



**Alzheimer's Talks  
with Teepa Snow  
September 12, 2016**

Welcome to [Alzheimer's Talks](#). I'm glad you are able to join us on this monthly teleconference series presented by [UsAgainstAlzheimer's](#).

My name is [George Vradenburg](#), and I'm Chairman and Co-Founder of UsAgainstAlzheimer's, a nonprofit entrepreneurial and innovative organization, seeking to disrupt business as usual and get to a cure for this disease faster. Please join us at [www.UsAgainstAlzheimers.org](http://www.UsAgainstAlzheimers.org) when you have a moment. We will send you something every week that will give you an opportunity to take some action that will work to end this disease.

We're very happy today that we have over 1,200 people who are either on the line or who have asked for the recap, from forty-four states, the District of Columbia, and Canada.

A couple of update notes: Our [Researchers Against Alzheimer's](#) network now has 400 researchers in the United States signed up, to give researchers in Alzheimer's a clear voice on the public policy front, and now we are joined by researchers from all the G7 countries: that's Japan, Canada, UK, Germany, Italy, and France. And we're extending that network of researchers now to the G20 countries, which will include a number of the most advanced countries in the world, to give global researchers around the world a voice, not only with their governments, but also with the G7, the G20, and in future, the WHO and the OECD. So, it is a great expansion of one of our constituent networks.

We also have our own [summit](#) coming up on September 27, 28, and 29. We'll have a diversity convening on the 27<sup>th</sup>, focusing on the health disparities that communities of color are experiencing, as well as the economic disparities that accompany those health disparities, particularly in Alzheimer's and in the additional caregiving burden borne by those communities. The 28<sup>th</sup> of September is our general summit; it will be attended by over 250 people, walking through the steps we're taking and intend to take in order to accelerate a cure for this disease by 2020 or 2025, depending upon whether you're a member of this organization—we believe in speed, urgency and passion so we're looking for a means to stopping this disease by 2020—or if you're listening to your national government; they're committed to find a means of prevention and treatment by 2025, a goal that was taken on as well by the G7.

And then on Wednesday night, [September 28, we will have our annual dinner](#) of 500 people. Laura Bush, Mrs. George W. Bush, will be there, being interviewed by Diane Rehm, and we will have videos from all of the other living First Ladies, Mrs. Obama, Mrs. Clinton, Mrs. Carter, and the senior Mrs. Bush, and so we're going to be well represented, demonstrating the respect that this organization now has, in both political parties and at the highest levels of government. We're also going to honor Nancy Pelosi, who is currently the minority leader of the House of Representatives; Senator Kelly Ayotte, a Republican Senator from New Hampshire; as well as the new CEO of Eli Lilly, Dave Ricks; and for many of you who may know by reputation or personally, a person living with Alzheimer's, [Greg O'Brien](#). He will be given the first Bea Lerner Valor Award. Bea Lerner was my mother-in-law and we're going to be giving an award in her name to those people who have both the humor and tenacity and the grit to tackle this disease, even as they're living with it.

This afternoon, we have a very special call with [Teepa Snow](#). She is a respected dementia and Alzheimer's care expert, with a background in occupational therapy and over thirty-five years of experience in clinical practice. With Teepa's [Positive Approach® to Brain Change](#), a trademarked program, she helps family members, friends, caregivers, and professionals build skills to be a better care partner.

We have received many great questions for Teepa in advance of this call, but if you have a question during the call, please press \*3 on your phone. By pressing \*3 you will be placed into the question queue. Please have your question ready to share briefly with a member of our staff, or if you are listening to us online, you can type your question in the box, and we are planning to get to as many questions as possible after Teepa's opening presentation. Please note that Teepa, like all our guests, is not able to answer personal medical questions.

Thank you so much, Teepa, for taking the time to speak with us today. We look forward to some opening remarks about yourself and your work and how you approach your work, and then we're going to open it up to questions.

**Teepa Snow:** Thanks, George. It's great to be with everybody. Long before I became interested in doing this professionally, I actually first experienced dementia when my grandfather moved in at the age of eight. And he developed a type of dementia we now know as vascular, but back in the day, we had no idea that that's what it was. And over the course of time, due to his COPD and black lung disease, a result of working in the coal mine, he became less and less coherent and more delusional, and we had greater and greater difficulty. My mom was not what you'd call a great caregiver. She was a terrific phys ed teacher but unfortunately, she and my grandfather had a lot of conflict and it turned out that I figured out how to ride the divide and negotiate.

Then later on, my grandmother on the other side developed Alzheimer's disease, and more recently I've had other family members who've developed cognitive neurodegeneration, which is a big category of dementia. And we figured out ways to make life livable until life wasn't present. And so my mission in what I do, having worked with head injury and a lot of other things, is not only just myself but now reaching out with other people, trying to open the door to have conversations about this thing called dementia, that aren't quite so terrifying and horrifying, because I can't stop the disease nor do I have the skill set to cure it. But what I can do is help people figure out how to get through this until we get to that place. Because until there is a cure, we've got to figure out, how are we going to help people live and how are we going to help families and staff and residences do a better job and how are we going to get the Feds and the national and international community to respond rather than react, which is, that part of your brain that's automatic versus thoughtful, and they're two different functions of the human brain.

