The Lewin Group
Beyond Alzheimer's Disease - Other Causes of Progressive Dementia in the Older Adult
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Caroline Loeser: My name is Caroline Loeser, and I'm with the Lewin Group. This is the second webinar in the 2017 Geriatric-Competent Care webinar series. Today's session will include a 60-minute presenter-led discussion followed by 30 minutes of discussion among the presenters and participants. This session will be recorded in a video replay. The slide presentation, as well as the Q&A, will be available at https://resourcesforintegratedcare.com/.

This webinar is presented in conjunction with the American Geriatrics Society (AGS), Community Catalyst and the Lewin Group and supported through the Medicare-Medicaid Coordination Office (MMCO) at the Centers for Medicare and Medicaid Services (CMS). MMCO is developing technical assistance and actionable tools based on successful innovations in care models, such as this webinar series. To learn more about current efforts and resources, please visit our website or follow us on Twitter for more details. Our Twitter handle is @Integrate_Care.

At this time I'd like to introduce our moderator. Carol Regan has over 30 years of experience with national and state based public policy and healthcare advocacy organizations.

Carol Regan: Hi. Thanks, Caroline. On behalf of Community Catalyst, we are so pleased to continue this wonderful partnership with MMCO, Lewin Group, and the American Geriatrics Society to educate and promote good models of care for older adults. Community Catalyst is a national nonprofit advocacy organization working to build the consumer and community leadership required to transform the American healthcare system and our belief is that happens when consumers are fully engaged and have an organized voice.

Our first priority is quality affordable healthcare for all, and we're also committed to transforming the healthcare system by promoting good care models for older adults through our Center for Consumer Engagement and Health Innovation. This Geriatric Competent Care series, which we have been working on for four years with our partners, is part of that effort. So thank you all for coming today.

What I'm going to do is introduce all of our speakers in the beginning so they can move through their slides. First, our focus is going to be talking about key diagnostic features. Then, we will focus on prevention and management, and third on the impact on individuals and families. We are delighted to also have a family caregiver share her experience with us today.

We are going to start off with Dr. Lantz who is the Chief of Psychiatry and Inpatient Psychiatry at Mount Sinai Beth Israel Medical Center. She is a Program Director of the Geriatric Psychiatry Fellowship Program, an Associate Professor of Psychiatry and has served on the Board of Directors for the American Association of Geriatric Psychiatry. She's the author of numerous publications and presentations in the area of dementia care and late life mental illness.

Then we have Dr. Geri Hall who's one of the pioneers in dementia care. Starting in 1978, she devoted her career to nonpharmacological management of Alzheimer's disease and related disorders. She developed and researched the progressively lowered stress threshold model for planning and evaluating care in Alzheimer's type dementias which has been disseminated throughout the U.S. and other countries.

About eight years ago, she noted that we weren't meeting the needs of families affected by non-Alzheimer's dementia, especially Lewy Body dementia and Frontotemporal. She has spent the last eight years in these areas. Geri also sees clients and families in clinics, facilitates support groups, conducts research and speaks on these poorly understood and often overlooked conditions.

Our third speaker will be Rebekah Wilson who is a Social Worker and a Dementia Care Specialist Trainer and Aging Care Coach with 14 years of experience in elder care services, including hospice, home healthcare, assisted living, and care management.

In these arenas, she has used her specialties in teaching, community outreach, marketing, and developing innovative strategies, providing comfort care for seniors and their care partners. She has presented at local, state, and national conferences as a trainer on Alzheimer's disease, frontotemporal dementia, behavior management, navigating transition, and other key caregiving topics. She serves as a care coach mentoring care partners and developing individualized nonpharmacological inventions and innovative care solutions. She has dedicated her time towards improving the care for older adults and considers it an honor to help those navigating the aging process.

Finally, we have Sharon Hall who currently is a family caregiver and will share her personal experiences dealing with these non-Alzheimer's dementias.

Now, I am going to turn it over to Dr. Lantz to start off our program.

Dr. Melinda Lantz: Thank you, it is wonderful to be here today. I understand we have a mixed group of clinical people in management, so what I will do is briefly go over the criteria for what dementia is and focus on three of the more common of these unusual dementias.

So I'm going to give just a quick overview. We all know that dementia, as a whole, are disorders of loss and decline. We have decline from a previous level of functioning in various domains, and in order to make a diagnosis, it requires a lot of evaluation in terms of getting a clear history from a patient, caregiver, or informant and performing assessments that may include neuro-psych testing, repeat clinical assessments and perhaps neuro-imaging in some of the dementias today. Neuro-imaging is of value. These deficits interfere with daily activities, social and occupational functioning and some of the dementias we'll talk about today, frontotemporal, for example, is an earlier on-set dementia and patients may be employed at the time they start having symptoms.

Mild neurocognitive disorder or impairment is the decline in cognition that does not meet the criteria for dementia. This, for many patients and caregivers, is an unfortunate almost kind of purgatory state in that they have objective declines, usually in memory, but do not have declines in other domains yet. Some dementias may start out as mild cognitive impairment, and patients may stay in that stage for years and some may then go on to decline. The dementias we talk about today often have prolonged or protracted impairment stages that often makes diagnoses difficult for patients and families.

The first of the non-Alzheimer's dementia we will talk about is vascular dementia or dementia due to cerebral vascular disease, which is where we know the cause because in order to have vascular dementia patients have risk factors for vascular disorders. This is the second most common type of dementia after Alzheimer's disease. These are patients who have risk factors and often have multiple medical problems. These are patients with hypertension, diabetes, hyperlipidemia, maybe a history of smoking or are still smoking. It is often identified because the patient has either a series of mini strokes, TIAs, or an actual stroke.

