

## Frontotemporal Lobar Degeneration (FTLD) with Movement Difficulties

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***PREFACE:*** *This session is a companion piece to two other sessions, 1) Frontotemporal Lobar Degeneration (FTLD) and 2) Frontotemporal Lobar Degeneration (FTLD): Brief Discussion of Tau and Ubiquitin Proteins, available on the web site [www.AlzOnline.net](http://www.AlzOnline.net). The companion piece, Frontotemporal Lobar Degeneration (FTLD) has more details about how people may act and function as a result of changes in the frontal lobes and temporal lobes of the brain; essentially, it covers frontotemporal dementia, primary progressive aphasia, and semantic dementia. . The other companion piece, Frontotemporal Lobar Degeneration (FTLD): Brief Discussion of Tau and Ubiquitin Proteins, provides a snapshot discussion of abnormal tau and ubiquitin proteins related to frontotemporal dementias*

*The following session on Frontotemporal Lobar Degeneration (FTLD) with Movement Difficulties covers progressive supranuclear palsy, cortical basal degeneration, and frontotemporal dementia with motor neuron disease.*

### Frontotemporal Lobar Degeneration (FTLD) with Movement Difficulties: Introduction

Frontotemporal lobar degeneration with movement difficulties refers to the group of progressive dementias that result from decline in brain cells which control personality, behavior, thinking, communication and movement.<sup>1-5</sup>

[NOTE: "Dementia" is a general term that refers to decline in thinking and/or memory function while an individual is awake and alert; the decline is enough to interfere with normal daily functioning, for example tasks on the job or at home. "Progressive" dementia progresses; it becomes worse over time.]

Most cases of frontotemporal lobar degeneration (FTLD) seem to be sporadic while 20 – 40 % of cases probably reflect heredity<sup>6,7</sup>. Some inherited or familial forms of FTLD seem to relate to genes on Chromosomes 3, 9, and 17<sup>8-13</sup>. Some research indicates that FTLD occurs in 15 to 20% of all cases of progressive dementia<sup>17,18</sup>. Alzheimer's disease is considered to be the most common progressive dementia; either vascular dementia or Lewy body dementia appears to be the second most common; and FTLD now ranks third<sup>4,6,19</sup>. About as many women as men have FTLD<sup>20</sup>.

FTLD seems to progress over the same amount of time as Alzheimer's disease, anywhere from 2 to 20 years or more. When there is motor neuron involvement, the time course of the degeneration in many cases runs shorter by about 3 years.<sup>20</sup>

An autosomal dominant gene may explain why researchers estimate that a heredity component may be at play in 20 – 40 % of the FTLD cases while recessive heredity appears to be rare (genes on Chromosomes 17, 9 and 3 seem to be factors)<sup>17,8,21,22</sup>. The rest of the cases of FTLD seem to occur without any reason, predictive pattern or timing<sup>6,7,20,23</sup>. Studies of brain tissue show that there are forms of FTLD that apparently relate to abnormal changes of the tau protein while some forms of FTLD have abnormal ubiquitin protein<sup>20,23</sup>. Some cases without abnormal tau or ubiquitin findings may show various kinds of cell inclusions while other cases have no distinctive abnormal cells<sup>7,8,20</sup>.

## **The Changes of Frontotemporal Lobar Degeneration (FTLD) with Movement Difficulties**

### **Personality, Behavior and Communication Changes**

When there is a dementia that impacts the frontal lobes and temporal lobes of the brain, early on there may be changes in personality and difficulties with routine tasks, activities, and interactions. New behaviors, different from the previous style of behavior for that person, may appear. The person may act more irritable, inappropriately friendly (with strangers) or blunt (even rude) with others. They may become disinterested in chores or other activities that they were once excited about; they may appear to lose all “get up and go”. They may become withdrawn.

It may become impossible for them to complete a task involving many steps or to plan an event or meal. There may be less ability to focus on one task, especially if there are any distracters, such as noises or activities occurring nearby. Sometimes behaviors, such as constant eating (especially sweets), chewing on or mouthing objects or hoarding items such as dirty clothes, old newspapers, or outdated mail, appear.