So these days, I go all over the U.S., Canada, over to the UK and beyond, trying to open that door, to let's talk about this thing, because it's not going to go away just because we want it to. If we don't invest, if we don't explore, and although we may fix Alzheimer's, we still have a bunch of other dementias to deal with. So that's what I'm about.

**George Vradenburg:** That's terrific. Tell me, in your travels, who are you meeting with? Who are you training, are you training professionals, are you training family caregivers? What is the nature of your work with others in terms of spreading the learning?

**Teepa Snow:** It's really soup to nuts, so last week, for instance, we had Supreme Court Justices, many of them from New York, who are dealing with guardianship cases, and the mental health support system as well as the legal team support personnel and so we did a training on what is this thing called dementia and its variations, and what might get people to a place of seeking guardianship, and is that always a place people need to go? And how do you know whether what you're looking at is in fact a dementia or a poorly managed hypertension, added to diabetes, added to depression. We're asking legal systems to try to sort things out that we have trouble getting physicians to sometimes be able to sort out.

I also do training for medical schools, and practicing physicians, I work with nurses, I work with rehab professionals, social workers, I work with communities and facilities and agencies at a national as well as a local level, and organizations, as well as working with families and family members and churches and temples where people who are living with dementia and their families are practicing faith or trying to live lives. And then in addition to that, we do work, and I have those that I'm training and working with, to become able to be supportive in a variety of settings, working in hospitals, working in community settings, and sites of day centers.

So we work with people who live with dementia, and I work directly with them, and consult with them and their families, but we also do educational programming.

**George Vradenburg:** And what are the most common questions that you get? Just take the top two or three most common questions.

**Teepa Snow:** *What's the difference between Alzheimer's and dementia?* That's number one. Number two is, *Why is it that she does that? I just don't understand why they do those things. It doesn't make any sense.* And so those are really the two most common questions that I hear.

And the first, *what's the difference between Alzheimer's and dementia?* What we know now is that dementia means that you're in neurodegeneration. The neurons in your brain are falling apart and not working right. That's a big category and we call it a great big umbrella. So it's an umbrella, and it's actually not a diagnosis, but it's a syndrome, and it's a collection of symptoms. We know some things; we know your brain is dying; we know that it's progressive; we know that as it progresses, it's going to continue to progress—we don't have a way right now to stop it or put it on hold—until it destroys so much of various parts of your brain that your brain can't run your body any more and it kills you.

So we have that great big umbrella, under that umbrella the current thinking is that we have 95 to 110 different conditions that are types, forms, and causes of this neurodegeneration. And the biggest box there is Alzheimer's disease. But we've got other boxes under there. And Alzheimer's, we know now, is not one type of dementia, it's actually a group of them. It means your brain is having neurofibrillary tangles, which means tau protein malformations, but it also means that your brain is experiencing beta amyloid malformations or plaque formations and that combination when we see them gets labelled as Alzheimer's, and it has a fairly predictable pattern. But what causes it varies a lot.

Now, the second question that I get asked a lot is, *Why does she do that?* And the answer is, because that's how her brain is behaving at this point. It's not a willfulness or an unwillingness to do, it's in that moment, she can't. And the combination of chemical shift and structural shift really is never static or stable. It's like you have a dimmer switch on a light, plus you have problems with the basic wiring. So, sometimes the wiring seems to work and then sometimes it doesn't. And then sometimes the bulb is really bright and then the next time you look, it's hardly on at all. And that's frustrating because you have all these different functions that your brain does for us, everything from recognizing and fighting infection, to being able to solve a complex mathematical problem, to being able to figure out whether something's in the rearview mirror of the car or whether it's right in front of the windshield, and judge the speed of the oncoming vehicle. So we are these highly complex neuro-functioning units that depend on input, throughout, and output, and dementia messes with it.

**George Vradenburg:** One of the first things that one often experiences in the very early stages of the public display of this disease is repetitive questioning, resistance. So how do you recommend the caregivers respond to the repetition, to the sense of the person is resisting an obvious truth in front of them. Do you go along with them? Do you try to point things out and correct them? How do you deal with repetitive questioning and denial of the obvious truths?

**Teepa Snow:** Okay. First of all, those are two actually different questions. So I'm going to break apart a little bit and then we'll put them back together. One reason people repeat information is, the part of the brain that stores the answer is usually located in what is called the hippocampus, which is your learning and memory center, and for many forms of dementia, that's the first area that gets zapped with brain failure.

