preparing for engagement and action.

So to cope with challenging behaviors, once again where do you start? Start with what I call talking, we got to communicate, all of us, anyone involved with that person's care we need to talk, what answers work for you and I respond with this because we need to have the same plan and the same answers, that's how we are going to be consistent and the best care partner possibly for this person, so always please once again look on our website you can call and talk with us to get that partner education and skill building and then it's crucial for caring probably for someone with Alzheimer's or related dementia and once again risky behavior that happen document, go back in your mind and talk with the people, what's the pattern, when does it happen, where does it happen, who is involved. Even what is said, what is done, what is attempted and then let's analyze what may make it better or what may make it worse.

And then is it a risk or really a problem, if not leave it alone, there are starters on the table that we know they are not snacks at table, you took care of the starters and you can move on. If they wear pink sweat pants every day and they never would have done that, they always had very nice clothes and make up was done, if it brings them comfort, is it really a problem. I just want to let that ring for a moment.

Now just as a wrap up, please remember when attempting to respond appropriately to a behavior, remember this, please explore all of these, personal background and type of dementia and level of cognition, health and sensory information, environmental issues, caregivers approach and assistance and please don't forget habits, schedules and time of day.

Then re look at the problematic challenging behavior and make a plan, implement your plan, then be ready and willing to change it, be willing to adapt and adjust. Once you settled on interventions that are effective recognize that this type of list can arrive again, so plan to reassess at periodic intervals. This concludes my presentation, I hope it was informative and helpful, once again before I go I just want to point out our 1800 number 24 hours 7 days a week, you can always speak to the Alzheimer's Association, I also have a local West Virginia Chapter it's alz.org/wv, you can also reach us on Facebook, so I just want you to remember 24 hours 7 days a week you can always speak with someone at the Alzheimer's Association and we are here to help in anyway possible. Thank you very much and have a great day.

Female Speaker: All right, thank you so much, JT for this informative presentation. I know we got a lot out of this, I am sure, we are going to begin the Q&A portion of today's webinar today and again I would like to remind each of you that if you have a question please to type that in the chat box feature which is located on the right side of your WebEx player. It looks like we already have a few questions queued up and so let me go ahead and check in with JT, and make sure you are still on the line.

JT Hunter: I am here, can you hear me?

Female Speaker: I sure am.

JT Hunter: Great.

Female Speaker: Okay, it looks like the first question that we have is from Henry and Henry asks, do you have any suggestions for safe and meaningful activities for people with Alzheimer's disease?

JT Hunter: That's a great question, Henry, first let me say this routine tasks such as getting dressed, doing chores are considered activities that can help create that meaning and purpose in life for people with dementia, so recreational tasks such as exercise, music or class can also be considered activities, so yes, I do have suggestions, we have something at the Alzheimer's Association called 101 things to do with an individual who has Alzheimer's disease, so I will keep it short and brief for you Henry. I have this list, it's available to anyone, all you have to do is call 1800-272-3900 or you can email us at wvinfo@alz.org So once again here is the philosophy, it's not in the activity in the doing, so we could be very broad especially for women, bath time could be spa time, that could be an activity, personal care could be an activity. It could be as simple as reading out loud, reminiscing because remember long term memory may stay intact longer from clipping coupons, I will give you another activity that we overlook a lot of times. They may tell us something, saying 'tell me more' can turn into an activity, so those are some ideas, keep it simple, it's not in the activity it's in the doing but if you want a complete list just let us know and we can make sure we get that to you.

Female Speaker: All right thank you very much, we have another question, this question comes from Juliet and Juliet asks is there an assessment tool to help families determine when an individual should no longer be left alone for any period of time?

JT Hunter: That's an excellent question, my answer is it could be different reasons for different people, I will give you some examples of those reasons, sometimes the reason is the care that they need or the disease is demanding not care that we can provide at this time, another reason can be wandering, they say statistically 6 out of 10 people with Alzheimer's will wander at some point. What I stress if they are mobile, they are at risk for wandering, so sometimes it can be safety, they wander, they have gotten out, other times it could be things in the home, leaving burners on, things like that, so it could be slightly different for each person. Here is my suggestion, especially in families how do we know when this day is coming we have something called the Basics of Alzheimer's disease, it's about the size of a brochure, it's a small booklet, walks you through things to expect. Things that will possibly occur in the future, so it could be different for each family. Here is what I would say, either I cannot provide with diseases demanding anymore, they are environmental safety issues or physical safety issues, sometimes as caregivers because especially personal care partner we care so much we love so much, we have that fire and desire, we as caregivers can get burned out and beat down very quickly, so it could be different reasons, but the Basics of Alzheimer's I would say is your best guide, something else we have is a Caregivers Handbook is an excellent guide whether you are professional or family care partner, that will provide you with the guidance to see those signs when they come up.

Female Speaker: All right, great, thank you very much, we have few more questions but I also just wanted to point everyone to the chat box window to the right of the screen, Carla is reminding everyone that the Alzheimer's Association website has a lot of different resources for care partners that we just encouraged you to check those out.

