Creating a Dementia Capable State in Illinois
Training for the Aging Network

Promoting the sustainability of a dementia-capable system through training on the most common types of dementia and the practical application for staff working in a variety of settings.
CREATING A DEMENTIA CAPABLE STATE IN ILLINOIS

The Illinois Department on Aging, in partnership with other state agencies, Alzheimer’s Association Chapters, Area Agencies on Aging, the Illinois Council of Care Coordination Units and other key stakeholders is expanding a statewide coordinated dementia-capable system that builds on the service infrastructure currently in place. The goal of this expansion is to develop and implement a sustainable, community-based service delivery system in that meets the needs of individuals with dementia and the needs of their caregivers; a dementia-capable system. This expansion includes training the Aging Network on the components of a dementia-capable service delivery system.

The Aging Network in Illinois that cares for individuals with dementia includes Care Coordinators, Adult Protective Service Workers, in-home care workers, adult day service workers, Area Agency on Aging staff, Aging and Disability Resource Center staff, managed care organization staff and supportive living facility staff. These providers need accurate information about caring for someone with dementia including the benefits of early diagnosis, how to address the physical, cognitive, emotional, and behavioral symptoms of the disease, and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities. Dementia-specific capabilities within the direct care workforce need to be enhanced.

With a grant from the Illinois Department on Aging, the Illinois Council of Care Coordination Units focused on the training component to promote the sustainability of a dementia-capable system. This training manual is a piece of this training effort to strengthen the dementia-capability of a workforce providing care to people with dementia.
ACKNOWLEDGEMENTS

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SECTION 1

WHAT IS DEMENTIA?

The term dementia is not a specific disease. Dementia is used to describe the gradual deterioration of “intellectual” abilities and behavior that eventually interferes with customary daily living activities. Customary daily living activities include balancing the checkbook, keeping house, driving the car, involvement in social activities, and working at one’s usual occupation. There may also be changes in personality and emotions. Contrary to popular belief, dementia is not a normal outcome of aging, but is caused by diseases that affect the brain. Dementia influences all aspects of mind and behavior, including memory, judgment, language, concentration, visual perception, temperament and social interactions. The Diagnostic and Statistical Manual (DSM 5) states that at least one or more of the following cognitive domains must be significantly impaired to be considered dementia (or neurocognitive disorder):

- Complex Attention (sustained attention, divided attention, selective attention, processing speed)
- Executive Function (planning, decision making, working, memory, responding to feedback/error correction, overriding habits/inhibition, mental flexibility)
- Learning and Memory (immediate memory, recent memory, very long term memory)
- Language (expressive language including naming, word finding, fluency, and grammar, and syntax; and receptive language)
- Perceptual-motor
- Social cognition (recognition of emotions, theory of mind; often described as a change in personality)

While there are at least a hundred types of dementias, this Training Manual will provide additional information on the 4 most common types of dementia in order of prevalence:

- Alzheimer’s Disease - 11% of the population affected (5 million) and up to 60 to 80% of those over age 65
- Vascular Dementia - up to 20% of all dementias
- Lewy Body Dementia (LBD) - 20% of individuals with dementia
  Includes sub-diagnoses of:
  Dementia with Lewy Bodies
Parkinson’s Disease Dementia

- Frontotemporal Dementia (FTD) - 2%-10% of all dementias
  Includes sub-diagnoses of:
  Behavioral variant frontotemporal dementia
  Pick’s Disease
  Primary Progressive Aphasia
  Corticobasal Syndrome
  Progressive supranuclear palsy
  Frontotemporal dementia with parkinsonism
  Frontotemporal dementia with amyotrophic lateral sclerosis