With the stroke related syndromes, the cognitive loss may be more focal. Sometimes patients are more aware of their symptoms, sometimes less, and disturbances of emotions and mood are common and very much related to the stroke type symptom.

Vascular dementia has a great deal of care needs. They are variable but often very high. These patients have multiple medical and physical conditions, so they may have tremendous physical care needs. They may need a lot of help with assistance of daily living right after an acute event, and decline is also more variable. They may have long plateaus or stability in their cognition and their physical care needs after a stroke, and then they have abrupt declines related to further vascular insults such as another TIA or another stroke.

It also is perplexing at times because it is common to have vascular features in Alzheimer's dementia mixed together. So caregiver burden is high related to the heavy physical care needs, heavy medical care needs and the cognitive loss as well, as long as it's also accompanied by mood and behavior problems.

This is a dementia that is more common in men than women at present because men still have more cardiovascular risk factors than women.

Neuro-imaging is certainly helpful in making a diagnosis of vascular dementia because we can see the vascular disease on a CAT scan or a MRI.

We will move on to another type of dementia. I included this in for your reference; mainly the Binswager's Type dementia. I practice in New York, and maybe the clinicians there just like to diagnose it. Patients are often confused by what they are referring to. It is also important for patients and caregivers to have a clear sharing of information. So, Binswanger's is a type of vascular dementia. I included a lot of material here for you to view after the webinar.

Lewy body dementia is a less common dementia. It has a striking clinical presentation. Lewy body is memory loss and cognitive design that occurs in the context of motor and Parkinsonian features such as tremors or muscle stiffness, and the patients usually have prominent psychiatric symptoms as well. They often have hallucinations, and often the hallucinations are visual. Lewy body has a rapid onset usually later in life, accompanied by symptoms that may make the diagnosis difficult in the beginning. Symptoms include an unsteady gait, fainting, many falls. It generally has a more rapidly deteriorating course. Also, it is more common in men than women, which differs from Alzheimer's disease as well. This is a dementia with many behavioral problems, psychiatric symptoms and many care needs. Obviously, we ca not make a neural pathology diagnosis prior to death, but we know the symptoms that I described, the visual hallucinates, the motor symptoms, cognitive decline, are correlated with a diagnosis later. The issue with Lewy body dementia is it is often accompanied by sensitivity to all psychiatric medications yet displays prominent psychiatric symptoms that often need treatment. In the interest of time, let's move on to frontotemporal dementia.

Frontotemporal, which you will hear from other speakers in the panel, is perplexing to diagnose from a physician' side. Onset is significantly earlier than the late life dementias appearing anywhere from 40 to 60 years of age. The reason why that range is variable is it is very slow and subtle in onset. It is accompanied by atrophy by loss of tissue in distinct areas of the brain, the frontal and temporal lobes, and those parts of the brain are associated with personality, mood, behavior, and impulse control. Frontotemporal is often misdiagnosed as different psychiatric conditions because it often first presents as behavioral in nature. Symptoms include a lot of disinhibition and socially inappropriate behaviors. Patients who are in the early stages of the dementia can still perform basic daily living tasks, such as math tests or memory. This is difficult to diagnose until it progresses, unfortunately.

You have prominent personality change, which is a great drain on families. It has an early onset and very slow decline with a lot of behavioral problems. There are a lot of symptoms such as lack of recognition; they do not recognize family members anymore, and the treatment is symptom driven because there are no agents available to slow the progression.

There are subtypes of Frontotemporal dementia such as Pick's disease, which was the first frontotemporal diagnosis; some of the subtypes have a genetic thread.

I have a picture of a pick body in the brain. They are found in the frontal and temporal that explains the unfortunate decline in the significant behavioral pathology of the dementia.

I'm going to move on and give a brief overview of strategies for treatment from a pharmacological overview. On this slide, I provide you with some tables of the medications. This all comes with one big caveat. We obviously have no magic pill for dementia, and we have medications that, in a carefully targeted situation, can help with certain signs and symptoms.

In terms of treatment of the cognitive symptoms, when we look at Vascular Dementia and Lewy body, we have inhibitors. There are three that are clinically used, Donepezil, Galantamine, Rivastigmine; they are approved for the mild to moderate stages. What we see with these inhibitors is a slowing in the rate of decline but not an improvement. These aim to slow the progression of the dementia. This makes it very clinically frustrating and also difficult because the individual responses are so variable. However, the greatest efficacy is for the target population living in the community where we might see a delay in a need for nursing home placement. This is regarding Vascular and Lewy body dementia only. Unfortunately, with Frontotemporal dementia, cholinesterase inhibitors have not shown to be of any value, and there is a small amount of literature that shows the behavioral symptoms may worsen. We are talking about the agents really for use in Vascular and Lewy body dementia and only for potentially delaying the decline.

Rivastigmine may be more helpful in Lewy body dementia than other cholinesterase inhibitors. Then, we have the drug Memantine in a different class, which is approved for Alzheimer's type but not for any other types because we do not yet have evidence it helps with slowing the decline. Again, with frontotemporal dementia we should avoid the cholinesterase inhibitors. Always remember, every medication has side effects. With cholinesterase inhibitors, there are gastrointestinal side effects, and it may also slow heart rate.