JT Hunter: Thank you, I forgot, missy, I probably should mention something else. On our website the questions I have gotten so far we have something on our website called the Caregiver Center, it is absolutely amazing, so if you use the internet or have access to it, anytime you can get on the Caregiver Center and see all these tools and guides and get some answers at your disposal at anytime, I wanted to mention that, you made me think of it as well.

Female Speaker: Great and good to know. And then also we as the Quality Insights and Quality Innovation Network we have a website that has resources available as well, so you might notice Carla is putting some links to those in your chat-box features, so check those out whenever you get a chance. All right, our next question is from Mark and Mark asks can people with Alzheimer's disease relive traumatic events that has happened in the past.

JT Hunter: Excellent question and my answer is yes, it can happen, early in the presentation, maybe slide 3 or so, I mentioned something that can happen is short term memory is key with Alzheimer's, that usually starts to go first. Now what may stay more intact or what they may tell you about or things that maybe happened a long time ago, but as they are telling you this it may feel like to them that it's happening now. So what can happen if it's a long term memory, if I have been in a war a very traumatic event to me, as I somewhat go back in time and use those old

memories as new, those things can pop up again, so they can relive those traumatic events that may have happened in the past as they regress or go back in time in their mind, so that's something I wanted to point out in my presentation because it can happen to almost any of us, on some level almost every person here is related to where I am at least in the mid 30s you probably had on some level a traumatic event or traumatic episode, so people with Alzheimer's lot of times those events will come back just as real and they can relive those, so that's something good for us to know as care partner that that can occur.

Female Speaker: We have another question, this is coming from Laura. Laura asks what is sundowning.

JT Hunter: Great question and I am glad you asked that Laura. To answer that question let me start by saying this, so research and studies indicates that as many as 20% of people with Alzheimer's disease they are going to experience increased confusion, anxiety, agitation, pacing and disorientation beginning at dusk and continuing through the night. Those late day increases in behavioral symptoms are often called sundowning, so sundowning can disrupt the body's sleep-wake cycle causing more behavioral problems, so some factors that cause this can be mental and physical exhaustion from a full day trying to keep up with a maybe unfamiliar or confusion environment, another factor could be caregivers who are just absolutely exhausted, by the events of the day, may give off those nonverbal cues of frustration. I may not even need to say anything but it may show on my face I am very tired or I don't like this situation, that can lead to negative reactions in a person with Alzheimer's disease. Another factor I want to mention that can cause sundowning is reduced lighting and increased shadows because they may cause persons with Alzheimer's to actually misinterpret what they are subsequently becoming more agitated. So yes, it can happen, it's more usually late day into the evening but it can also affect the sleep patterns, so without going into tips to managing sundowning I want everyone to know in this call if you are interested or want to know about some tips to know about sundowning, email us, call us let us know I will pass this along to anyone who asks me for it.

Female Speaker: The next question we have in the queue is from Natalie and Natalie asks are people with Alzheimer's disease prone to become violent and if so what are some tips?

JT Hunter: These are some great questions today, so I will say this people with Alzheimer's disease are not prone to become violent but let me take it back to what happens here, some of the things I mentioned in my presentation, there is a lot of factors, there is a lot of areas that are affected in the brain of a person with Alzheimer's disease, so my perception and interpretation of the event maybe slightly different than the reality of it. I basically have two options here, to fight or flight, so what happens is I misinterpret the event or misinterpret action, or read your nonverbal language wrong. So what happens I am responding appropriately to what I am interpreting, so it's not that I have become violent now that I have Alzheimer's disease. It is more attributed to maybe an altered perception of the events, so you get that reaction, that would be appropriate to the way they interpret it, so once again they are not prone to become violent but misinterpretations of situation. Also other things that can happen are prescription drug interactions. A change in the environment or caregivers arrangement, moving to a new nursing home, even fatigue, can cause these things that look like they have become violent but remember

all behavior has a reasons, they are communicating something, once again they are not prone to become violent but the things that this disease does can make them very agitated at times.

Female Speaker: We got another question in the queue, this one is from Sarah, Sarah asks do you have to have a diagnosis to reach out to the Alzheimer's Association.

JT Hunter: Great question, I am so glad that somebody asks that question, so let me address this, first of all, you hear our title as the Alzheimer's Association, but if I had to rephrase that I would say Alzheimer's Disease and Related Dementia Inc and we help family members who are caring for someone, sometimes family members who may not provide the care but just need to talk and get some information we do not discriminate so whether you have a diagnosis or not, maybe you just need to see a friendly face and talk , our doors are open. So my answer is no, you do not have to have a diagnosis, we have families that come to us sometimes and know something is going on, but there maybe no diagnosis yet, so we are not going to turn anyone away, and whether it's Alzheimer's disease or related dementia our information and resources are still going to be helpful and appropriate. So long story short, it doesn't matter, your connection or if there is a diagnosis, we are always here for whoever needs us.

Female Speaker: Thank you, our next question comes from Lewis, Lewis asks what are some of the resources to help when a person with Alzheimer's disease is found wandering?