Even though there is evidence of personality change, general language skills, such as understanding and expressing ideas or needs may remain strong for a while. Mild language problems may involve a struggle to recall specific words during conversations. They may take a great deal of time or become unable to express words in response to questions for specific details. Over time, the persons with the degeneration may need to hear simple phrases in order to follow a conversation. They may need to hear the specific names of people or objects mentioned in every spoken (short) sentence in order to keep up with the topic under discussion.

Typically their short-term memory ability changes much later as the condition progresses<sup>1,6</sup>. To complete a task, they may need to do only one step at a time. Even personal tasks such as dressing or eating may require ongoing prompting from a caregiver. Or, the caregiver may need to remind the person and point to or act out each next step.

The changes in behavior, thinking, communication and, later, memory result from brain cell loss in the frontal lobes (the front top part of the brain) and/or the temporal lobes (both the lower left side and the lower right side of the brain). When the brainstem and related pathways, located in more central and lower areas of the brain, are involved, movement difficulties occur.

## **Movement Difficulties**

Movement difficulties reflect the specific areas of the brain undergoing change. Some movement difficulties are called a *parkinsonism* (sometimes referred to as a *parkinsonian plus syndrome*). *Apraxia*, the inability to do learned, skilled movements such as brushing one's hair or making a simple sandwich, may also become an increasing challenge in handling one's daily routine of tasks and self-care.<sup>24-29</sup>

### **Parkinsonism**

Signs of parkinsonism are:

- ▶ difficulty starting to move,
- ▶ difficulty moving the whole body or parts of the body,
- ▶ difficulty doing skilled hand movements with one or both hands or arms,
- ▶ stiff muscles,
- ▶ trembling limb(s), and/or
- ▶ balance problems.

For example, the person may have difficulty starting to move an arm to pick up a glass. They may struggle to get up out of a chair into a standing position. Then they may have difficulty starting to walk, but once started, may be able to walk well. Or, they may have balance problems resulting in a "tipsy walk". The trembling in their arms may occur when their arms are resting but stop when the arms are moving to do a task such as raking the yard or washing dishes.

In parkinsonism the muscles may be a bit stiff even when the person is sitting in a relaxed way. The stiffness may interfere with balance whether the person is sitting or walking. Walking may be slow, clumsy and unsteady. The person's face may show less emotion than is typical for that person or show no emotion (known as flat affect). Though symptoms may be similar, parkinsonism differs from Parkinson disease.

Parkinsonism differs from Parkinson disease though there is an overlap in the symptoms. Some researchers consider Parkinson disease to be its own group of diseases (there is some variation in the symptoms from one person to the next) while other researchers consider Parkinson disease to be one of the conditions in the cluster of conditions known as parkinsonisms. Sometimes Parkinson disease is diagnosed by health history, a medical evaluation and a trial with one or two

pills of low-dose levodopa to see if the levodopa improves movement function. Improvement from levodopa makes a strong case to confirm a diagnosis of Parkinson disease.<sup>25,30-32</sup>

### **Apraxia**

Difficulty doing learned, skilled, hands movements is called *apraxia*. Apraxia may affect one hand or both. Examples of apraxia include clumsy handling of a knife with a fork to cut food at mealtime. Other examples are difficulty working a TV or radio, buttoning a shirt, or turning pages in a book or magazine.

Apraxia may be the result of losing the know-how or mental directions about how to do a skilled action such as not knowing the correct way to handle a fork or spoon to hold food. Or, apraxia may result from the brain not sending down appropriate directions to move the parts of the body at the correct rate or in the correct sequence of motions. For example, the person may know that a pen and paper are used when writing and know how to hold the pen, but may push the pen back and forth clumsily rather than in controlled movements that would form words on a piece of paper.<sup>26-28</sup>

## **Frontotemporal Lobar Degeneration with Motor or Movement Disorders**

The group of disorders that comprise the frontotemporal dementias fall into three general categories based on the clinical picture of beginning symptoms<sup>30,33</sup>. The first category, behavioral and personality changes, and the second category, language or communication changes, are discussed in the companion session on FTLD mentioned earlier in the Preface. Three categories of motor or movement changes follow:

- a. progressive supranuclear palsy
- b. corticobasal ganglionic degeneration
- c. frontotemporal dementia with motor neuron disease

As the decline of FTLD continues, personal hygiene and dressing may become neglected. Some people become restless and impulsive over time while others seem to lose interest and motivation; they may refuse to do any activities or interact with anyone. After a while, memory and language changes may decline to the point where the caregiver serves as the translator and the memory system. Often as the changes continue, the person has limited self-awareness of the decline and little concern for the effect of such behaviors on family, friends or co-workers.