Now, moving on to pharmacologic treatment of behavioral symptoms. Again, if there is no magic pill for cognition, there is definitely no magic pill for the psychiatric symptoms. Treatment is symptom driven, so we want to identify target symptoms such as clear psychosis or distressing hallucinations. We want to choose a medication that may target those symptoms and carefully monitor side effects and very much want to avoid polypharmacy. I have given you many tables and sort of basic clinical pathways to illustrate the approach we would take. The problem is the side effects of the medications and the risks versus the benefits. Use of antipsychotic agents is justifiable when the patients are distressed by their psychotic symptoms or when the symptoms become clinically dangerous. Patients become paranoid and want to act on their delusions.

However, those are more extreme cases, and those come after other interventions are exhausted. They are not meant to be a substitute for good clinical care and behavioral intervention. I want to point out that depressed mood and anxiety are very common in the more early stages of these dementias and that antidepressants certainly could be considered if we can help boost mood at all in these patients. We can certainly increase their comfort level knowing that the antidepressant medications also have significant side effects as well.

The other issue that comes up is what to do about patients who display significantly severe physical aggression to the point that people are thinking of hospitalization, and what can you do to alleviate or just diminish some of the severe physical aggression that might be dangerous to a caregiver. These are all off label recommendations, but they have a clinical consensus. Mood stabilizers may help with impulsivity and aggression to a limited degree, and they certainly might diminish the behavior to a point it could be more clinically and behaviorally managed. That is the best use of these agents. How can we diminish the behavior enough that other interventions help as well knowing these medications have significant side effects.

In the next few slides, I provided tables of medications and CMS recommend guideline doses for maximum use. I know a few people who work in long term care have these manuals. I also included several medications and mood stabilizers as well on the last slide that I have, and I included side effects. Please remember all medications have side effects; we want to limit polypharmacy. If we go to the last slide, I will use this as a way to transition you to Dr. Geri Hall who is going to absolutely mesmerize you with her nursing ability and behavioral techniques. Thank you very much.

Dr. Geri Hall: Thank you very much, Dr. Lantz. It is very nice to be here today. This is a topic I care deeply about. Like Dr. Lantz, I made a lot of slides people can use when looking at handouts because there is so much material.

Symptom presentation in dementia depends on several things. The first, and the most important, is the location of the areas of degeneration; that primarily determines the symptoms of the dementia. Pathologic changes such as with Lewy body dementia and comorbid conditions along with environmental factors make a huge difference in symptom presentation.

Look at the areas within the red circle on the FDG PET results; within the red circle or confined area is where you would expect Alzheimer's to be. The first brain is a normal brain. The second one has mild cognitive impairment. The third one has early Alzheimer's disease, and you see that the blue was where the damage is and it fits right within that redline area. D is frontotemporal dementia. You can see the redlined area is well preserved, but the front of the brain and the side is impaired, and finally E shows what happens when you have a complicated dementia. The E patient has Lewy body disease. If the location and symptoms are different, the care needs are different. I am going to cover Lewy body disease and some Frontotemporal lobar degeneration.

With Lewy body disease, there are three common presentations which is why diagnosis is sort of challenging in the beginning. Some individuals start out with a movement disorder leading to a diagnosis of Parkinson's disease and later develop dementia. Another group starts out with memory and cognitive disorders. However, it is not quite the same as Alzheimer's. It can fluctuate more greatly, and there are often psychiatric symptoms associated with it.

Lastly, there is a small group that first present with neuropsychiatric symptoms. The most common are hallucinations. Usually, it is visual hallucinations, but it can be olfactory or auditory hallucinations also.

The first common symptom, which often presents up to two years prior to a person developing Lewy body disease, is a realm sleep disorder. The patient acts out the dreams while asleep. There is very often excessive daytime sleepiness and restless leg movement, and often a spouse will tell you that they have to leave the bed and go into another room just because of the restlessness.

Second is impaired thinking with problems with executive function, planning, and processing information. Again, the memory tends to be episodic. Patients may do well for weeks or months at a time and have a short period where their memory is impaired and then it gets better. So, it fluctuates.

Third is problems with movement including tremors and stiffness similar to typical Parkinsonian presentation. The important thing about Lewy body dementia is that few of these people respond to the anti-Parkinsonian medications, and the anti-Parkinsonian medications can make the hallucinations worse or cause them for the first time. Altered sensory perception, particularly visual spatial perception, hallucinations, behavior in mood symptoms, are towards the moderate parts of the disease. You get changes in the automatic body function, so they have problems with orthostatic hypertension, temperature regulation, and postural control. They tend to fall a lot and lose bowel and bladder function. These patients are exquisitely sensitive to medications, particularly those that affect the central nervous system, so that you have to use very small doses of medications. You have to use slow progression of doses and watch for side effects. The care of a person with Lewy body dementia is similar to all of types of dementia in terms of decreasing stimulus, increasing rest, and promoting exercise, including breathing loud such as with programs which help the patients to breathe more deeply.

Safety issues due to the realm sleep disorders and fall precautions are important. You cannot prevent falls in all of these patients. Supportive self-care activities help control misleading environmental stimuli. Think of the television because TV is often a huge trigger of hallucinations and delusions and prepare the family for a potential aggressive response, so they have a plan and then there is the Lewy body dementia association and support groups. Physical therapy, occupational therapy, and recreational therapy have all been helpful plus pharmacist consultation on OTCs and prescription medications and how they interact.