Other less common types of dementia include:
- Dementia Pugilistica due to traumatic head injury (moderate head trauma is related to twice the risk of developing AD or other dementias as someone who had no head trauma)
  [2014 Alzheimer’s Disease Facts and Figures p. 11]
- HIV associated dementia (HAD)
- Normal pressure hydrocephalus (excess cerebrospinal fluid accumulates in brain’s ventricles)
- Huntington’s Disease (symptoms usually show up between ages 30-50)
- Creutzfeldt-Jakob Disease (a prion disease, is rare with sudden onset)
- Wernicke-Korsakoff Syndrome (severe deficiency of thiamine commonly caused by alcohol misuse)
- Mixed Dementia (2 or more dementias)

To see how the brain is affected in these types of dementia, open the following hyperlink:  http://www.medicinenet.com/dementia_pictures_slideshow/article.htm

Dementia is caused by damage to brain cells which disrupts the ability of those cells to communicate with one another. The area of the brain that is damaged determines the diagnosis and progression of symptoms. Not all symptoms happen to all people and most dementias progress over time. Medications may help with managing various symptoms for a period of time.

Frequently, increased difficulty with memory and other areas of cognition are key symptoms which will prompt an evaluation by a physician. Unless the individual or family member expresses concern, a physician will not always be able to perceive a problem during the early
stages. Individuals may not display any memory or cognitive deficits in general conversation or
during a short visit in the physician’s office. As well, typical medical tests performed in a
routine physical will not identify a cognitive problem.

In the early stages, special evaluations are necessary to demonstrate the abnormalities. This
may include referrals to a Regional Alzheimer’s Disease Assistance Center or one of their
primary provider sites. An assessment will rule out treatable conditions such as B12 deficiency,
depression or abnormal thyroid function. A patient history will be obtained from someone who
knows the person with dementia well and can identify the changes in behavior. A physical and
neurological evaluation will be completed. A brain scan may be done to look for evidence of
stroke and identify other changes in the brain. Cognitive and neuropsychological tests will be
done, lab tests completed as well as a psychiatric evaluation to address the possibility of
depression.

Risk for Dementia
Age is the primary risk factor for developing dementia. “The number of people living with
dementia could double in the next 40 years with an increase in the number of Americans who
are age 65 or older—from 40 million today to more than 88 million in 2050.” (National
Institutes of Health).
Many individuals with Down Syndrome develop signs of dementia by the time they reach
middle age.

Mild Cognitive Impairment (MCI)
Individuals with Mild Cognitive Impairment experience a decline in their usual cognitive
abilities. Symptoms may be noticed by others but may not affect the individual’s abilities to
complete their normal day to day tasks. While individuals with MCI are at higher risk of
developing Alzheimer’s disease, not everyone with MCI will develop the disease. “Ten to
twelve percent of individuals with this set of symptoms develop dementia in subsequent years
for at least 5 years” (Mace, p. 77). Individuals with MCI may still be able to do their activities of
daily living but may lose things often or forget to go to appointments or have more difficulty
finding the right word in a conversation.
Dementia Stages

The Global Deterioration Scale (GDS), developed by Dr. Barry Reisberg, et. al. provides an overview of the stages of cognitive function for those suffering from a primary degenerative dementia such as Alzheimer’s disease.*

**Stage 1: No Cognitive Impairment**

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

**Stage 2: Very Mild Cognitive Decline**

Individuals at this stage feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

**Stage 3: Mild Cognitive Decline**

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word-finding or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people
- Performance issues in social or work settings noticeable to family, friends or co-workers
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

**Stage 4: Moderate Cognitive Decline**

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events
- Impaired ability to perform challenging mental arithmetic—for example, to count backward from 100 by 7’s
- Decreased capacity to perform complex tasks, such as shopping, planning dinner for guests, paying bills or managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations
Stage 5: Moderately Severe Cognitive Decline

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated,
- become confused about where they are or about the date, day of the week, or season,
- have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4’s or from 20 by 2’s,
- need help choosing proper clothing for the season or the occasion,
- retain substantial knowledge about themselves and know their own name and the names of their spouse or children, or
- require no assistance with eating or using the toilet.