And so what happens is, when I say: "What time is the appointment?"  
You say, "Two o'clock"

And I go, "Oh, yeah, two o'clock." I say it, I seem to get it, and I try to put it in a storage spot and there's no brain tissue there, so I drop it. And then in a second, I'm thinking, *now what am I going to do today?* "Oh! What time is that doctor's appointment?"

And you say, "Well, what time did I just tell you?"

"I didn't hear you say anything. What are you talking about?"

"You just asked me what time you were going to go to the doctor."

And I say, "When did I ask you that?"

"A couple of seconds ago!"

"Well, I don't remember you saying that! Why are telling me you told me something when I . . . " So now it sounds like I'm being resistant, when what I really never got was, I couldn't lock the information into my brain.

So this is where your perception of why I'm doing what I'm doing is actually not accurate. My perception of why I'm doing it, is that I don't know the information. Your perception is, I know the information and I'm not admitting that I got it. So what we want to do is change a little bit.

So, could you ask me what time your appointment is? You ask me, George, *what time is my appointment?* You be the person with dementia, and you're going to ask me what time is my appointment.

**George Vradenburg:** What time is my appointment?

**Teepa Snow:** You're wanting to know what time your appointment is, the one with the doctor today?

**George Vradenburg:** I don't know.

**Teepa Snow:** That's where you would say, "Yeah, that one." And I would go, "It's at two o'clock."

**George Vradenburg:** What's at two o'clock?

**Teepa Snow:** The appointment that we have, yeah, that doctor's appointment. And so we start doing that, and I'm recognizing, okay, it's not going into storage. And that's the first thing I have to do. I have to admit, George's message isn't getting where I want it to go. So, I can keep pushing it, or I can say, "Yeah, that appointment." Tell you what. George, could you do me a huge favor? Do you mind?

**George Vradenburg:** No . . .

**Teepa Snow:** Ok. Tell you what. Can you come help me just a second? I want to ask you something over here.

Now what I've done: I answer your question. I recognized it isn't working. And I decided, you know what, I'm going to substitute. It's not going to get us where we want to go. Now later on, in a minute, after you've done the thing I've asked you to, and I've said thank you, trust me, *when's the appointment* is very likely to come back up, but I've bought you and me something else in the interim. I gave up on the thing I wanted, because I can't get you to do what I want. And I can't make you get it, by getting angry or frustrated with you, because the reason you're not getting it is not because you're not trying, it's because your brain doesn't take it on and hold on to it in that moment.

**George Vradenburg:** Are there other techniques, like writing things down?

**Teepa Snow:** Yes, like Post-its. Visual cues are much more powerful than verbal information because when we see something, our brain processes it differently in a different part, so there's a time in the disease where using visual cuing is so much more effective. You say, "Look, let's take a look here and see what time the appointment is," and I'm actually pointing at the calendar with you, and you go, "Oh, yeah, two o'clock," and so we have an X on the day before, so this is

the one with the two o'clock. And so the next time I say, "I don't know, check on the calendar, see what it says," and you go, "Oh, it's at two o'clock."

Well, now I've empowered you, rather than made you feel stupid, so when you say, "What time is the appointment?" I can say, "Hey, George, I'm not sure, take a look on the calendar and see." Now I have a new way of coping with it, and so do you. So visual cues matter.

But then I have to be picking up on when you're looking at the calendar, and you're going, "I don't know what you're wanting me to look at." And it's like, "Okay, we've come to a new place now." "Okay, let me put a Post-It here. Your appointment is at two o'clock." No calendar any more; I've eliminated it, because it's too complicated. And then I get to a place where you look at the note and you go, "What's this about two o'clock?" And I go, "Hmm, yeah, that's that doctor's appointment; I thought I said something about it, I may not have."

The fact of the matter is, I know I did say it, but I know you didn't get it. So me saying, *I told you that, what did I tell you*, is going to make a part of your brain that's not working so well called impulse control also not work well, and now you're going to get angry with me, and that's what we call you being resistive. But what it really is, is another part of your brain besides memory is also having trouble, and that part is being able to control an impulse. And you're struggling with it, it's not easy for you. It may never have been easy but now, it's really hard.

**George Vradenburg:** And do you find that being able to put on someone's cell phone, all the appointments and little instructions that actually come with alerts, is a useful technique to remind a person almost in the moment of what they should be doing?

**Teepa Snow:** Yeah, that's perfect, George. Early in the disease for many people, that is a life saver because it means I don't have to rely on another person. Here's this system we have, that when that thing goes off, I look at my phone, and I recognize what I'm supposed to do. For example, it says, *you have an appointment in fifteen minutes, get in the car*. And I go get in the car, because I have an appointment.

But there comes a time when I read that information, and between the time I read the information and I'm supposed to go get in the car, things in the world around me are distracting me, and I get to the door, and I look at the phone, and I go, "Oh yeah, I've got to get my pocketbook." And then I get some other things that I'm doing, but I hit the thing that says, *well, I did it*, and it's unfortunate, I didn't, and now I'm getting more turned around. So, yes, but no, is the honest answer. It depends.

