

# Easter Seals Military Caregiver Training Webinar Series

## Caring for a veteran with ALS and anticipating their future needs.

June 22, 2017

1:00 p.m. CST

Easter Seals.

Caring for a Veteran with ALS and Anticipating their Future needs.

>>OPERATOR: Ladies and gentlemen, thank you for standing by. Welcome to the caring for a veteran with ALS and anticipating their future needs webinar. At this time all participants are in a listen only mode. I will turn the call over to Bryan Vidal to begin. Please go ahead.

>> BRYAN VIDAL: Thank you, and welcome. Greetings on behalf of Easter Seals that we host the latest webinar in our military and veteran caregiver webinar series titled, caring for a veteran with ALS and anticipating their future needs. We are pleased to partner in this effort as a proud member of the Elizabeth Dole Foundation National Coalition for Military Caregivers. Let me begin by thanking our operator, Maria, for her support. Thank you, Maria. Now specific details related to today's webinar. The phone lines will be muted throughout the webinar, should you have any questions or concerns, please use the on-line chat feature of our webinar software, on the left-hand side of your screen, and send a E-mail to [militarycaregiver@easterseals.com](mailto:militarycaregiver@easterseals.com). If you are experiencing issues accessing the Blackboard webinar platform, please send a E-mail to that same E-mail address, once again, [militarycaregiver@easterseals.com](mailto:militarycaregiver@easterseals.com). We will send you a copy of today's slides so you can continue to listen and follow along.

We will address questions once our speakers conclude their presentations.

Please note that this session is being recorded. Transcripts of the recording along with copies of handouts and other valuable resources will be posted to [easterseals.com/carewebinar](http://easterseals.com/carewebinar).

Also available on our Web Page are the archived recordings of all our previous webinars. We are pleased to provide live captioning for the webinar, to access that feature, type in control F8 into your keyboard.

Now I'd like to review our agenda. I'll begin by introducing Mary Ward and Elizabeth Dole Foundation fellow from the state of North Carolina, I'll introduce today's host, Alisa Brownlee, who will share with us her knowledge on caring for a veteran with ALS, and anticipating their future needs.

Immediately following the presentation, we reserved time for all our speakers to respond to on-line or E-mail questions. We are also fortunate to have Dr. Michelle Stefanelli, representing the VA Caregiver Support Program, joining us as a additional resource expert and we have the pleasure of having Dr. Elise capman, deputy director of VA Caregiver Program joining us today. Today's webinar supported by a incredible group of organizations, they include Atlas Research, Caregiver Action Network, Family Caregiver Alliance, National Alliance for Caregiving, Rosalynn Carter Institute for Caregiving, USO. And the Elizabeth Dole Foundation.

Now I'd like to turn things over to Mary Ward. Mary is a Elizabeth Dole Foundation fellow of Wilmington, North Carolina, she holds a masters degree in healthcare management and policies and a masters in public administration, Tom, Mary's husband served as you states marine during the 1970s, in 1993 he contracted encephalitis and suffered cognitive difficulties. In 2010 he was diagnosed with

ALS, which veterans develop at a higher rate than the general population. Mary hopes that her time as a Dole Fellow can help her encourage, support and inspire other caregivers, having worked in the healthcare management field, Mary decided to switch careers and began serving in education. She is now a high school social studies teacher and finds herself teaching on-line in order to accommodate the care of her husband. Mary and two others joined by their veteran husbands testified on Wednesday, June 14, before the senate special committee on aging, and advocated for support of military caregivers. She urged lawmakers to pass proposed legislation that would expand eligibility for the department of veteran affairs, Caregiver Program to veterans of all generations, not just the post 9/11 generation. Mary, please take it away.

>> MARY WARD: Thank you, Bryan. I thought we could go to the slides for diagnosis, if you can advance to that, that would be great.

Next one. Road to diagnosis. Great. That is good. I'm going to talk a little about the road to diagnosis for us. It is different for everybody who has ALS. It took us a long time, Tom is in a category called slowly progressive. It takes longer than for those who advance more quickly. It seems like it was going to take forever and we felt like -- with ALS you never know. You are hoping that it's something else. It's a scary time, in anybody's life, when you are trying to figure out what it is that is wrong with them. [inaudible] a lot of twisting -- next slide, please. Diagnosis on June 21, he is 7 years into his diagnosis. I don't think anybody knows why somebody lives longer with ALS than somebody else. Typically, what we know about ALS is people live three to five years from diagnosis. He's exceeded that time frame. It was the day after our 30th wedding anniversary. I

was really glad, we were really surprised but not surprised about the diagnosis, we kind of expected it. But at the same time, it took Tom's doctor, finally the last doctor we saw, we had seen many of them, said ALS. It's sort of like, a lightning strike. Now we really have a concern, that is really hard. There is a lot of thinking that you have to do about that, and -- next slide.

So, Bryan talked about the connection. September, 2008, the veteran administration made ALS a presumptive condition. They had done a thorough study that looks back over time, and they saw that more veterans get ALS than nonveterans. Tom was diagnosed in 2010 then, we were able to get him service connected, and Tom joined the paralyzed veterans of America, successfully, very quickly, they handled his claim, they handled all of his paperwork. [inaudible] you can imagine, it is so great to have somebody take that from you, and say we have this. We are going to handle it. To this day, the P VA walks alongside of me. I received some assistance with something for Tom, and the PVA stepped in to help me out. It is special to have that kind of help. Anybody who is with us today who is veteran connected, I encourage you to reach out [inaudible] I cannot say enough good things about them.