Now we get to Frontotemporal dementia. The best thing I can say about it is it's implicated. There are three common types. The first, and most common, is what we call bvFTD or Behavioral Variant Frontotemporal Degeneration. It is sometimes referred to as a fixed disease. You've got apathy, reduced drive, and loss of executive function, inappropriate and impulsive behaviors, and importantly what we call anosognosia, which means the patient has no insight into their condition. Even if their arms and legs fell off, they would have no insight.

The second is prerogative language decline. There are three different types that basically the patient loses the ability to gradually understand and use language, and prerogative motor decline, which is rarer. Things like frontotemporal dementia with ALS are fairly common.

The patient will have what looks like behavioral variant dementia for a year or two and after that they tend to develop motor symptoms, they pass on very quickly.

Mixed dementias are common but usually diagnosed at autopsy. It is not uncommon, particularly in older adults who present with Frontotemporal dementia, to have a mixture of Alzheimer's disease and Frontotemporal dementia.

These patients are often misdiagnosed. I completed a study of misdiagnosed patients, and we found some patients went as long as twelve to fourteen years without having a diagnosis because people kept getting psychiatric diagnoses. The patients are young, so it is hard to believe that they have a dementia. Often, these patients are labeled as late onset bipolar disorder, which there is really no such thing. If you see somebody with a diagnosis of late onset bipolar, you might automatically begin to think of someone with FTD.

People with Alzheimer's disease tend to have behavioral symptoms that worsen with progression. With Frontotemporal, it is just the opposite. They tend to have initial more severe behavioral problems that remain stable for a couple of years and then tend to improve a little bit. Again, the patient has loss of insight. Patients tend to exaggerate the positive personality qualities and minimize the negative. They have more problems with dominant cold hardedness, introversion and ingeniousness. They are extremely challenging to care for particularly because you cannot reason with them, and they have no idea they have a problem.

One of the things about Frontotemporal dementia is that it tends to attack the brain more on one side than the other. You can have the behavioral variant in the non-dominant side of the brain or the language variant in the dominant side of the brain. As the disease progresses, the degeneration tends to move across the brain so you get mixing of types.

For the community based interventions, you want a good diagnostic evaluation and hopefully care team. If you look at http://www.theaftd.org, you will find places with resources all across the country for people with FTD. Follow up with social workers and advance practice nurse for long term care strategies and management and also ongoing interventions that are pharmacologic and non-pharmacologic. Psychiatric assessment is very helpful with behavioral variants. A number of these patients will become quite aggressive, and a psychiatric omission is not uncommon. Guardianship and conservatorship empower the family to make decisions. The problem is that when applying for an involuntary guardianship, this patient looks and feels normal. They will tell everybody they are normal, and when you send them for a neuro-psych evaluation or any kind of neurologic evaluations, they can pass the mental status test because mental status test rely heavily on memory for their scores, and this patient has an intact memory. The family needs to manage a patient's money, deal with driving issues, eliminate Internet connections because these patients will spend huge amounts of money taking steps to block own solicitors, applying for disability and SSDI. These patients are not 65 for the most part. Although my average patient is right around 60, but they do not automatically qualify for Medicare. Then, explore using companion services for activities because very often the spouse or partner is still working, and in many cases these patients still have young children at home, which is a host of problems unto itself.

Use with these patients a palliative care approach. The average patient lives about five to ten years with FTD, and so we're not going to use things like Lipitor and things that are going to hopefully work in about ten years. We minimize the medications to only the essential. We try and get families into support groups. Medical alert bracelet and tiles for tracking systems may help; many of these patients become hyper motor, and what they tend to do is wander in their car, on their bikes and then wander on foot. So, that can be a problem.

We avoid these activities that trigger obsessions. Obsessions are an interesting part of FTD in that they are normal for the disease. If you discuss with a patient why they playing one song on the piano for 18 hours a day, what they will tell you is it helps manage their stress. In Alzheimer's disease, what you might do is try and distract the patient. What you are going to do, if you can, with the Frontotemporal dementia is try and use those obsessions to keep the patient busy and engaged. Many of these patients have violent episodes, and you have to get weapons out of the house. You are not going to tell the patient about it, but have a caregiver escape plan. We insist that caregivers wear life alerts, so that if they are trapped in a room or hiding in the basement or wherever to keep away from the patient, they need some way to summon help immediately. So, life alert works well, and there are any number of ones on the market right now.

Repetitive behaviors serve a valuable function. They improve the patient’s mood and help them remain calm. The most common are motor activities.

When we stage behavioral variants, the average lifespan after diagnosis is five to seven years. The profound behavioral symptoms become apathy as the disease progresses, lack of sympathy, severe disinhibition, language disabilities, and cognitive losses. The patient may be fully independent in basic activities of daily living. However, that does not necessarily mean they are going to bathe or shave for you. This is a patient who can become quite aggressive over issues such as bathing, so we have the motto that no one ever died from not bathing.

Late in the disease is a patient who may develop spontaneous vocalizations, which are not helped by medications. Particularly, the benzodiazepines will make the problem worse.

If the patient goes into long term care, large dining rooms ought to be avoided if it is at all possible. Monitoring intake for stuffing the mouth with food to avoid choking, stealing food from other residents and eating nonfood items are important. Many patients with Alzheimer's disease will essentially stop eating. People with FTD may stop eating but very often they binge and will gain large amounts of weight. They need structured activities and a simple routine. If they are wandering and obsessive, we want to make sure they get calorie dense foods and snacks and encourage activities, but one of the things that people say is why isn't John interacting with other people? That's part of the FTD. That's just the symptom. Focus on brief physical activity, such as exercising, walking, and dancing. There are some research showing that painting can be appropriate for these patients. Conduct psychiatric assessments periodically if the manipulation, sexual gestures, and arguing get worse.