**George Vradenburg:** You wonder whether we're going to get a system of alerts that we can increasingly rely on, that give you almost a continuous alert, that give you half an hour away, fifteen minutes away, ten minutes away, five minutes away, so that one can sort of be the distraction to the distraction in a sense.

**Teepa Snow:** Yeah, it might, but what if—and let me give you a for instance—what if your third alert came on, and you weren't where you thought you were. And so, you're not going to make it to the appointment that you really want to go to, it's an important meeting, and you now realize you've gone the wrong direction. You are now lost.

**George Vradenburg:** By that time, we're going to have driverless cars. The driverless car will come over, pick you up, or you can go out and wave an Uber down, and the Uber driver will take you to the address.

**Teepa Snow:** [laughs] Yeah.

**George Vradenburg:** A lot of other issues here; the violent outbursts, the physical reaction. How do you talk to people about interacting with the person with the disease who gets angry and physically reacts to what you're doing?

**Teepa Snow:** Typically, that is the kind of thing that what folks haven't recognized is, *I've tried to warn you, this is really, this is getting to me.* So, let me give you a for instance. This comes up a lot, earlier in the disease, when I say to you, "You can't drive, I'm taking your keys away. That's it." And I grab the keys and I try to remove them. And your brain goes "Excuse me, those are *my* car keys. And you have no right to do that." The physical act that I performed, by grabbing the car keys and taking them away from you, said *You are no longer in control; I am grabbing control from you.* If our relationship has never been like that before, your brain goes *Who do you think you are?* And you want those keys back. The more I try to keep them away, the greater the risk you will take a swing at me, if you have lost the ability to control an impulse.

Instead, you start to pick up the keys, and I say, "Ooh, George . . . the doctor had talked about you not driving." Now notice how I hesitated there, because that's that moment when you go, "Oh, crap, if I argue with him, he's going to get upset."

You're right, he will. So let's try something different. So: "The doctor said, 'no driving.' I know that's bothering you, you hate it, you want to drive, you still can drive, but he's saying, 'not right now.' So for this time, can I drive this time? And you can drive next time. And I'm sorry, I'm sorry that he's saying, 'not right now.'"

Now did that feel a little different than, "You're never going to drive again, and I have these keys in my hand and you want them"?

**George Vradenburg:** It did.

**Teepa Snow:** Yeah. So I can provoke you, and I don't mean to, I'm not doing it to provoke, I'm trying to help, but without an awareness of what's causing you to do what you're doing, I think I can help by doing something that I would do with a two-year-old, but you're not a two-year-old!

**George Vradenburg:** We've got a good question here from Kathleen MacIntyre from Douglas, Massachusetts. Kathleen, you're live, would you like to go ahead and ask your question?

**Caller:** Surely. My husband's much more advanced; he no longer speaks or walks or functions really in any way, he sleeps most of the time. My problem is, at meal time, is there a way that I can somehow get his attention or wake him? I've tried a wet face cloth; that sometimes works. He's now been put on puree because of his swallowing. Sometimes he does come around, and I get a smile, but just wondering if there's some way I can grab his attention?

**Teepa Snow:** There are a couple of possibilities. One is, if he's been sitting still a lot, and that's very common at this place in the disease, because active movement is difficult, if at all possible, one of the things we might try doing is just rocking the chair back or moving the chair backward and forward a little bit. What that does is, it stimulates what's called the vestibular system which is your balance and coordination system, and when you move it, and it's not a rough rock, it's a smooth rock, but it gets you to move back and forward, it actually causes people to wake up and it's a way that you can cause a brain to pay attention because movement, whether you did it or somebody else did it. If anybody's ever started to trip and you find yourself catching your balance, that's really what's happening. It's an automatic thing. So I'm using an automatic reflex to get his brain to sort of alert a little bit.

So rocking the chair forward or back, or maybe moving the chair, if it's a wheelchair, moving the chair a little, not big movements, little movements that cause the brain to go, "Whoa, what's going on here?" and cause it to alert without making it so anxious that it can't think.

And then, the second way is to try the tips of your fingers—but not your nails—the pads of your fingers, in quick circular motions around the shoulder girdle in the back because when you do those quick circular motions around the back, in a motion, it actually causes your brain to go, "Huh? What?" in a friendly way, not a scary way.

And the third is to take his hand, and actually use music or rhythmic and bring the frequency up, not the volume, but the frequency. So an example might be, [humming to the tune of *When the Saints Go Marching In*]

“Duh dum dum dum . . .

Duh dum dum dum . . .

Duh dum da dum da dum da dum [increasing pace]

*Ah rat tat tat . . .*”

Because that rhythm wakes a brain up too. So I want to do things, and if he has any music that has emotional value, that’s even better, it causes the brain to rouse up when it hears something of value to it. What he’s able to process is limited, but he might be able to process something of value still.