Next slide. Struggles with the VA. For the most part, the VA connection is so great, because [inaudible] including health insurance, which makes it possible [inaudible]

(audio is very muffled).

In terms of Tom's care, we had most other things that we need from the VA [inaudible] times that we struggle, and a good example of that would be his breathing mask. That seems to be a struggle sometimes. When the mask starts to break down

because he perspires a lot during the night. When that breaks down, it gets [inaudible] he is not sleeping as well. That sometimes is a struggle. Most of the time the VA is really good for him. But the VA [inaudible] I started making phone calls. That is the best thing you can do, get somebody on the phone is the best approach. Patient advocate sometimes helps. Social work. VA. My husband Tom [inaudible] Wilmington [inaudible] that personal [inaudible] try to help. Next slide, please.

How do we live with ALS. I like the idea of saying that we live with ALS. We had a big house in North Carolina [inaudible] his diagnosis, we knew it was a [inaudible] it was going to be tough for us to stay in that house. [inaudible] a hundred percent, dependents will qualify [inaudible] but at the time of Tom's diagnosis [inaudible]

(audio is muffled)

Handle all of this going forward. [inaudible] move to the beach. Tom and I grew up on Long Island, we absolutely adore the beach. It has been a good move for us. It has been a good place for us. We try to get out a lot [inaudible] he often goes down there and does painting down there. We try to live every day as well as we can, and living by the beach has definitely improved our outlook.

Next slide, please.

Taking care of Tom, the activities of daily living has increased more recently. That is typical with ALS. He no longer drives. That is him backing out of the van with Maddie his service dog. He no longer drives. So that is a big responsibility to me, to make sure that, he can do the things he wants to do, but huge dependence, no longer drive. I do all the food shopping, I do the meal

preparation. He drops things so we moved from regular dishes to plastic dishes [inaudible] he can still feed himself but it takes time for him to feed himself. His hands are shaky. I have to cut his food. I give him a bath every day, I'm looking forward to seeing things Alisa has on her slides because we moved to a bigger bath chair and I don't struggle getting it down but struggle getting it down. I'm anxious to see if there are other ways for me to do that. I help him get dressed. He can't use his left hand at all. His right hand is weakening. He definitely needs help with those things. He needs help with putting his breathing mask on at night. Don't have to brush his teeth yet but I think that is coming.

We have the ability to do that so I think that is great, with a little bit of practice before the need is actually there. Next slide, please. He moves, as you know, with ALS you move towards more dependence than independence. We try to handle that pretty good, as good as we can. It can be frustrating for him, not driving is huge for him. Sometimes, he wants to go to Home Depot, I'll go sit in the car and bring my iPad and let him go. I keep his service dog with me sometimes, so he can be by himself. Having Maddie as service dog is great for him. She brings things to him. If he drops something she will pick it up for him. [inaudible] her favorite thing that she does, opening the refrigerator sometimes she gets a lot of attention, so it's nice sometimes that I can let him go out by himself [inaudible] 14 years [inaudible] second grade teacher. This is rare for us. I like [inaudible] handle the disease [inaudible] sadness [inaudible] but you know it's there.

Next slide, please.

Anticipatory grief, I didn't know anything about. I first stumbled upon it

somewhere in my readings about ALS, I tried to read a lot about it and learn from other people who are dealing with the disease. I don't think conquered it, I don't think anybody can conquer it because it's anticipatory, Tom is everything to me. [inaudible] 7 years. When we met, he proposed [inaudible] it was crazy, we got married a year later. I was 20 years old when we got married. I can't even imagine future without him. We all have to do that at some point in our lives, but ALS [inaudible] a lot of grief at times. Sometimes I'm good with it and sometimes I'm not. It sneaks up on me sometimes when I least expect it.

Next slide, please. I guess that's it.

>>ALISA BROWNLEE: Thank you. I want to thank everyone for this opportunity to speak is about the anticipating future needs for people with ALS. This presentation specifically focuses on durable medical equipment and communication devices, things that I'm asked for all the time. I have been fortunate enough to be with the ALS Association for almost 22 years now. And I have experienced clinics, hospital, veterans administration clinic and a lot of caregivers and people with ALS would like to think about what their future needs would look like. So I have this presentation about talking about future needs. As I'm sure almost everyone on the phone knows, ALS progresses differently with every individual. So what I'm speaking about and showing you might never be needed for you as a person with ALS or you as a loved one caring for someone with ALS.

We simply do not know how the disease will progress.

I've been fortunate to work for the greater Philadelphia chapter for the past 21 and a half years, and for the national office for the past eight years. I would encourage anyone who has a family member, a friend, diagnosed with ALS, to reach

out to your local ALS chapter. You can find that through the national ALS Association, which is at the tail end of my Power Point. The national ALS Association obviously covers the entire United States. We have local chapters, and chapters for example even though I'm working for the greater Philadelphia chapter, we cover three states. Almost every state has chapter representation. Every chapter offers different services, one of the services we do offer are certified center treatment of excellence, and we do have a significant number of people who not only go to the VA for care but they will go to a specific ALS, because as certified centers, the ALS clinics it is a multi disciplinary team. What that means is that you will have almost 13 different professions. Neurology, nursing, social work, occupational therapy, physical therapy, you have all these professionals in one clinic visit. It's one stop shopping for someone with ALS.