As the brain cell loss continues, indifference may seem to grow. The person may show less caring, empathy and sympathy toward others even when others express great distress or sadness. Moods may change suddenly for no obvious reason.

Movement difficulties over time may include parkinsonism which shows up as:

- ▶ slow movement of the body,
- ▶ stiff muscles,
- ▶ limited control of muscles or movement,
- ▶ decreased display of emotion on the face,
- ▶ balance difficulties, and
- ▶ difficulty walking.<sup>32</sup>

### **Progressive Supranuclear Palsy (PSP)**

Progressive supranuclear palsy (PSP), a tauopathy, starts typically with difficulty walking and problems with balance. Some people describe the walk as a tipsy walk or drunken walk; the off-balance walk of actor Dudley Moore resulted from his progressive supranuclear palsy.<sup>25,30,31,34-36</sup>

One of the identifying signs of this condition is doll's eyes, an inability to coordinate eye movements and to aim them when quickly looking up or quickly looking down. Most often early movement problems in PSP affect looking up (the upgaze). On occasion, the problem to aim the eyes occurs when the person quickly tries to look from side to side (for example, shifting the eyes from seeing a person or lamp on the right side of the body to seeing a person or a chair on the left side of the body).<sup>3,4,30,31,34</sup>

Some the symptoms that develop resemble Parkinson disease, such as:

- ▶ tremors (involuntary shaking in the arms when the arms are resting),
- ▶ stiffness in movement,
- ▶ slowness when moving, and
- ▶ being off-balance when walking.

Later, the person may struggle to form words (dysarthria) when speaking. They may struggle with swallowing (dysphagia) foods and liquids. Sometimes there is less ability to show or express feeling and a more neutral facial expression or voice (called flat affect).

People may develop a depression. Sometimes the depression appears before the movement problems appear. Sometimes the depression occurs early on as the movement difficulties become apparent.

Much later in the course of the disease, there may be difficulty recalling specific words when speaking. Later, also, there may be short-term memory loss.

The changes seen in the person with PSP result from changes in the more central parts of the brain such as the basal ganglia, the subthalamus, and the substantia nigra (which regulate large muscle movements), the oculomotor nucleus (responsible for coordinating eye movements), and the brainstem (the area that deals with balance).<sup>30,32,37</sup>

## **Corticobasal Ganglionic Degeneration**

Corticobasal ganglionic degeneration (also called Rebeiz Syndrome) is a tauopathy<sup>36</sup>. It is a slowly progressive movement disorder that affects women and men in equal numbers; heredity is not a factor in most cases. People may begin to experience symptoms when they are middle-age, in their 50s or early 60s.

A typical picture of corticobasal ganglionic degeneration is the asymmetrical decline. Often the first sign of corticobasal ganglionic degeneration is clumsiness with one hand, such as being unable to hold a pen to write a note about an appointment or to use a knife when preparing food. There may be clumsiness in moving only the fingers of that hand, such as struggling to pick up a coin or a piece of jewelry.<sup>30,38-41</sup>

There may be difficulty using tools or objects; as mentioned above, this difficulty is called *apraxia*. (*Apraxia* is difficulty with learned skilled hand movements such as difficulty combing one's hair or using a coffee-maker or carpentry tools.) Typically in corticobasal ganglionic degeneration the apraxia affects one side of the body first. The one-sided limb apraxia often begins with paratonia (early on, more stiffness in the muscles of the arm of the affected side; later stiffness involves the leg muscles).<sup>26-28</sup> Sometimes the person stumbles with walking because of difficulty moving the leg that is on the same side of the body as the more apraxic hand. Eventually the decline affects both sides of the body.

The clumsier hand may show a *magnetic apraxia* or, the opposite, *alien hand movements*. *Magnetic apraxia* is seen when the affected hand seems magnetically drawn to the other hand or to anyone else's hand that comes near it. The hand may seem to be drawn in that same magnetic way to an object near the hand, such as a pen that the hand grabs, though the person may not have intended to pick up and use the pen. The *alien hand* seems to, on its own, push away the other hand or remove from the other hand any object that other hand tries to hold or use.<sup>42</sup> For example, if the person tries to hold a pen to start writing, the other hand may take the pen and put it on the table.