**Caller:** Awesome, thank you so much.

**Teepa Snow:** You’re welcome.

**George Vradenburg:** Question online here from Cameron: How do I go along with my mother’s belief system, when some of the things she believes can be quite painful and dark? For instance, she believes she is being visited by the devil, that she is going to hell, that her caregivers are going to shoot her.

**Teepa Snow:** Okay, so the first thing that you want to do is not necessarily go with her, but you want to acknowledge her journey. So it’s called validation. The first thing I would say is: “This is an awful place. These people that are here, you don’t trust them, you think they’re up to no good, you think they’re going to hurt you. Tell me about that, Mom, what’s making you feel that? What are they doing that’s making you feel that?”

Because something is happening here . . . It’s not reality but there’s a sense, on her part, that something’s bad.

“So you’re feeling like you’re going to hell and that’s not a good place, nobody should go there and nobody, nobody, no devil should come and spend time with you, you are such a good person, that shouldn’t be happening.”

And so what we want to do is get her to believe we believe it shouldn’t be happening for her. We believe that it’s bad, and it shouldn’t happen. And what we don’t say is, in fact, “It isn’t happening, Mom.” So, you affirm, “You’ve never done anything that should make people do that. What in the world, why are those people wanting, what did they do? Did they do something that really scared you?”

And it could be as simple as—I will tell you, if the person might have some Lewy Body symptoms—it could be as simple as what they tried to do is get her out of the chair and it scared her. Or if somebody turned off the light when they put her to bed and she saw that as going down into hell, because in her damaged moment, that the light going out—light represents going to heaven and dark represents going to hell—in her mind, that’s what happened and then somebody said, “You stay in here,” and suddenly that became the voice of the devil. Now, all of that is like, *but that doesn’t make any sense*, and it doesn’t make any sense to an intact brain but it could actually make a lot of sense to a brain that is electrically firing in really bad ways and being destroyed.

**George Vradenburg:** That was terrific, Teepa.

We have some other really great questions here on the other major category of things where people are concerned; it’s basically the intimate caring, showering, toileting. This is more of a caregiver issue, but I am curious as to how you work with people who are either offended, grossed out, physically unable, maybe the nature of what the problem is, but I’d be curious as to how you approach that?

**Teepa Snow:** So, if I'm working with the care partner, what I'll ask him is, not everybody is meant to be a hands-on caregiver. It's really not a good match. Or the person you're trying to care for doesn't feel you're a good match. So I've had wives who didn't want their husbands to be their care provider for intimate care and vice versa. I've had children who were willing to provide the care but Mom was having no part of it. Or I've had moms who wanted to care and the kids were like, *I'm not doing that*. If it's not feeling like something that is respectful and that is something that, I see the person and the care just happens to get done, that's very different.

Or if the person is saying, "I don't want you to do that," then I'd say, "You don't want me. Okay. The doctor's saying 'we've got to get somebody,' so I want you to try something."

And she may or may not go that way. I frequently can get people to get started with intimate care by saying something really simple like, "Wow, George, you have really dry skin. Jeez, man, that's flaky. Look at that, ugh." And I'll be looking at your arms, or maybe your ankles, and I'll say, "Tell you what, I've got some lotion here. Um, I think on the thing, that it said what would work best if skin is a little moist before we start. Tell you what, take this wet wash cloth, it's just damp, it's nice and warm, put it on your arm and see. Tell you what, pull your sleeve up a little bit."

Now, what I'm actually doing is getting you used to me being around when you start moving clothing around. And that seems like, *Oh my god, that's crazy*, and what I'm going to tell you is, well, for really private people who've never had another human being around them, when they did intimate tasks, taking your clothes off and they keep their clothes on and doing care, that's what's crazy! So it's like, okay, well, I'm trying to figure out, what's driving their resistance to my assistance. Is it me the person? Is it the task? Is it the relationship? Is it the expectation? What is it? And until I can figure that piece out, the thing that's stopping me, I'm not going to get anywhere with it, I'm just going to get frustrated as a care partner.

And some people in my life are not going to be care partners. And it's okay, because they'll go out and manage the finances, they'll be the ones that can manage the house, they can do the laundry, they can do driving, but they can't do intimate care. Well we do need someone who can do intimate care, but it may not be the person that everybody thinks that it should be. It may be a professional, for that matter, who has skills.

**George Vradenburg:** How do you handle a person who sleeps a lot? Or put another way, how long should you let a person with dementia sleep if they want to sleep all day?

**Teepa Snow:** Okay. So part of the question is, was their evidence of depression at all? Does this person have depressive symptoms in addition to the sleeping a lot? And, what kind of medications is the person on? Because sometimes the medicines that people are given to manage distress can make you what is called somnolent or sleepy. So one of the things we might want to try to figure out is, okay, what else is going on here? Many people with Lewy Body will be awake in the night, but during the day they're much more likely to go to sleep because they relax when there's visual regard for the great outdoors and there's space, in their place, than at night when they're really anxious and busy, and they can sleep in the day.