I would again encourage you to reach out to your local chapters, see what services they offer and see if there was a clinic around you.

I want to give you an overview of ALS. Probably everyone on the phone knows this, but anticipating future needs means understanding the disease and the impact that it has on somebody's body.

Obviously, ALS is amyotrophic lateral sclerosis known as Lou Gehrig's disease, most basic information, but people can give, is that the motor neurons between the brain and spinal cord stop firing.

Every muscle in the body except involuntary muscles are affected by ALS. Your arms and hands, legs, feet, etcetera. Diaphragm muscle which is the muscle underneath the lungs that is what helps us breathe, that is what inevitably leads to death in ALS. It's respiratory failure, that causes the death in ALS.

We try to relieve that discomfort, from difficulty breathing, through machines like biPap or trilogy, noninvasive inhalation that can help somebody breathe a little easier.

There is a cognitive impairment with ALS. 50 percent of people diagnosed with ALS will have some form of cognitive impairment but that can be mild to severe. We simply do not know.

But the cognitive impairment is called FTD, frontal temporal dementia. ALS cognitive impairment is characterized by personality changes, you will hear, this is not the person I married. Behavioral disturbances, acting out sexually, lack of empathy, your person with ALS all of a sudden has no insight about how their disease is impacting the rest of the family. And they don't care. But they used to care is what our caregivers will say.

Problems with judgment, we have people who recklessly spend money and don't tell anyone, they open up lines of credit. They will drain bank accounts and unfortunately, spouse or the children or the rest of the family have no idea. They just didn't know.

Then we do see some people with FTD, primary progressive aphasia, also called PPA. What that means is that if a aphasia like what would happen with a brain injury or a stroke, so it is a neuro degenerative disease, that impacts the language part of the brain. People with progressive primary aphasia will have language recall difficulties. They will be searching for words and they can't find it. Again, similar to stroke or a brain injury.

The cognitive impairment is important to realize for future planning, and for future needs. The cognitive impairment is focused on the frontal lobe, which is

the decision-making part of your brain. Not only you have lack of insight, lack of empathy but certain people with FTD can't make a decision. Caregiver will say, do you want a feeding tube, I don't know, do you want a feeding tube, I don't know. It is not because they are being stubborn or resistant. It is maybe because they have FTD and they simply can't make a decision.

The medical decision someone needs to make with ALS are ventilation or not ventilation. Because the diaphragm will eventually fail, that will lead to death. If you opt to then go on a ventilator, which means having a tracheostomy tube placed in your throats and being hooked up to a ventilator the rest of your life, there are about five to 10 percent of United States, of people with ALS, that opt to live in a ventilator. You are in essence on life support. Medical insurance does not cover nursing. Medicare doesn't cover nursing care at home. We even know, we do have some folks with medical insurance, that have coverage for nursing, when someone is on a vent. We can't get nurses to cover them. So you might live in an area where there is simply no ventilator trained nurses that can work in your home. Ventilation means a change in body image, because you do have this tracheostomy in your throat. You do have a lot of strangers in your home because somebody on a ventilator needs 24/7 care. You can never, ever leave that person alone.

The other decision is that a feeding tube or not, often called a PEG tube. Where to live, because as you will see with some of my future slides, many houses are not handicapped accessible. Who will be the caregiver, and I have to tell you after my years of experience, do not assume that your spouse will take on that role. Financial costs, there is obviously, if you are working, there is a lack of income because you can no longer work, if the disease impairs your body too much or your

mind.

Then if you stop working and you are carrying medical insurance, lack of that medical insurance, but this would obviously not impact somebody if they enrolled in the VA system if they were a veteran. Transportation, co-pays, if you are only relying on medical insurance and know that the average cost of keeping somebody alive on a ventilator is over \$400,000 a year and that is including all the equipment, the nursing, etcetera.

Durable medical equipment needs for people with ALS, durable medical equipment the acronym is DME, they still use iron lung, oxygen tents, nebulizers, CPAP which are noninvasive, ventilators that are used for people with apnea, but for folks with ALS, I mentioned biPap and trilogies. Power operating vehicles, and wheelchair, etcetera. This is what we are going to talk about DME needs for people with ALS. We will often, people will say a seat lift chair, one of the recliners that will help you stand up. We have a lot of folks that request that. I can only attest to Medicare will only cover the mechanism but not the chair. Maybe someone from the VA can answer this question, but as far as I know, that is not a covered item under veterans administration. Transfer boards and pivot disks, transfer boards to help somebody move, for example, from a bed into a wheelchair, it's a long board that you slide a person over. Once a person can't sustain their body strength anymore, or they can't independently stand, then you are going to need some form of transfer lifts, Hoyer lift, Hoyer is like Kleenex, you know, it's the generic, or not the generic, the name brand, but all this means is that it's an automated lift or ceiling lift.