Post-admission with staff education is very important particularly with the family. The family's been dealing with this; they sort of know what to do. I always worry when a family comes in and says we found a unit and they deal with patients with FTD all the time. Sometimes we do not know what that means. Sometimes these patients will develop Pika and will eat things that are nonfood items, including defecation and so we have to be very careful about that.

Terminal care is similar to all dementias with terminal care. With primary prerogative aphasia, the one thing I would strongly recommend is periodic speech therapy consultations, both for chewing and swallowing and for language production, whether the person can use adaptive devices and also how much the patient is able to understand.

As diagnostic specificity improves, not all Alzheimer dementias are going to be diagnosed frequently, and a one size fits all program does not work with people with non-Alzheimer's dementias. If somebody tells you that FTD is the same as Alzheimer's, this is a person who really does not understand. Families and care providers, as Sharon will tell you, are desperate for answers, ongoing support, and to seek out others suffering from similar conditions. Interdisciplinary care and research are critically important.

Now I'm going to throw it to Rebekah who's going to talk about the most important thing, which is the family.

Rebekah Wilson: Good afternoon, everybody. Great information so far. If you can go to the next slide, I will provide an overview of what I plan to discuss today. Again, I will be repeating some of what has been discussed. What is the impact or implications on the individual in the family system when we look at the challenges they experience throughout the diagnostic process? What are symptoms that are less recognized and understood? I will provide more emphasis on that caregiver burden that Dr. Lantz and Geri Hall have addressed.

With the diagnostic process, as has been shared by our previous presenters, misdiagnosis is very common. Frontotemporal is often misdiagnosed. I have heard a lot of sleep apnea misdiagnosis. Even one of our family caregivers shared that she had been told by her healthcare provider she must be having marital problems, and that she is making up the symptoms because her 46 year old husband did not exhibit those symptoms when they were in the doctor's office trying to get the diagnosis. So, she was told that she should seek counseling because they must have marital problems. Lots of misdiagnoses that we hear, again as Dr. Hall said, involve late onset bipolar disorder. Once a diagnosis is made, then we can see clearer in the rearview mirror why these symptoms have been occurring; that it is the disease process and not the person. By that point, there are often sequences that have resulted. In many frontotemporal degeneration families,

there has been involvement with the legal system potentially or a divorce has occurred because these symptoms are misunderstood. In retrospect, when we look back, those symptoms are clear and make sense. There is often a sense of relief to get that diagnosis. Negative or unfavorable behaviors are suddenly explained. Once we know what it is, as family members and providers, we can feel a sense of empowerment. Now that is what we are up against, I can learn about it, and I can, as a care partner, face the future with more confidence learning about the disease process. Again, I am greatly looking forward to hearing Sharon talk about her experiences and how she has become empowered, and this is, in a sense, became a platform for her to connect with other families dealing with similar situations.

Support in a community is often very limited beyond Alzheimer's disease. Many dementia care programs and community adult day programs are set up on an Alzheimer's disease model. More specific programs for Lewy body, Frontotemporal degeneration, and young onset Alzheimer's are often started at a grass roots level by impacted families or friends or support groups. So we see some areas of the country have more resources whereas others do not. It is always a challenge to help family members get connected with others in a similar situation.

The symptoms that Dr. Lantz and Geri Hall described are often less recognized. For many people, who have limited experience with dementias or non-Alzheimer's dementias, the word “dementia” equals memory impairment, but memory impairment may not be a factor with some of these non-Alzheimer's dementias that were described earlier. Particularly in Frontotemporal dementia, memory may be fine so the person may score well on traditional neuro-psych testing that are more geared towards Alzheimer's disease. As the presenters have also described, with Vascular Dementia in particular, symptoms may vary depending on the severity of the damage and the area of the brain impacted. When people use Alzheimer's as a reference point, these other symptoms seem more irregular. As has been discussed, safety considerations, because of a lack of insight into the disease process, becomes a huge concern for families and providers. That is part of the symptoms of these non-Alzheimer dementias. Safety is a huge issue early on, and we are going to talk about resources and services in particular down the road. With the Lewy body dementia, as has been described, these fluctuations in mental status, the falls, hallucinations, can be challenging for caregivers. It can be difficult to manage the mood disturbances and the increasing physical care needs in Vascular Dementia. These symptoms are different than what we typically see in an Alzheimer's disease patient, so we have to give unique consideration to the different types of symptoms. With the Frontotemporal degeneration, we may see legal implications. Again, someone may have encountered the legal system in some capacity. Oftentimes, the family needs to seek out an elder law attorney to look at conservatorship or guardianship as Geri Hall presented. We will talk about employment and social implications as well.

So the nature of the symptom for these non-Alzheimer dementias tends to create extra challenges for the caregiver and require increasing physical care earlier on in the disease process with Vascular Dementia. Something I've seen with caregivers, when talking with families and counseling them through caregiving with Lewy body degeneration, is that when they do not understand that these cognitive fluctuations and the fluctuations and their ability to understand and comprehend and care for themselves is common, families tend to think this person is messing with me.

So, here is an example that I have heard: I said to my mother in the morning, let's have coffee and donuts, and she was able to swing her legs over the bed and get dressed fairly independently. Then in the afternoon, I am trying to get her off the toilet, and I'm saying stand up and she looks at me blankly. The easy misinterpretation of that is for families to say, well, she's just messing with me. This is just my mom, and she's always tried to manipulate me. Well, that may be true, but this is different now. Now, she has the disease process that is impacting her ability to respond at different times in these fluctuations. It is really important for us as providers to explain the fluctuations and that this is the disease not the person.