Sometimes as the brain cells continue to decline, a person's arms or legs will move into a strange position as if on their own and without any purpose. One hand or arm (or both) may form abnormal postures such as reaching up as if to pick an apple from a tree and holding the arm in that position for several minutes. In some people one or both legs may move into an abnormal position, for example, lifting a leg as if to kick and then holding that lifted leg for 15 minutes or longer.

As the disease progresses, people with corticobasal ganglionic degeneration may struggle to say words clearly or choke occasionally when swallowing. They know what they want to say but struggle and take great effort to form the words to express them. They may experience emotional ups and downs. As the disease process continues, they usually develop neurological signs such as a firm hand grasp (similar to a strong handshake that refuses to release the hand of the other person). They may struggle to keep their balance while walking and sitting in a chair. Their walking may become unsteady to the point of frequent falling. Then incontinence may become a problem.

Much later in corticobasal ganglionic degeneration, the person has difficulty recalling words which leads to hesitant and very slow speech. This difficulty may include a struggle to form the words when speaking. Later, also they may begin to have short-term memory problems and other cognitive (thinking) problems.

When there is confusion about some of the movement problems appearing to resemble Parkinson disease, a brief trial of Parkinson medicine (levodopa) is worth trying. If the taking the medicine leads to no improvement in body movement or tremors, that evidence will confirm that Parkinson disease is not or is not part of the health change.

### **Frontotemporal Dementia with Motor Neuron Disease**

Frontotemporal dementias with motor neuron disease include sporadic conditions<sup>24,43</sup> and some conditions related to (genetic) findings on Chromosome 17. One Chromosome 17 condition is named FTDP-17T<sup>9</sup> and another is named FTDP-17U<sup>44</sup>. FTDP-17T represents frontotemporal lobar degeneration with parkinsonism related to a gene area on Chromosome 17 with tau protein abnormalities<sup>36</sup>. FTDP-17U represents frontotemporal lobar degeneration with parkinsonism related to a gene area on Chromosome 17 with ubiquitin protein abnormalities.<sup>14,15,33,44-48</sup>

When the examination of the affected area of brain tissue shows a significant amount of tau protein and minimal or no ubiquitin protein, these conditions are called frontotemporal dementia with tau-positive/ubiquitin-negative inclusions (inclusions are abnormal protein forms in the cells)<sup>14</sup>.

The opposite may occur. The examination of the affected area of brain tissue may show significant amount of abnormal ubiquitin protein and minimal or no tau protein; these conditions are called frontotemporal dementia with ubiquitin-positive/tau-negative inclusions<sup>14,33</sup>. While some researchers have found the appearance of both abnormal tau and abnormal ubiquitin in a study of a patient with a clear clinical presentation and course of FTLD with motor neuron disease<sup>49</sup>, other researchers think that FTLD-U should not be considered in the category of a frontotemporal dementias with motor neuron disease<sup>50</sup>.

[NOTE: More information about abnormal tau and ubiquitin proteins is presented in the session, Frontotemporal Lobar Degeneration (FTLD): Brief Discussion of Tau and Ubiquitin Proteins, available on the web site [www.AlzOnline.net](http://www.AlzOnline.net).]

The symptoms of frontotemporal dementias with motor neuron disease include changes in thinking functions that involve the frontal lobes and the temporal lobes but early on also involve changes in the motor system. Changes in the motor system show up as some or all of the following:

- ▶ increasing difficulty with movement, tight or stiff muscles
- ▶ fasciculations (muscle twitches or flutters)
- ▶ muscle jerks
- ▶ muscle cramps
- ▶ loss of muscle tone
- ▶ general weakness

The arms and legs may be affected first and then problems forming words or swallowing may appear. The reflexes may be overactive. For example, the gag reflex in the throat may be extra sensitive; the knee jerk and other reflexes in the body may be extra jumpy or weaker.