The ceiling lifts go into the joists on the ceiling, or they have these poles

here, the Hoyer lift does not and it is just a stand alone unit.

Excuse me, let me go back. We would use one of these lift systems, Hoyer or the ceiling, to transfer the person from a bed into a wheelchair or vice versa, the wheelchair into a bed. Most people do not use lifts when they are going into a bathroom, if their bathroom is accessible. They will use a shower chair which I'm sorry, I don't know if I have a picture of it. Let me go ahead. No, I don't have exact picture of but it looks like this chair, in this bottom, so this is just a shower chair, which is a chair, I hope you can see it, this is a cutout, so once you slide this chair back on the bottom, you would bring this chair into the bedroom, transfer a person with ALS onto this chair and move this chair into the bathroom where you could use this sliding tub transfer system to get them into a tub, or because there is this cutout, you can wheel this right over a toilet and have them toileting themselves, and then you can help them clean themselves up, if you want, and then move them into the tub transfer system, or take the shower chair into a shower or a bathtub. There are different types of tub transfer systems. This is the most simple one, just a bench outside that has these legs outside for stability, with the person with ALS you slide them over. More people that are advanced, that don't have the upper body strength to keep themselves upright anymore, you would use this kind of tub transfer system.

Then shower assistance, you want, if you are building a shower or converting your shower, you want a shower that is flat to the ground, that does not have a lip. You do not want one of these, because you can't get a wheelchair in here, and you would still have to have the individual with ALS walk into that. This is not what you want, this kind of lip. You want something flush to the ground like

this.

And you don't want to have to build the shower. There are companies that will come out, like a bath fitter type of company that will take your existing shower and put in a standing shower. Okay? But you always want to make sure that you can roll that shower chair, this one, into the shower, and then you can shower someone as they are seated. You don't have to transfer them again. This shower chair, I know it's hard to see but it's made of mesh. The water will go through it. You actually shower them in their shower chair. You don't have to put them in any other seat in the bathroom like this woman, just an example of her sitting there so you can get the idea of what the shower looks like.

For those people who cannot modify their bathroom, or who opt to live on the first floor and there is no bathroom, there is a foldable shower called a Fawssit. This gentleman is using it outside but most people use it inside. It is hooked up to a kitchen sink or any other type of sink, and there is a hose that goes into the Fawssit and a pump behind here that you can't see, and a hose that goes out. So the water comes in through the kitchen sink, gets pumped in, comes out through the handle here that this gentleman is holding, and then it comes back out into the sink. Once this individual is done showering, this whole thing folds up. You don't have to take a shower every day, if you don't want to, so you could fold this up and get it out every few days. But it at least gives the individual an option to shower, if they have bathrooms that cannot be converted.

Or again, if they are living on the first floor or second floor and there is no access to a bathtub.

I want to mention hospital beds, we get a lot of people who ask us, can I get

a craft matic but the problem is they don't fit high off the floor like a hospital bed. When I mentioned that Hoyer lift, Hoyer lifts have bars that have to get underneath the hospital table or hospital bed, excuse me, and then there is a sling, and the person gets moved out of the hospital bed. Their beds do not have the empty space, so you can't get a lift underneath it. So that is why we recommend hospital beds.

For stair glides, for folks with ALS, stair glides are only useful for someone with ALS as long as they have trunk support. Once they lose trunk support, they are not safe. We advise people not to use them anymore because it's not only unsafe for the person with ALS, that they can tip over, it's unsafe for the caregiver who is trying to keep them upright, and could essentially fall on the steps from trying to keep someone upright.

There is stair glides that go up and down, a straight staircase, or there are ones that will curve around the staircase, as you can see here. This is an interior lift, that obviously you can see you, instead of having to transfer onto the stair glide seat which is just a traditional seat like this woman is sitting on, instead, you actually take your wheelchair up and down the steps totally, so you never have to transfer out of your wheelchair, and although this is pictured as a manual wheelchair, they do have heavy-duty ones that have actually take a power wheelchair up and down the step. Obviously we need a wider staircase than you do here. Okay. But that is part of the decision-making process of, when I'm anticipating future needs, am I going to get a regular stair glide that can only be used until my loved one doesn't have trunk support anymore and then what do we do? Do we move to the first floor? Does he live on the second floor? Or instead, do you get this from

the beginning, and you don't have to worry about it. These are all the decisions that folks with ALS and their families are making on a daily basis.

In terms of wheelchairs, we do not recommend scooters for people with ALS. This is not recommended. As you can see, there is no trunk support here. So if somebody can't hold themselves upright, they are going to tip right over on here.

And also, if the person's hands are weak they are not going to be able to drive. Now, that being said, if somebody really wants a scooter, you can rent them, you do not have to buy them outright. Some folks will get it from their medical insurance. Now, this is nothing to do with the VA. I'm strictly talking about Medicare, Medicaid, etcetera, or if you have private insurance, something like Blue Cross but those insurances will only pay for what they call one power operated vehicle. If you get a scooter, you are never going to get a high end power wheelchair from medical insurance.

That being said, scooters have a, unfortunately because ALS is a progressive disease, and we know it's going to continue to progress, they have a short life span, with somebody with ALS. That is why we don't say buy it outright, perhaps rent it instead because inevitably, if you start getting weaker, and you can't sit on this scooter, or you can't drive it, you are eventually going to need a power wheelchair at that point.