For other people, early in the disease, they don't have sleep issues. But by late in the disease in many ways brain failure mimics brain development. And so if what I'm looking at is someone who's very late in the disease, then that would mean their brain is very damaged, so I'd be looking for a pattern that was as much wake and sleep, 50-50, or, more sleep than wake. But what we want to be careful of is, it's not long, long blocks of sleep. Because what can happen is the brain doesn't know how to wake up on its own, or go to sleep on its own. It has lost its circadian rhythm, its pattern, and so I look for periods of wakefulness, even in sleep, and bring the person on up to full wakefulness for a short period and then when they look like they're drifting back off, then allow them to go back to sleep.

We want sleep to be in wave motion, which is what sleep is, it's a staged process in and out through the night, and we don't come to full awakesness typically until we get older and have to



get up and go to the bathroom in the middle of the night, we will sleep through the night, although we have periods of wakefulness. But as we age, we frequently wake up enough that we have to get up and go to the bathroom and then we come back, and some people have more trouble going back to sleep than others. But we know that [sleep disturbance is tightly linked with some dementias](#), particularly, so people who sleep a lot, what's going on during the day? What's drawing their attention? Are there things they still enjoy happening? Or is it a case of, when we time those things isn't a good match for when they have their greatest possible alertness or arousal level. And it takes practice. It's also where we may want what they're not able to do. So it's a judgment call, quite frankly, there's not a yes or a no answer on it.

**George Vradenburg:** Got some questions here, more in the context of a care facility. How do you deal with resident to resident bullying? This is from Jennifer Caretti of Pennsylvania.

**Teepa Snow:** One of the things that sometimes happens is, early in the disease, many forms of dementia, *I think I'm okay but that other person is an idiot*. And unfortunately when we combine my sense of *I'm okay but you're not*, with a lack of impulse control, then whatever I think comes out of my mouth. If I don't like how you're behaving, I can't seem to stop myself not only from saying it, but approaching you and trying to get you to behave differently. So, it looks like bullying, but in fact, what it is, is an expression of my disease. So one of the things that staff have to become very skillful at, is, as soon as I register that person and you see me watch them, and you see me start to get up, somebody needs to come over to me and say, "Teepa, you're not liking how she's looking. You know what, I need to take care of that. But would you help me in a second? Come here, let me show you what I need. I know you're not liking her, you don't like the way she acts. That's really getting on your nerves."

So what has to happen is, I need to be respected. But you can't fix me. You can have as many lectures with me as you want, about what I should and shouldn't do, but I will tell you, that right after I yell at her, I'll say *I'm sorry but she just shouldn't come to the dining room like that*. You're not going to fix me because my brain isn't healed, all you're doing is trying to impose external control on a system that's broken. And you and I are both going to get frustrated. And you can kick me out, or you can put me on notice or whatever you want to do, but if we don't change how we respond, I will continue to do those kind of things, because every time I see that person it triggers in me *That's wrong, she shouldn't be doing that*, and this causes that back and forth. Now if she is also early in the disease, we're in real trouble, because then that's where the resident to resident conflict, not bullying, but actual conflict, can happen. So you need two skillful staff members in that moment.

**George Vradenburg:** What about residents who are intimate with each other? And one or both of them are married?

**Teepa Snow:** Yeah, it's a really messy thing right now. We do not have good systems for helping people meet their desire and their needs, because what's happening is, I'm losing relationships and I'm very close to this person, visually and verbally in the building, and I'm not recognizing where I am in my life, frequently. So many people, what's happening, in that moment, is, I've lost my present. And I'm more frequently found in episodes of my past. And although you look at me and see an eighty-two-year-old, I don't see me in the mirror. There's some old woman who's in the mirror and who I am, is twenty-two and I'm not married yet, because I didn't get married until I was twenty-five, and there's this fellow, and you know, he's older but at least it's somebody and I'm lonely and I've been married for sixty-five years.

The emotion of having been married and connected to someone tightly for sixty-five years is there, my ability to find them and recognize that is missing, and so I start looking for somebody to be with. Now the question is, can I find a friendship that doesn't have to be that intimate? And how do we meet that need for feeling that I have a connection that's tight, because when my spouse is there, I don't recognize my spouse as my spouse frequently, or I might. It's hard to tell, it depends on each person. But the challenge is when the spouse comes in, they don't act like a spouse, they act like a caregiver because that's what they've been for way many years now.

And so it's this really difficult thing that we don't like to talk about; nobody wants to talk about sexual intimacy. We don't have really good policies or procedures or even how to address this issue. We have situations where we have people who are living with dementia who might come on to their daughter or come on to their son or grandson, and again, the thought is, I'm being sexually inappropriate, the problem is actually, my brain is not getting what it should be getting, data-wise, and I'm making really bad choices. And because people don't talk about this and don't acknowledge and don't make this part of what we need to know, it ends up being really devastating for everybody. And we just don't have strategies in place to pre-think this before it gets to where we have to deal with it. And it makes it horrendous for everybody without any support in place. It's hard enough when you do it.