In frontotemporal dementia with motor neuron disease the brain cells (neurons) in the frontal lobes, the temporal lobes and the brain stem undergo degeneration and atrophy. The dementia from frontal lobe and temporal lobe changes may occur before or after the motor neuron disease. The changes involve the nerve tracts that bring signals from the brain down the spinal cord to the motor neurons to the muscles of the rest of the body (in other words the descending cortico-spinal tracts, brain stem, motor nuclei and peripheral nerves that innervate the muscles).<sup>45,51,52</sup>

**Amyotrophic Lateral Sclerosis (ALS) with Dementia or Lou Gehrig's Disease with Dementia:** A well known motor neuron disease because it was named after a famous baseball player is Lou Gehrig's disease. Lou Gehrig's disease may involve only the motor or muscle system. Lou Gehrig's disease which includes the frontal and temporal lobes is a frontotemporal dementia with motor neuron disease; it is called ALS with dementia (amyotrophic lateral sclerosis with dementia or Lou Gehrig's disease with dementia).<sup>11,24,29,43,48,51,52</sup>

[NOTE: It bears emphasis that some people with amyotrophic lateral sclerosis (ALS) have progressive decline only in their ability to move. There may be no change in their memory or thinking skills. As an example, Professor Stephen Hawking, the world famous physicist born in 1942, started having muscle weakness in his third year of college and at 64 (in 2006) years of age continues to have full memory and thinking functions. His special wheelchair, a special computer and voice synthesizer and caregivers help him with personal needs so he may continue to teach, write and travel all over the world to lecture.<sup>53</sup>]

**ALS Medicine:** Rilutek (formerly known as riluzole), the first drug given FDA (Food and Drug Administration) approval to treat and slow down ALS, may help the problems with weak muscles and general movement. Riluzole slows the progression of ALS but does not cure it. Further information about riluzole is located at the web site: [www.nlm.nih.gov/medlineplus/print/druginfo/](http://www.nlm.nih.gov/medlineplus/print/druginfo/).

### **Heredity**

Due to research related to the Human Genome Project, there is evidence that about 50% of reported cases of FTLD have a family history of progressive dementia. Researchers think that these cases may relate to autosomal dominance. Evidence on Chromosomes 3, 9, and 17<sup>9</sup> indicates that a gene different from the tau regulating gene may be responsible for these rare forms of FTLD with motor neuron disease.<sup>7-9,54,55</sup> [NOTE: More discussion about abnormal tau and ubiquitin proteins is presented in the session, Frontotemporal Lobar Degeneration (FTLD): Brief Discussion of Tau and Ubiquitin Proteins, available on the web site [www.AlzOnline.net](http://www.AlzOnline.net).]

## Medical Evaluation

The medical evaluation of symptoms resulting from changes in thinking, memory and movement abilities should be thorough. The companion session **Frontotemporal Lobar Degeneration (FTLD)**, available on the web site [www.AlzOnline.net](http://www.AlzOnline.net), covers details that are important for a medical evaluation.

## Care Management

An important role of the physician, other medical and social service providers, and caregivers (paid caregivers and family caregivers) is to offer hope. One way to offer hope is to frame the test results, the diagnosis, the care management plan, and the general information in positive ways. Discussions covering the following will help the patient and family adjust to the changes and make the best of every day ahead: health goals, expected changes over time, ways to manage the changes, ways to optimize self-sufficiency and self-worth of the person with the diagnosis, ways for the caregiver and care receiver to appreciate each other, and resource people and programs available to help.<sup>25,56,57</sup>

Living a healthy lifestyle with regular physical exercise, social activities, proper nutrition, enough drinking water (10 to 12 glasses a day unless restricted by a physician), and brain exercise are critical for improving health and the ability to function well in daily life. It is important to remember that people who move or speak slowly need more time to move or to respond to a request. When starting an activity or after asking a question, a caregiver should allow 15 seconds or more (counting slowly and silently to 15 or 20) to provide enough time for the person to move or to respond in a conversation.

The companion session **Frontotemporal Lobar Degeneration (FTLD)** on the web site [www.AlzOnline.net](http://www.AlzOnline.net) covers details that are important for care management, medical treatment, and planning for long-term care both at home and when using community programs, resources and facilities for residence. The recommendations include information about driving, speech therapy, occupational therapy, and activity including brain exercise.<sup>25,56,57</sup>

### Eye Doctor (Ophthalmologist) Help

Changes in movement ability may affect the muscles that control eye movement. As a result, the eyelids may blink less often. Reduced blinking leads to dry eyes. Dry eyes lead to sensitive or painful corneas (the cornea is the white surface on the front of the eyeball). Dry corneas may tear or even split, leading to intense pain. Artificial tears help keep the eyes moist; many types of artificial tears are available. An ophthalmologist may suggest a few types of artificial tears to try and may have some samples available.