It's important to know that power wheelchairs, even through the VA, take six, eight weeks through medical insurance it can take five months. So it's not something that you can say, oh, my loved one fell again, we need the power wheelchair tomorrow. That is not the way it works through any type of system. You have to get measured. It has to be ordered. Then it has to be delivered. Even though

the person might not be at that point where I have to use it 8 hours a day, it would be beneficial to start earlier, especially if you are a veteran, and get it well before the person is falling like four times a day.

You would get a power wheelchair that would have specific features. Power wheelchairs for people with ALS have a tilt and space function. That means that the person with ALS sits in the same position, but the wheelchair tilts back anywhere from 45 to 55 degrees, in order to alleviate the pressure on the buttocks and move pressure to the back. You want people to be able to weight shift at least twice an hour. So that they don't get bed sores.

This person is actually in a wheelchair that has a full recline, which most of our wheelchairs also do, so they will come with something, with a tilt and space and come with recline. Then the feet can move up and this person can actually be laying flat on those. Some of our folks find that they like to sleep in their wheelchair. The wheelchairs are more than just transportation. We use them for weight shifting. I can't stress enough how important weight shifting is, because you do not want to get a bed sore on your buttocks or anywhere else on you, because that is caused by not being able to shift your weight. That is why using tilt and space and/or recline is crucial. Also, for people with ALS, we always tell them, it is a disease that causes fatigue. We want you to conserve your energy. If walking from point A to B is tiring to you or you are out of breath, using the wheelchair can save your energy.

Things to consider, if somebody is going to be using a wheelchair in your home are your exits and entrances, and is there a ramp or stairs, which we have talked about. And if you opt not to use a stair glide or a lift like the wheelchair lift

that I showed earlier, are you going to build an elevator in your home? The general layout of your home, we tell people to lift up your throw rugs, especially somebody, if they are using a walker to get around you should not have throw rugs, if somebody is trying to walk and use a walker. That is a tripping hazard. For wheelchairs you could have throw rugs down but they can get stuck and start bunching underneath the wheelchair and it could burn the motor out. We do recommend that throw rugs come up at all times in a home with somebody with ALS. The doorway widths, in order to get a wheelchair through a doorway, is 32 inches or more. Access to the sink if somebody wanted access, many of our folks don't care about that, access to your tub, your shower, commode, do they want access to the kitchen. Some people want it. Some people say it's not important. Then what type of floor surface, like I mentioned floor rugs, the other impediment could be a heavy shaking carpet for a wheelchair -- shaking carpet. If you have heavy shag you can put down runners for a wheelchair instead of a heavy-duty shag carpet. The features that I mention in power chairs for people with ALS, tilt space, recline, elevating legs, electronics and there are various electronics for people with ALS. Obviously this one is a joystick. That would be operated by the right or left hand. If somebody can't operate that, then this is a chin joystick, this gentleman is driving his wheelchair through his chin. This person who is driving their wheelchair through what is called a head away so there are sensors when they press gently back on this part, it goes slower, when they press gently here it goes right and left. You are actually driving the wheelchair through minute head movements. Just because somebody doesn't have hand function, doesn't mean that they can't operate their power wheelchair. Even if they are not driving it like some folks will go, driving

is not the most important thing, but I want access so that I can weight shift, so I can operate my tilt and space, so you can operate tilt and space with this, or with this too.

Okay? Many of our folks like seat elevators for their wheelchairs, what the seat elevator does is takes the wheelchairs, you can see, and puts it up about, sometimes up to 28, 30 inches. So that you can actually -- I'm putting this in air quotes, bar height, so that you can actually have social interaction, you can be eye to eye with someone. We have had several teachers who want to do this, so that they can reach a chalkboard or white board now. As you can see, with the power elevated seat, you can still do the tilt and space. This really comes in handy, because I elongated the picture it looks a lot higher than it truly is.

(coughing).

Excuse me.

But we have seat elevators are really handy for especially men, who have ALS, that are tall, and their caregiver and/or spouse is small, and this way, they can, the caregiver can get the individual almost to a standing position and gently bring them forward. We have a lot of people who use this base on size and ratio of people with the ALS and caregiver. For ramping once home you have choices of wood or steel, aluminum ramps. What is a permanent fixture in your home, steel, aluminum can easily be removed. You can also with steel aluminum ramps, rent, lease or purchase them. Steel aluminum ramps but do require permits but we recommend you check with your local government office anyway. But it is important to know not every house can be ramped. Why I put this out there is that many of our folks have to make these decisions about whether or not they can stay in their home with ALS.

90 percent of homes in this country were not based on accessibility. Okay? So as you can see, there would be no way to ramp this home. Some of the discussions that has to be made are, if I want to stay in this home, what do we have to do to modify it or do we end up having to move? It is a hard conversation to have, but it's important to have. It's important to have early enough where you would if you opted to move, have time to sell your home, find an accessible place to live or find another place to live and make it accessible.