**George Vradenburg:** From Rodney Dempsey in Louisville, he asks, how's the best way to handle the 'Why can't we go home together?' when your spouse is in an institution?

**Teepa Snow:** Yeah, one of the things is not to visit in the evenings, if you are. One of the hardest times for me not to be in my own place with my own people doing my own thing is at night, and in the evening. So if you're visiting me later in the day, be prepared that that's the most frequent time when where I'm at is not where I want to be; I want to be back in the place and the space of safety and action, and that's going to be home. And if I recognize you, that's going to be with you, and you get to go and I don't.

So one of the strategies is to look at when you're visiting, and can you vary that? Well, if you can't, visit, but then what you want to think is, Okay, when can I exit, that doesn't create a sense of *I get to go home and you have to stay here*. So what we might do is engage in an activity, and I say, "You know what, I will see you again, I'm going to go right now, I've got to stop by the store. I've got to get some groceries. Is there anything you need?"

What I quit saying is, "I'm going to go home; I'll see you tomorrow." Because that said, "I get what you can't have." And I said, "I'm going to go do something, can I get you something while I do it?" But I've not provided that option of, "I'm going home."

"Ooh, I've got to get back to work. I've got something to do. I forgot about it until right now. Love you. Give me a hug. I will be back as soon as I can." Now, *I will be back as soon as I can* is true. *I have something to do, ooh*. You better think of what it is, 'cause if they ask, you want to have something in mind. But what it says is, I'm not going to the place you can't come, because you can't come with me, you don't get to go there any more because even if I took you there, the reality is, you probably won't recognize it for what it is. And that's the hard part. Or being at home is hard, too hard for both of us. I can't do the care that's needed.

Bringing another person that I like, but not as much as you, and having that person be with me while you step away first, and then when the other person steps away, I care less about them than I cared about you. Those are a couple of options.

**George Vradenburg:** Good suggestions.

A number of questions here, one from Felicia Serr in New Jersey, one from Wendy Apgar from St. Louis. What have you seen, in your work in nursing homes or senior living facilities, about the best activities for persons with mild to moderate dementia?

**Teepa Snow:** The first answer is, it depends on where they are in the condition, but all people have a need to be doing something every day that gives a sense of value and purpose.

So if it means you always used to run a company, then figuring out an office setting where you can give me some direction and supervise me a little bit may give you a sense of value and purpose. So rather than trying to put you in an activity group where we've having a fun time, you need to go to work. "So listen, could you do me a huge favor, George, would you mind helping

me set these tables up? We're going to have a meeting later and I didn't ask maintenance to do it. Do you mind?" It's much more valuable to you than:

"George, let's go play Bingo."

"I'm not going to play Bingo."

"George, c'mon, let's go."

"I said no."

So we have to recognize, people need to feel valued. How do I create something?

"Hey, George, come here, I need your opinion. Do you think that flag looks better over here or should it be moved over here? What do you think?"

Now, it seems small, but in fact, having moments where I feel like I still have purpose and value is critical. And an opinion is something somebody has, even when they have very little capacity for doing things. But, gross motor abilities last longer than fine skilled abilities. So: "Hey, George, could you carry this? Oh, gosh, you're great, man. Thank you, thank you."

Asking you to carry a box, push something, do something, that's preserved, so finding those opportunities: "George, would you carry the mail around? I'm going to deliver it; do you mind? Oh, here's Mary's. I'm going to put it in her box. Would you? Thank you. Thank you."

On the other hand, everybody needs to have moments of joy each day, so I better figure out something that you like that gives you a sense of joy and you should get a chance to do it every day. Something that has been demonstrated to be effective for most people is music—music and rhythm. So finding out what kind of music and then singing, dancing, enjoying music, playing big band music, whatever it is, that sense of joy and connection.

So for many people it may be, quote unquote, cocktail hour. Do we really have to have cocktails? Probably not, but we could put cranberry juice and sparkling water in something and make it look like something that has value to me, and then I'll stand around and talk.

There are other ways to find value. And one that gets left out way too much, and we're finding more and more is important, is physical activities and brain activities that use what you have left. I should be getting you up and moving. I don't want you just sitting in chairs in one location and sitting in chairs in another location. Even if it's limited, sit to stand, sit to stand, stand to sit, stand to sit. Increases probability that we buy you time from fall-related injuries. It keeps your muscle strength and your coordination up a little bit. So giving you opportunities to do that makes sense to your brain.

A simple thing is, instead of just crossword puzzles, which people can't do any more, what if I did one that said, "Okay, George, 1 Across, [sings] My Wi-i-i-ld Irish . . . Now George, you must know that one." So we use *rose* and we fill in the blank with *rose* and then I go, "Okay, here's 1 Down, [sings] Let Me Call You . . ."

And people shout out *sweetheart* and we fill out the second part of the crossword puzzle. We take Scrabble tiles and do things.