JT Hunter: Excellent question, there are some safety features out there, I am going to mention a few of them today, and for more information call us, email us, stop by our offices, we can supply with all this information about the services I am about to tell you about. Once again if I say they are mobile there is always a possibility and as a care partner, I think about the 'what if' God forbid what if, this would ever happen, so the safety features I use them as well and have them in place to hopefully prevent that God forbid what if, so the first thing I want to mention is something called safe return MedAlert, it is a bracelet, now it is not going to have their name, phone number and address on it, what it will have on the bracelet is it will say I am a person with a memory impairment and it's 1800 number that they call if you find this person, so if you enroll in Safe Return there would be the bracelet. Your loved one's information will be on record with the EMS services and police as well as with the Alzheimer's Association, so God forbid what if that person is lost, or wanders they have the bracelet, so hopefully if someone locates them they will call that number and then there is a great search network and team behind that for support helping to find that loved one.

One other thing I want to mention real quickly about safe return, it's just as important for us care partners, If I am the primary caregiver of a person with Alzheimer's disease and related dementia God forbid what if I go down or I have an accident, people need to know that I am caring for someone with Alzheimer's disease and related dementia so I actually say it's a good idea for us care partners and our loved ones to may be enroll in Safe Return MedALert, if you are interested or want more information or want to know how to enroll contact us and let us know I will get you that information.

There is something else called Comfort Zone out there, sometimes early stages people with the diagnosis may still be driving or at least could be pretty active. This thing called Comfort Zone

is a great device, now it's a device that you would have to clip on a belt, put in a pocket, or put in a purse, so it may not fit for everyone but you can also put it in the car, so with comfort zone it's kind of like a GPS tracker and a monitoring device, so let me walk you through this, if I signed up my mother for Comfort Zone what I would do is first of all I could decide who gets alerts, and how do I want alerts, so it could be either email, cell phone or both, so what will happen is I am using it for mom's car, so I am going to set the perimeter, and say, here is about as she would ever go, so what can happen is first of all I can get online or through my phone see where that car is or whatever that device is attached to, I can see where that is at any time. now, God forbid what if my mom is in the car, and she tries to get closer and closer to this perimeter, I will get notifications and it will say, hey your loved one is right here getting close to this perimeter, so it can be preventative, it is very helpful for people more in their early stages and especially if they drive, it will make me as a family member feel a little more safe but not also having that rip that independence away yet, so it could be beneficial for both people.

One other thing I have to mention especially in the state of West Virginia is a program called Project Life Saver, almost every county in West Virginia has it, and in those days if the immediate county doesn't have it it would be covered by the sheriff's county at the Project Life Saver, it's a GPS bracelet, it's overseen and ran through each county's sheriff's department and that is a GPS tracking bracelet it would come through sheriff's department they would come attach it, I cannot say impossible to remove but very difficult to remove, and once again it's GPS tracking so God forbid what if that person is lost GPS tracker, now I know some places in West Virginia with the mountains and the hills there maybe areas where it might not be effective but in most places it would help. The other thing with Project Life Saver there is a trained search network behind this program, so God forbid what if that person is lost hopefully they still have that GPS bracelet on but also there is a trained search team behind that program that will go out and help search for this person. These are all features that are very important. I encourage people that this day never come and hasn't happened yet and plant one of these devices at least, so God forbid what if that day ever comes we have these things in place that will hopefully help.

So those are the big three that I always mention in West Virginia. And once again if you are interested in Project Life Saver all you have to do is contact your county's sheriff's department and tell them you want more information on Project Life Saver it's all ran through them, but on the other two programs, Comfort Zone and Project Life Saver, if you would like more information or want to hear more about it please just let us know.

Female Speaker: Thank you so much, do you know if Project Life Saver or any other programs are available in other states as well?

JT Hunter: I can tell you the first two, Comfort Zone and Med Alert Safe return and I am glad that you asked this, are national programs, so wherever you go in whatever state, Comfort Zone and Safe return, Med Alert should be available, I can say that pretty confidently. Now in our region in West Virginia we do cover couple of counties and other surrounding states, so for example, other states I believe would have a similar program let me say that, the hope would be that they have a similar program but I can't say 100% that every state has Project Life Saver but hopefully they have a similar version of it.

Female Speaker: It looks actually like a Carla put a link to Project Life Saver, so maybe folks could go, if anyone is interested that's on West Virginia if you want to click on that link that might not be able to tell you Project Life Saver is in your state. Well, unfortunately that's all the time we have for today. JT, I want to thank you so much for being our presenter today, it's a fabulous presentation and I want to thank all of our webinar attendees as well for joining us and learning more about Alzheimer's disease and related dementia. I would like to ask that everyone please take a moment to complete the evaluation form that will pop up on the screen when you exit the webinar. Your input is definitely valuable to us, it will help us improve any future webinars that we do, and I also want to remind everyone as well to visit our website which is www.qualityisgihts-qin.org to learn more you can contact any of our experts at any time. You should have contact information as well as link to some resources that we have available as well. So again I just want to thank everyone for your participation today and have a great afternoon.

JT Hunter: Thank you all.