Here are some different ramps. This is a steel ramp. This is actually made of mesh. So that hopefully if snow happens, some of the snow will come through the mesh, obviously you are going to have to shovel if you live in a snowy area, all of these ramps. But this one has mesh, hopefully, some of the snow goes through it. This is an aluminum ramp and as you can see, they all have bars for safety, and just a different material. This I put in here is a threshold ramp, they come in various sizes. But this is actually a folding ramp so this one folds over a mat and as you can see there is a handle here. So you can actually bring this type of ramp to a neighbor's home, if you were trying to get your wheelchair in, if they only had a one or two steps, or have this to carry to go to other places that are not ramps. If your home cannot accommodate a ramp, there are stairless for the outside, you can see many different forms, but one thing that you have to understand is that they all sit on a concrete block, as you can see here. And what they do is you back the wheelchair into the lift. This lip comes up and the whole thing lifts up to the second floor, and then you slide your wheelchair out. There are stair lifts for both outside and inside accommodation. Also inside I mentioned an elevator, that is also an option, like a standard elevator they come in many

shapes and sizes. But you can put a elevator in your home too.

In terms of transportation, can the individual still safely transfer into a car? As you can see here, this gentleman is helping this woman into a car, and you probably can't see it but she has something around called a gate belt and he has his hands in the gate belt. In order for her and him to successfully make the transfer she has to be able to assist somewhat in the transfer, whether or not that means that she can keep her trunk supported, or hopefully she can move her feet a little bit, and move her hips a little bit, in order to get into the wheelchair or into the car. Then because this is a manual wheelchair, it folds up and can go into the trunk of the car. If someone cannot assist in the transfer of themselves, a person with ALS into the car, they are no longer safe for the caregiver to put them into the car. Then we have to look at accessible transportation, which would be handicapped accessible vans. An accessible van can be used to transport a person in a wheelchair both power and/or manual and you don't ever have to get them out of the chair. There are two different types of accessible vehicles. There are the minivans, that you can see here. Then this is a full size van, and the difference also between the full size and the minivan is the lift system. So the minivans have just an automatic or a manual ramp, it's just as you can see it's not a long ramp. You just either push the person in on the wheelchair or they take their power wheelchair and drive themselves in. The minivan, what ends up happening is you can buy a standard minivan and you take it to a conversion company, and they will convert it for handicapped accessibility, or you can go to a conversion company, and just buy the whole thing outright. If you were looking for an accessible vehicle and I'm sorry, I forgot to put this one here, there is a great website called disabled

dealer.com. They divide the country up into four quadrants. I'm in the Philadelphia area, I would get the Philadelphia, Boston, New York version. If I was looking for a accessible van the disabled dealer would help me find it in my area. Or you can look on Google, and say accessible vans and put in your zip code. They will give you places that you can go. But if you, for example, just bought a Ford minivan, and you wanted it converted, you take it to the conversion company and basically what they do is, they cut the entire bottom off and lower the chassis. You can see here, handicapped accessible vehicles sit much lower to the ground. The reason they do that is because they want to give you more of a height ratio to get your wheelchair in there. Some people will opt to actually sheer off the roof and put one of these on top of the minivan. That is great. Except then you are not going to fit into the underground parking garage which is why a lot of people who live in urban areas like the minivan. You cannot park this in an underground parking garage. You will sheer the top right off.

If you know that you live or travel in an urban city and you need to find a garage in order to house your vehicle, you are going to need a minivan. At least I can say this for my City of Philadelphia, we are losing a lot of our exterior parking lots, so if I was driving this, I would be driving around for a long time trying to find an exterior parking lot because now we are getting more garages built. You have to think about these things, what kind of, where am I driving, what kind of climate am I driving in. What is the size of the person who is driving me? Because if you had a really small person driving, it's really hard to get the seat up, and for a very tiny petite woman to drive this type of vehicle. Much easier for the minivan.

Just something to think about, when you are considering vans. I am a communications specialist, this is my area. So I want to talk to you about communication issues for people with ALS. We know statistically that 50 percent of people with ALS will become speech impaired, that is called dysarthria. It can be mild, moderate or severe. But it's slurred speech. 25 percent of people with ALS will have an arteria which is inability to produce any sound. 25 percent will be understood throughout the course of the illness. If you add the top two numbers together, 75 percent or more people need some form of communication assistance when they have this disease. We don't know what level of intervention that communication will be. But there are ideas that I hope you can walk away with today, to know how to communicate with your loved one, should communication become an issue. There is no one right answer in terms of what people ask me all the time, what do other people do? It depends. But the most important thing I hope you can take away about communication and ALS is that every person with ALS uses multiple modalities of communication. They are not using the same communication method when they are sitting on the toilet as they are when they are in the dining room or on the deck outside or on the front porch.

You have to be prepared, to have different communication systems, depending on what environment that you are in.

Before we start talking about electronic communications, I wanted to put a note or a slide in here about voice banking and message being. This is something -- message banking. This is something people need to do at the beginning of the illness, because you need a clear and articulate voice. The idea behind voice banking is that you download a software from model talker and you repeat about

1800 phrases from model talker. It takes about 20 hours to do. You do this over a course of days or weeks. You can't do this in one sitting.

The idea behind model talker is should you ever need a communication device or a computer to act as your voice, because you can no longer speak, the voice that will be coming out of the computer or speech generating device will be your own voice. You have banked your voice. Whatever you type into the machine is, it's very hot out today, would come out in as close to my voice because it is my voice, but it is still being run through a synthesizer. It is not 100 percent your voice. But message banking would be 100 percent your voice. Message banking is using technology, your smart phone, MP3 player or just your computer, and what you do is you record messages. I love you. Did you, you can record messages for your cat or dog, come here, buster, no, don't do that!