Additional stress with caregiving can be impacted by the diagnosis, I can't tell you how many families have said, when coming to a support group specific to Frontotemporal dementia, that they really appreciate connecting with others in a similar situation. Alzheimer's disease has its own set of challenges, but when a 40 something year old comes to a support group to talk about the symptoms of Frontotemporal dementia and their loved ones impulsivity and erratic behaviors and maybe getting involved with the legal system, that is a very different set of circumstances than an 85 year old person dealing with repetitive questioning. I am not trying to minimize Alzheimer's disease, it is just a different sense of stress these caregivers often experience. Since the age of onset with young onset Alzheimer's and Frontotemporal dementia is younger, it is less expected. If we run into someone in a grocery store who is confused in their eighties, it is much more accepted than a 40 something year old who is undressing in public; that is not as normalized. We start to think this person has mental health issues, so that burden on the caregiver is unique as well.

What do families need most from us when they are dealing with someone with all types of dementia, though in particular looking at these non-Alzheimer's forms? First, they need advocates, like us and like you. They need recognition of the loss that they are experiencing, support and help with care, and respect and dignity for their loved ones. They are experiencing this loss. Their loved one is still there and may look similar to when they were pre-symptomatic. They are noticing these changes over time and dealing with learning to navigate this illness. With the young onset, we have to think about the developmental stage of the family. There may be young kids at home. With aging parents, people may have been previously considering care for them, but with young onset, the parents are the caregivers for their children. With Alzheimer's disease, we tend to see caregivers as a spouse or adult children.

As Dr. Lantz and Geri Hall suggested, we potentially see a stronger genetic component with younger onset. There is this concern about genetics and what happens if I am also on the path to having this type of illness as a loved one of someone with Frontotemporal dementia or early onset Alzheimer's. The concern about genetics tends to be something we hear quite frequently.

The person with dementia, who has been an earner, may be now have to stop working, and the caregiver, who is also potentially needing to earn money, is transitioning into a caregiver role as well may need to consider family medical leave and other employment considerations.

As with any chronic illness, planning documents are needed. If those are not in place, then conservatorship or guardianship may need to be explored, and just to repeat, many caregivers may need to consider family medical leave and other resources as they transition into caregiver roles.

Often families dealing with these non-Alzheimer's types of dementia, are at their peak of their career in earning power and potentially thinking about retirement in the next phase of life. They may be raising the children, going to college, and having their children leave their homes. They are in a different life phase, and now they find themselves facing this deteriorating illness and know that increasing care needs are coming down the road. The legal and financial implications are quite different than we might see in the traditional Alzheimer's patients who you see in your practice. I want to highlight awareness for the compassionate allowance initiative, a way to expedite SSVI and SSI disability claims and also expediting accessibility to Medicare benefits. This information was copied from SSA.gov, so you can find that information there. Again, the application process is no different than the traditional application process because this FTD and early onset Alzheimer's are considered these compassionate allowances. This would be something to refer families toward again to expedite accessibility to benefits.

Family support groups are a great way for caregivers to connect with others in similar situations, not just from an emotional perspective but also from a problem solving perspective. Families can see how others dealt with similar issues and explain how they encountered and managed those issues. Hopefully, support

groups are going to be a great opportunity for families to get that support they need. A lot of the care models are set up on Alzheimer's disease, so it may be a challenge finding providers who have a greater understanding of these non-Alzheimer's forms of dementia. However, we have seen an increase in providers reaching out for more information. As Geri referenced, the Association for Frontotemporal Degeneration has a lot of resources related to FTD on their website as well as the Lewy body.org website, so there is information out there. It is just a matter of getting that information into the right hands of the right people.

When family members are looking at planning for the future, helping them know the next steps is going to be very helpful. It is important that they know this involves a care team, not one person alone and to determine what their goals for care are. When we set out with knowing what the goals are early on, then we can use that goal as a guiding factor. So if our goals are comfort and safety, how do we make decisions based on using those goals as the guiding factor? Oftentimes when counseling families, I'll go back to asking what their primary goals are. When we go back to those primary goals, it helps in making decisions. If safety is a primary goal, and we are discussing at home care, then safety is a big consideration. At home, they have one caregiver, whereas if my loved one were to be in a memory care facility that is experienced in dealing with non-Alzheimer's dementias, then their safety would increase. So again, use those goals as a guiding factor.

The challenge when we consider options out of the home is that the person with non-Alzheimer's dementia does not always fit. The symptoms may be different and may not fit in as naturally. They are younger, and not all facilities and programs are willing to accept and meet the needs of individuals with non-Alzheimer type dementias.

A challenge we see across the country is this lack of awareness and lack of understanding when most professionals use Alzheimer's disease as the reference point. So understanding the disease process and learning more about the disease process is vital in order to meet the needs of these individuals.

Also as Dr. Hall mentioned, hospice care and the idea of palliative or comfort care should be a guiding philosophy. With hospice, we tend to see denials for folks with Frontotemporal degeneration because that criteria for hospice is geared towards Alzheimer's disease. So denials may be common for the younger and stronger individuals. Again, it takes advocating for how this person meets hospice criteria, so they can receive the benefits that they are entitled to use.