The challenge is not so much what to do, but how to do what to do. How do we find the right match for people? How do we give them opportunities to be themselves with the limitations that they live with?

**George Vradenburg:** What's so striking about the way that you look at this is the ability to read people, the ability to read each individual person, and to have an imagination about how to get past the immediate thing into some other domain, which is either distracting or reinforcing or purpose-giving or joy-giving and that takes both a skill in some technical sense of the word but it also takes an enormous amount of empathy and creativity. So how do we get that into professional staff and how do we also provide support to family caregivers..?

**Teepa Snow:** Step one is awareness. If you believe that people who live with dementia are nothing but losing skills and have nothing, it's all coming apart, then your mind says, *well, what's the point*. If however I'm looking for the light in the darkness, then what I do is go, okay,

so tell me more about what can they still do, what is their strength that I can work with? Who has this person been? What have they always cared about? And if I can take that and give you some knowledge and skill on so what does that mean, how could you take that and use it? And I say to you, music lasts longer. So give me three songs that made him dance when he was young. Then all of a sudden, I can come up with things, and that's where, as a team, we start to work.

If all else fails, what I'd say is, family caregivers, don't try to be a Lone Ranger. Reach out and start looking early on for who else can I bring in to this, that's going to support me and give me a break and take time with my person so I can step away and they feel that thing that I can't give them. Recognize this is not something to try to do on your own. Figure out, where can I find some support? I can't be creative when I'm exhausted. I can't really be empathetic when I'm hurting so much. And recognize when I'm feeling a certain way, I need to take a step back, take a time out and go, "Look, I need you to take time and do this for a bit, I need a break here."

Without awareness, we think it's love that's going to get us through this, and love makes a difference but there are other brain functions you have to use to be successful. And all too often, people just rely on the old relationship, and don't acknowledge that they're grieving the loss of what was. And yet you still have somebody in front of you who is able to do some things, not like they used to, so, who around can do that? So what we're doing is a lot of training in facilities, but it has to be a whole team, it has to be a whole culture shift. It's not about taking care of people, it's engaging in life *with* people. And we've got to find those people, and I do, I find them a lot, that really do get that. We have some folks who just want a job, and this is not the right population to work with, if you just want to do a job.

**George Vradenburg:** We have a great sign-off here from Michael Ellenbogen, who is one of our most articulate people living with Alzheimer's who says, "There's no one better than Teepa. How do we get all caregivers to be the same as you?" That's a great question. How do we replicate you? How do we embed you in all of our heads to think the way you think, to be as creative as you are, and to be as empathic as you are. It's been absolutely terrific, Teepa, thank you.

**Teepa Snow:** My pleasure, George. Thank you for the opportunity. You are creating this new culture of, we need to address this issue. I so support and applaud you for your vehement support because until we start opening that door, people just think this is a minor problem and they have no idea. So thank you.

**George Vradenburg:** Thank you for that. Sorry we couldn't get to all the questions that came in online today, and pre-call, but Teepa gave us a real insight into how to think about this differently. The challenge of course is to take it and get infected by both your infectious quality and your skill set, but that's another challenge.

[If you're interested in joining our next call, please click here.](#) Our next call is Monday, October 17, from 4 to 5 p.m., with Dr. Rudy Tanzi. Dr. Tanzi is so popular that he's our first guest to join us, over the last three or four years, for the third time. He's going to be talking about his new microbial hypothesis that, in fact, Alzheimer's is caused by microbes and what it means for new research directions. You don't want to miss this call.

If you haven't joined us, please go to [www.UsAgainstAlzheimers.org/](http://www.UsAgainstAlzheimers.org/) and sign up to our organization. We'll send you a recap of this call, invitations to future calls and every week important updates and simple ways that you can get involved. I hope that you will join us. As my wife continually emphasizes, Trish says, it's in the numbers, at least politically and from a movement-creating point of view, it's the number of people who are willing to talk about this disease, willing to talk about how to care for those who have the disease, and for the caregivers who need our own care and support. We need numbers of people. We're finding, here in Washington, that what's really helped move the needle is that members of Congress themselves are talking about the disease and how it's affected their own families, and what we find is, that when they do that, they have a number of their fellow colleagues in the House or the Senate who say, well you know, that's happening to my family too.

I was at a small event for Tim Kaine the other night—I am a bipartisan Alzheimer’s party person so I go to both parties—but Tim Kaine, I thanked him for mentioning Alzheimer’s from the floor of the national convention when he accepted the DNC nomination for vice president and he went into a fairly emotional story of how his sister-in-law was diagnosed at fifty-five, she’s now fifty-nine, and what that disease has done to her and what the disease has done to her husband, as a caregiver, and he is personally committed, should he be elected, to making sure that in fact this country is dealing with this at a deep level with particular emphasis on caregivers and caregiving.

Thank you for joining us today, we thank Teepa Snow for her insights, her empathy, and her love, and her skill set. Have a good afternoon, everyone.