So this is your authentic voice that is being captured in an MP3 or a .wav file. Then you upload it into your device, whatever you are using, your computer, your speech generating device, and message would come out in your voice. The difference is, with model talker, whatever you type into it will come out in your voice. This message banking is only the certain things that you said. You can't type into a message bank phrase and expect it to say something different. I have a whole handout on this, should you want it, and my E-mail is at the end of this presentation. But I want to mention it, because this is a big movement within the ALS community right now.

There are amplification for people who have low vocal volumes. We have people with ALS who talk like this.

Because they don't have the breath support but they can still talk and speak

fine. We recommend an amplifier for them, so that they don't have to push as hard to get their voice out. For those that are really having problems speaking, they have significant slurred speech, we have various options for communication. Rapid access, you have High Tech and in the mainstream middle.

The most important thing, I've said this before but this is the most important thing that I would like everyone to walk away with today, is that with your loved one, you always need to establish a yes/no, maybe system. It's not just yes and no because if the caregiver or whoever is speaking to the person with ALS has asked the question wrong, you are [inaudible] answer because you are only giving them yes or no. It should always be yes, no, maybe. I tell people, put it on [inaudible]

(off microphone).

John says yes, no, maybe, bye, because then any stranger could walk in, a first responder could walk in and know how to communicate with the person with ALS by doing the yes, no, maybe. Some people like eye Blinks. I'm not a fan because sometimes I miss the Blink. I ask people look to the right for left [inaudible] whatever is going to work for you.

Various letter boards here which I provide free of charge from the national ALS Association. This is a laser pointer that this gentleman is using on his eyeglasses, in conjunction with a letter board. A boogie board, which is an LCD board that you can buy on Amazon. And basically when you write or draw then you press the button, it goes away.

Many ideas for what I call quick and easy communication.

For people that want something electronic, a lot of our folks are using iPads, tablets, Android tablets, etcetera, and you can get an application for them for

free or low cost. You do not need to spend \$119 unless there is no other option. So try some free things first. They work on smart phones. They work on tablets. We have, this is an app I love, called flipwriter. This is only available on the iPad. But it enables you to have a private conversation with somebody, because say I'm the typist here, and I have somebody sitting across from me at a restaurant table, they can see what I'm typing here and I don't have to turn the iPad around or anything. They can see it because it's like a mirror image.

There is a free version, not this one but if you wanted it to speak out loud, it's \$25. But you don't necessarily need the speech, if that is not what you want.

There are many ways of accessing the iPad. I would encourage people to, if they are working on the iPad, and you are having difficulty and you are in the VA system, to reach out to the speech pathology department, and they can help you, not only find a good app but they can help you find access to your iPad, because all the iPads now have built-in what is called switch access. Your speech pathologist or your occupational therapy department can work with you, if you can't use your hand, you can still use your iPad.

Basically, in the iPad, it's called switch access. A switch is something that you put near a muscle movement on the body that shows the device to do something. The easiest example I can give is a joystick on the computer. The joystick when you move it, it sends a current to the engine of the power wheelchair to do something, left, right, up, forward, back. Same with a switch. It sends a current to the iPad to do something. It's scanned. So it goes, come, come, you hit your switch so it comes to the letter or the icon that you want.

Just because someone can't use their hands does not mean that they cannot use

a device. In order for them to use it, it should be mounted on the wheelchair. This is also something that the speech therapy department can work with you on getting an appropriate mount.

(audio breaking up).

In your lap, it can slide off or it's not easy to see but there are mounts that you can work with tablets. These are the Android tablets which you can see here. Again, the Android are switch access, the androids also have eye gaze.

(audio breaking up).

We are going to talk about that in a moment. Some folks are using laptops. You can use your own laptop and download, let me see, download software which is free, like E-triloquist. You can download this on a Windows environment or actually works on my Mac, free. You download it into your laptop, and you can be typing away in five minutes. This is what it looks like. You can say phrases. You can type things out here. It will say it all in a synthesized voice. This is free.

This is a great way to help your loved one maybe transition into using a communication device. Let's just download E-triloquist one and see if you like it, okay, and it's free. You can use your existing computer to do it.

Some folks want a high tech communication device, and these are also provided by the speech therapy department at your local VA. This is ordered through your speech pathology department. These are machines that obviously either can be symbol-based or can be alphabet-based, and they will type out whatever you type into them. A lot of our folks are using these and I'm not -- eventually, what they will often do is use an iPad, an Android, until they lose their hand function, and then they will transition into one of these high tech devices. You can access them,

like this is all eye gaze technology, so the basics behind eye gaze technology is right here, there is a camera, and this gentleman is looking at the camera and the camera is watching his retina. As he moves around the screen, go down here and he dwells on the letter A, it will type letter A up here. He moves his eyes down to N, and he dwells on N and you set the time, however long he wants to dwell on it. It types an N.

These are called eye gaze communication devices.