An ophthalmologist may recommend eyeglasses or sunglasses with prisms. Eyeglasses with prisms, though uncomfortable to wear, may compensate for the inability to look down, often a problem for people who have a diagnosis of progressive supranuclear palsy.<sup>31</sup>

Eyeglasses with side or top extensions similar to swim goggles protect the corneas from drafts of air that may dry the eyes. Dry eyes usually are extra sensitive to dry air in settings such as air conditioned buildings during the summer, well heated homes during the winter, or environments with low humidity such as the southwestern United States. Dry eyes are also sensitive to environments with chemicals such as chlorinated water in swimming pools, fumes from outdoor cooking grills or fireplaces, and smoke from tobacco products.

### **Physical Therapy**

People with movement difficulties such as slow body movements or clumsy walking may benefit from an evaluation by a physical therapist. The physical therapist will offer suggestions and training in appropriate exercises. Exercise helps to increase and maintain physical movement, agility and strength. The suggestions from the physical therapist will include ways to move about more easily and more safely. As a general rule, easy stretching and low impact exercises in short periods of time such as 10 to 20 minutes three to four times a day will help keep the muscles working as well as possible while not over-taxing them.

### **Occupational Therapy**

An occupational therapist will offer suggestions on how to manage personal care activities and provide ways to ease the tasks that are part of a person's daily routine. The occupational therapist is trained to do a home evaluation and offer suggestions to ease function and increase the safety of the home setting. Over time, ramps, ankle supports, braces and walkers may be useful to keep the person mobile. Special walking aids that are weighted on the bottom, for example quad-canes with a low center of gravity, a weighted base and weighted, rubber tips on bottom surfaces, help people to maintain balance. A variety of walkers, some of them collapsible for easier carrying, are available: with baskets, flat trays, sectioned trays, wheels or folding seats. Wheelchairs or motor scooters save the energy of people who tire quickly and help people struggling with balance problems and falls.

### **Speech Therapy**

As the movement difficulties spread, there may be new struggles with speaking or swallowing. A speech therapist will recommend ways to help the person function better. Recommendations for swallowing difficulties may include a slow progression from foods that are harder to eat to foods that are easier to chew and swallow. For example, dry meat, crackers, popcorn, crisp apples, and potato chips are harder to chew and swallow. Foods in small pieces and with sauces are easier to chew and swallow, for example, omelets, macaroni and cheese, cooked greens served in a yogurt sauce, beef or vegetable stew, and jello containing small bits of soft fresh fruit such as ripe bananas, melons, peaches, etc. Liquids that are thicker such as orange juice, tomato juice, milk, and thick soups are easier to swallow than water, apple juice, or broth. Foods that are "active" such as peas, spaghetti (cut up), rice or blueberries are managed better when they are mixed with a sauce.<sup>25,56,57</sup>

For people with swallowing difficulties, it helps for them to slow down the steps of eating. The following directions for eating may keep the lungs clear during mealtime, particularly a problem for people who may have some food leaking into their lungs (bronchus or breathing tube) when they swallow:

### **Eating Tips**

1. Take a small bite.
2. Chew.
3. Swallow.
4. Cough.
5. Swallow again.
6. Take the next small bite.

For drinking liquids, the following directions may be helpful:

### **Drinking Tips**

1. Take a small sip.
2. Swallow.
3. Cough.
4. Swallow again.
5. Take the next small sip.

### **Driving Issues**

Caregivers should be alert to the challenges and safety risks of people with movement difficulties. Not only may they be clumsy in starting and operating a motor vehicle, but they may not be able to react fast enough to avoid a sudden accident. Their fingers or hands may no longer have the strength or skills to operate a motor vehicle, which includes not only a car, but also, rider mowers (lawn mowers), golf carts, motor boats, etc. Weaker decision-making skills, decreased judgment and less ability to focus on driving especially when distracting passengers or road conditions may increase the potential for minor or major car accidents. The following Table 1 contains sources of information about driving safety.<sup>56-61</sup>