As I said, I do a lot of teaching around the country in facilities and day programs about how care for someone with a non-Alzheimer's dementia is different? First, recognizing it is different is very important. Tailoring activities to the person's ability, their past interest, and recognizing that they may not initiate activity on their own, but they may actually engage in an activity once they are helped to get started. Unfortunately, the individual with Frontotemporal degeneration tends to benefit more greatly with individual activities versus group activities, and in a lot of the day programs and facilities, group activities are the norm. There is a challenge getting that person who is younger engaged in that activity and who with Frontotemporal degeneration may not participate group-wise. They need more individual activities. With the younger onset dementias, we are going to see people relate more toward the younger staff members than perhaps the older Alzheimer’s residents.

I am going to transition to Sharon and look forward to hearing her presentation from a family perspective on how we can all tailor our support for family members. Sharon?

Sharon Hall: Yes, my name is Sharon Hall, and I am a full time family caregiver to my 94-year-old mother who has Vascular Dementia who lives with us, and also my 64-year-old husband who has Behavioral

Variant Frontotemporal Degeneration. His symptoms are different and a challenge for me. I will sort of be focusing on him today.

I want to thank the previous speakers. You've done a very good job of explaining. There are some things that I would like to point out to you. I feel that the hardest part of caregiving for those with any dementia is making that transition from a traditional role as a wife or daughter to the role of a care partner. I affectionately call my mom and my husband the twins. Once I was able to emotionally separate myself, my role became easier because it became less personal, and I think that is a really important thing for caregivers to do to avoid going through that ambiguous loss process that Rebekah was talking about.

One of the biggest challenges in the earlier onset dementias is finding adequate care, as Rebekah was saying, whether it be home care or long-term care. Day centers and long-term care facilities are usually filled with aged Alzheimer's people. My husband is a healthy, robust mobile person whose memory has no impairment other than short term and word finding issues. His behavior is what can pose an issue for us. Although we have more when his anxiety goes up, he can still have outbursts when he is triggered. Also, since he presents as a normal person to most people, they react differently when he displays behavior than they would with an elderly Alzheimer person. People react to his dementia behavior as though it is deliberate in nature just because he is younger and healthy. That is one of the biggest challenges. Along with that challenge is finding a day center or facility that has a younger population and activities that will interest him. Respite is absolutely needed for family caregivers to be a home care partner without burning out, especially with the more challenging behavioral dementias. My twins go to a day program for five hours two days a week. Basically, that is all I can afford; it is not cheap.

In home care and long-term care can be an issue due to the disinhibition of FTD. They say inappropriate remarks. When caring for someone with dementia, people tend to have a tendency to hug and rub the backs of dementia folks. With FTD, if you touch, be prepared to be touched in a similar fashion. There is also what we in the FTD community call the look; this can be interpreted by others as a mean look, and it can cause fear. I have never witnessed anyone with the look act aggressively due to the look. Disagreement comes when you underestimate the abilities of the FTD person and treat them like a frail person whose memory is impaired or you misunderstand their intent. Public situations can pose a very different set of challenges when behavior is an issue.

My husband is fully aware of his diagnosis. His mother also has DDFTD. I initially carried cards saying please excuse my husband's behavior, he has a disease and please be patient, but I found simply saying that to people gives us an opportunity to educate. Education in these other forms of dementia is so very vital and important. They actually laugh because he looks and acts so normal. For those who professionally care for dementia folks, it is imperative you learn techniques for controlling behavior. PRN medications are not the only answer. They will work if you have escalated the incident to an uncontrollable behavior but most behaviors can be managed with the right knowledge and practice before it gets out of control. A late stage dementia looks very similar. Early FTD stages are different than the AD population. In an early dementia stage, asking them to assist with more advanced people really makes them feel needed and gets a really good response from them as well. Giving them purpose and not making them feel frail and competent is key to management, along with understanding where the behavior is originating from and being their advocate instead of their adversary.

The financial burden, as Rebekah talked about, is enormous in earlier onset. You have someone in their forties and fifties at onset, so you are looking at people who have to stop working in their prime years. It is far less than most social security recipients as far as their income. FTD people are also very taken in by scams, and they buy extravagant things they do not need. They can blow through your life savings if no one is watching. Many spouses end up penniless for their future.

They also have unusual eating habits and may eat one thing exclusively. They very often crave carbs and sweets, and as Geri said, they often refuse to shower or brush their teeth. As Dr. Hall said, no one ever died from not taking a shower, so I would encourage people not to force those behaviors. If you force hygiene tasks, you can definitely trigger unwelcomed behaviors.

The community has a tendency to put all dementia in the same care basket as Alzheimer's and that causes untold issues in the FTD population and their care partners. Each FTD person can show different symptoms. Listening to the care partner about how to handle their person is paramount to success. I recently attended a webinar by Dr. Allen Holm, and these words stuck with me: "You can't expect one with a deteriorating brain, no matter their age, to live in your world with your rules. You must enter their world and accommodate your rules to their ability." The best advice I can share is if they are not hurting themselves or others, let them do what they do. Let them hump, sort the blocks, whatever helps calm them and what is happening in their brain.

FTD people are square pegs in the dementia world. Try to remember not to pound them into your round holes for convenience of care. That is really the best advice I can give to anyone.

I want to thank everyone for inviting me. I hope we left enough time for questions.

Caroline Loeser: Thank you for sharing your experience as a family caregiver, and thanks so much to Melinda, Geri, and Rebekah for your presentations.

We have a few minutes now for questions from the audience. At this time if you have any questions for our speakers, please submit them using the chat feature on the lower left of the presentation.

Sharon, we just got a question for you, so I will start with you. What kinds of techniques have you found that work best for your family members for managing behaviors?