I just want to also tell people the imperative of having a call bell system, both in and out of the house. For example, if the person with ALS is laying in bed and their caregiver is in the kitchen or in the living room, you want that person to have a call bell system in place, and for people who have hand function that could be a remote door chime. For people who don't have hand function, there is something called a EZ call bell and alarm which is switch activated, you can put it near their head or chin, where they have muscle movement and it will emit a high-pitched beep, until that person lets go of the bell.

For the outside of the home, if your caregiver is working and you are leaving your loved one for a few minutes, an hour a day, hours a day, make sure they have the ability to call for help, and that is usually the I've fallen and can't get up system, the lifeline system. You can activate the lifeline system by your hand, wrist, ankle.

If you can't use your hands or feet, there are switch adaptable, I've fallen and can't get up systems. Just because somebody doesn't have hand function doesn't mean they can't use the emergency alarm.

I want to, the last two slides I have are talking about the psychological issues

of ALS. Obviously with the disease itself, anticipatory grief was already mentioned, so that is right here. But it is like stages of bereavement. Not only are people going through it with ALS but going through it when it comes to assistive technology. For example, the wheelchair. I don't need the wheelchair. I'm fine. But dad, you are falling every day, three times a day. No, no, I'm fine. That is denial. Why are you getting, why are you telling me this? They get angry with you. Then they are going to bargain with you. Then they are going to go through depression and move into acceptance.

Unfortunate part of this is that if they are falling all the time during this denial, they might hurt themselves, fracture a skull or a hip. But it is part of the process, the unfortunate part is this is the psychological process, but meanwhile, physically the disease is still progressing every day. Sometimes the psychological component doesn't keep up with the physical component, and the physical happens much quicker than the psychological component.

Because people are upset about, not only the disease, but the assistive technology interventions that they have to use because of the lack of them being able to do something. You know, so they are going to experience the grief, coping with the loss, going to use the wheelchair, coping with the loss of walking, of independence. They are going to feel inadequate. My loved one has to do everything. Mary mentioned brushing teeth, what they are anticipating, the person with ALS is going to be angry about that. So we go through this coping process, along with [inaudible] the family, the person with ALS can make interventions as appropriate. But sometimes, as I said, the disease happens quicker than we can either get the interventions or that the person is just not ready for them yet.

I want everyone to walk away with, that's normal. It is normal. It's not ideal. But it's the whole psychosocial component has to happen before anybody can accept an intervention, whether or not it's a wheelchair, a walker, or anything else.

There are many resources on YouTube that you can go through. These are my references for my presentation, and as I said, I will be happy to answer any questions that you have further. I know that this is being recorded, and a link will be provided to you. But if you have further questions, if you have a problem or you want to send me a picture, here is my bathroom, tell me what you think, I'm happy to help. With that, I will turn it over to Bryan. I'm sorry, I went over.

>> BRYAN VIDAL: No worries. Thank you so much, Mary and Alisa for your amazing and inspiring presentations. We have a few minutes for questions that you have submitted to us through the chat feature. If your questions weren't answered, please send us a E-mail to [militarycaregiver@easterseals.com](mailto:militarycaregiver@easterseals.com).

The first question comes from a caregiver, it says is the cognitive impairment noticed before diagnosis? Or is that more of a result of the ALS process?

>> ALISA BROWNLEE: I will tell you from the narrative that I've heard, sometimes it's the first symptom. There is no physical symptoms, but we have had several caregivers say there was something cognitively wrong before anything else appeared. So it could be the initial onset of ALS with no other symptoms.

>> BRYAN VIDAL: Mary, would you like to share a bit about the early onset of your husband's and your experience?

>> MARY WARD: Sure. With Tom, his biggest symptoms early on was the [inaudible] and cramping. [inaudible] if you have never seen them before, it's twitching but high intensity twitching. You can see underneath their skin and sometimes after

that is cramping. With Tom, we saw that a lot on his left side and [inaudible]

And muscles.

>> BRYAN VIDAL: Thank you. This question goes to Michelle. Seems like everyone seems to be asking around this. What are the devices that are covered by the VA, or can you shine some light as to what is the process for accessing assistance with devices through the VA?

>> MICHELLE STEFANELLI: Thank you, Bryan.

First of all, I would definitely encourage the caregiver to contact the CSC, have them evaluate them and if they are not involved in the Caregiver Program, to really get involved with their social worker at the VA, because there are resources that I had put in the chat box.

>> BRYAN VIDAL: Great, thank you.

>> MICHELLE STEFANELLI: There is not a blanket, this is what they are going to get.

>> BRYAN VIDAL: Thank you, Michelle.

Unfortunately, we have run a little bit on time, past the time. If we are not able to address your question today, please send us a E-mail to [militarycaregiver@easterseals.com](mailto:militarycaregiver@easterseals.com). We will be sure to get back to you. All those who registered for this webinar will receive a very brief follow-up on-line satisfaction survey. We hope you are able to take a few moments to share your feedback with us, as it is greatly appreciated. Lastly I'd like to let everyone know that within two weeks you can find the recording and transcription of today's webinars along with the presentations at [easterseals.com/carewebinar](http://easterseals.com/carewebinar), along with

many other valuable resources. Thank you again to our presenters. Elizabeth Dole Foundation, and to the many caregivers who participated in today's forum. Have a great afternoon, everyone.

>> Thank you.