**Table 1. Some Internet Resources on Driving Issues and Safety<sup>59</sup>**

- ▶ **Alternative transportation:** <http://www.eldercare.gov>
- ▶ **American Occupational Therapy Association:** <http://www.aota.org>
- ▶ **Association of Driver Rehabilitation Specialists:** <http://www.aded.net>;
- ▶ **CarFit:** [www.eldersafety.org/latest/roadmap-to-driving-wellness-and-car-fit-two-exciting-new-programs.html](http://www.eldersafety.org/latest/roadmap-to-driving-wellness-and-car-fit-two-exciting-new-programs.html)

- ▶ Driver refresher courses: <http://www.aarp.org/drive>; [www.aaapublicaffairs.com](http://www.aaapublicaffairs.com)
- ▶ Driving & Dementia Toolkit (published in Journal of the American Geriatric Society): <http://rgapottawa.com/dementia/english/default.asp>
- ▶ DriveWell: <http://www.asaging.org/drivewell>
- ▶ GrandDriver information & references: <http://www.granddriver.info/>
- ▶ Independence Drive: <http://driving.php.ufl.edu/index.php> (NODRTC website); <http://www.php.ufl.edu/ot/> (OT website); <http://www.IndependenceDrive.php.ufl.edu>
- ▶ Older driver facts: <http://www.seniordrivers.org>; [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov); [www.aoa.gov](http://www.aoa.gov)

### Resources

Resources are essential for caregivers and care receivers. Resource programs provide educational materials and workshops, support groups or other services whenever appropriate and often at no cost. For those who can use a computer, information on the (computer) internet is available 24 hours a day. The internet provides readily available (usually free) help. Many community libraries, religious organizations and schools welcome public use of computer equipment to access information. Entering in a name of a diagnosis or a medicine or a challenging behavior will result in a wealth of explanations and suggestions. Some excellent internet web sites and toll free phone numbers are listed in the following Tables 2 and 3 (these resources are listed also in the companion session *Frontotemporal Lobar Degeneration*, [www.AlzOnline.net](http://www.AlzOnline.net)).

**Table 2. Information on FTL D:  
Internet sites and Toll Free Phone Numbers**

- ▶ Association for Frontotemporal Dementias: [www.ftd-picks.org](http://www.ftd-picks.org)
- ▶ National Aphasia Association: [www.aphasia.org](http://www.aphasia.org); (800)922-4622
- ▶ ALSA (Amyotrophic Lateral Sclerosis Association); [www.alsa.org](http://www.alsa.org) or [info@alsa-national-org](mailto:info@alsa-national-org); (800)782-4747
- ▶ Society for Progressive Supranuclear Palsy: [www.psp.org](http://www.psp.org); (800)457-4777

Other resources listed in the following Table 3 provide general information about progressive dementias and caregiver management that may be of help to people dealing with frontotemporal lobar degeneration. (These resources are listed also in the companion session *Frontotemporal Lobar Degeneration*, [www.AlzOnline.net](http://www.AlzOnline.net).)

**Table 3. General Resources**

- ▶ Alzheimer’s Association (USA): [www.alz.org](http://www.alz.org) or [www.alzheimers.com](http://www.alzheimers.com);  
(800)272-3900
- ▶ Alzheimer Society of Canada: [www.alzheimer.ca](http://www.alzheimer.ca)
- ▶ Alzheimer’s Society (United Kingdom): [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
- ▶ AlzOnline (at University of Florida): [www.AlzOnline.net](http://www.AlzOnline.net)
- ▶ American Academy of Neurology: [www.aan.com](http://www.aan.com); [www.thebrainmatters.org](http://www.thebrainmatters.org)
- ▶ (National) Aphasia Association: [www.aphasia.org](http://www.aphasia.org); (800)922-4622
- ▶ Family Caregiver Alliance: [www.caregiver.org](http://www.caregiver.org); (800)445-8106
- ▶ Helpguide, Aging Issues: [www.helpguide.org/elder/lewy\\_body\\_disease.htm](http://www.helpguide.org/elder/lewy_body_disease.htm)
- ▶ Los Angeles Caregiver Resource Center: <http://geroweb.usc.edu/lacrc>;  
(800)540-4442
- ▶ National Institute of Neurological Disorders and Stroke:  
[www.ninds.nih.gov/disorders](http://www.ninds.nih.gov/disorders)

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