Sharon Hall: I do a lot of apologizing. If I have triggered something and he begins to show behavior, I apologize. It is no skin off my teeth to make my life better. I do a lot of, "I'm sorry, that was totally my fault," so I am on his side. Being on his side always helps to diminish the behavior.

Caroline Loeser: Thank you, Sharon. Rebekah, we have a question for you. Can a healthcare surrogate with no family member present place a dementia patient in assisted living or long-term care if it is in the best interest of the patient legally?

Rebekah Wilson: As we know, surrogacy and laws are different in every state. If a person does not have a family member who has been designated as a medical decision maker for them and there is a legal guardian or conserver, they can make those decisions for the person.

Caroline Loeser: Great, thank you. Dr. Hall, I'll move to you. Do you have any suggestions for alternatives when access to site services is a challenge?

Dr. Geri Hall: This is very difficult. It is a national problem too. I wish I could say, yes, we have all kinds of things. If your patient is a veteran you might try the V.A., but generally looking at hospitals that have geriatric site units or even regular psych units, may be your only options. Dr. Lantz might be able to help with that more.

Dr. Melinda Lantz: You could start with any psychiatric unit that can do a basic evaluation, but it is going to vary in terms of how much insight and awareness the individual staff has. Some are great, and some simply do not have the trained staff to do it. I start with the basic services that are available in terms of medical and neurologic workup, and then you can try and go from there in terms of what you find.

Caroline Loeser: Thank you. Dr. Lantz, we have another question for you. Is Frontotemporal dementia the kind that has been connected with frequent concussions or head trauma?

Dr. Melinda Lantz: No. In terms of different types of dementias, chronic encephalopathy is a different neuropathology. That is related to neural fibroid tangles, and it also comes with a different set of behaviors. The patients are younger, and often were physically strong and healthy. They have a lot of impulsivity and fluctuating memory loss. It is a different type of dementia in that population.

Caroline Loeser: Thank you. Dr. Hall I will turn to you again. Are sensory rooms used to treat patients with challenging behaviors arising from dementia?

Dr. Geri Hall: Sensory rooms are used for treating dementia, but nothing has been studied in Frontotemporal dementia. People with Frontotemporal dementia are sensitive to noises, lots of visual input and overstimulation, so you have to be pretty careful with it.

Caroline Loeser: Thank you. Dr. Lantz, I believe this will be another question that applies to you. In early FTD, what techniques do we use to encourage treatment and diagnosis?

Dr. Melinda Lantz: The best is good clinical monitoring and careful evaluation of the symptoms as they emerge to try and mitigate behavioral problems. It is clinically driven and hopefully with a provider that can monitor the patient over time. Unfortunately, we do not have a diagnostic test, and they use PET scans early. They are limited in availability, so they may not be in the research center. You are dealing with a very clinically driven problem. Often people end up shuffling between primary care, neurology, and psychiatry. If you can stick with one provider who can monitor the patient over time, that can at least help deal with the symptoms as they emerge.

Dr. Geri Hall: This is Geri, could I add one thing to that? Often, a family will be referred to a neurologist. It is important that the neurologist has behavioral neurology training because if it is somebody who specializes in things such as multiple sclerosis or strokes, they may miss that diagnosis too.

Caroline Loeser: Thank you. You all stressed the important of the interdisciplinary team when supporting those with dementia and their caregivers. What community resources are out there to help with nonmedical support?

Dr. Geri Hall: This is Geri, and I imagine Rebekah can answer this as well. We usually start with the Agency on Aging because they know of resources for dementia. Also start with the Alzheimer's Association if you have regional office or chapters in your area because that is access to social services, etc. If the family needs to apply for medical help, the Agency on Aging is usually a good starting place.

Rebekah Wilson: I would echo that as well. There are great national resources for Frontotemporal degeneration as well as Lewy body dementia. However, when you are looking to find local resources, we tend to turn to the boots-on-the-ground professionals who are familiar with care at a local level.

Sharon Hall: I would like to add to that that local support groups for the various dementias are a good source of information. Those of us that are doing this every day find resources and share them in those groups.

Caroline Loeser: Thank you all for sharing. We will have one final question before we turn to our closing remarks. So, I have heard about something called dementia friendly communities. How do I find out if there is one in my space? Does anyone on the line know anything about dementia friendly communities?

Dr. Geri Hall: I know a fair amount about it because we have one starting in Tempe, Arizona. They look at developing activities and resource places for people with dementia that use the arts. They use painting and all kinds of things. They have a coffee shop where people who have dementia can get together. Again, they are based on an Alzheimer model, which is shorter activities, less stress, and the development of social relationships. A person with Lewy body dementia can often be quite successful in these programs. Somebody with Behavioral Variant FTD or Language Variant FTD would have a much harder time because of the difficulty of interacting with individuals who are not able to participate in conversations or have no empathy.

You can find out about it through your area's Agency on Aging. Also, you could call the local newspaper and see if they have done an article on dementia friendly communities if there is one in your area.

Caroline Loeser: Thanks, Dr. Hall, and with that we will have to turn to our final remarks. Any questions that we didn't have time to address today we will post to our website in the form of Q&A. If you have any additional questions or comments, you can e mail us at RIC@Lewin.com.

The slides for today's presentation, a recording, and a transcript will be available on the Resources for Integrated Care website.

And as a reminder, on this slide you will see the various continuing education options for today's Webinar. So I will leave this open just a moment and.

Thanks again to all the speakers. Have a wonderful afternoon, and thank you so much for your participation.