Stage 6: Severe Cognitive Decline

Memory difficulties continue to worsen, significant personality changes may emerge and affected individuals need extensive help with customary daily activities. At this stage, individuals may:

- lose most awareness of recent experiences and events as well as of their surroundings,
- recollect their personal history imperfectly, although they generally recall their own name,
- forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces,
- need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet,
- experience disruption of their normal sleep/waking cycle,
- need with handling details of toileting (flushing toilet, wiping and disposing of tissue properly),
- have increasing episodes of urinary or fecal incontinence
- experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding, or
- wander and become lost.
Stage 7: Very Severe Cognitive Decline

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence of urine
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

(Reisberg, B., 1136-1139)

Reversible/Treatable Causes of Dementia

Several reversible conditions can cause similar symptoms to AD or another dementia. Remember that confusion refers to a state of being which is often due to outside influences. By eliminating or modifying the environment, many symptoms of confusion can be reduced or eliminated.

- **Infections and immune disorders:** Fever may cause dementia like symptoms. Urinary tract infections or more serious brain infections (meningitis and encephalitis) can cause thinking problems. Untreated syphilis or Lyme disease can also cause dementia-like symptoms.
- **Diet:** Diet may change with economic circumstances, social isolation, problems with teeth or mouth or lack of nutritious food. Malnutrition will lead to significant metabolic changes and vitamin deficiencies, particularly B12 deficiency.
- **Chemical Imbalances:** Many physical diseases are caused by an imbalance in the body’s metabolism; and certain disease processes cause chemical imbalances. These same imbalances can cause intellectual problems. Too much potassium or sodium is as harmful as too little. Uncontrolled diabetes can cause one to exhibit symptoms of dementia.
- **Mismanagement of Medications or Drug Interactions:** Sometimes an elderly person will not understand his/her medication schedule or remember to take medications as directed. There is also the old adage, “If one is good, two is better.” Individuals who see more than one doctor (and go to more than one pharmacy) may not remember to report all medications already being taken and the doctor may unknowingly prescribe additional medications. The individual
may not know the difference between a generic and a non-generic of the same medication and take both or “double up” on the same medication. Side effects or the interaction of prescribed medication may cause symptoms of dementia.

• **Alcohol Abuse:** Use of alcohol is known to impair intellectual functioning. Chronic use of alcohol will damage brain cells. The use of alcohol with medication can cause agitation, drowsiness, sedation or memory loss.

• **Depression:** It is often difficult to determine whether a severely depressed or anxious person has an irreversible brain disorder or a severe emotional condition. Depressed persons may exhibit memory problems or a decreased ability to complete activities of daily living.

• **Visual or Hearing Losses:** Persons who have difficulty with hearing or sight often miss much of what is happening around them. They are unable to communicate appropriately and sometimes appear to be confused.

• **Toxins:** Lead poisoning in adults can cause hypertension, strokes, heart and lung disease or mental disorders. Lead is a cumulative poison which can remain in the blood for up to 20 days and in the bone and tooth tissue as long as 20 years. It can be found in drinking water if the old pipes are made of lead. Paint chips can be a source of lead poisoning if the paint used prior to 1950 has not been removed and is chipping; persons with poor eyesight might not notice if paint chips fall into their food. Even though old lead paint has been covered with new coats, the hazard still exists unless the leaded paint has been fully removed.

• **Carbon Monoxide:** This is an odorless gas which can eventually cause death if the individual is exposed to it for an extended period of time. Old or malfunctioning furnaces, gas water heaters, or exhaust fumes from a car are often associated with this problem.

• **Isolation and Sensory Deprivation:** Persons who have no or few outside contacts, who do not watch TV, listen to the radio or read the newspaper will exhibit symptoms of confusion and/or dementia. The individual will usually score poorly on a mental status questionnaire.

• **Abuse Victimization:** Individuals may appear confused at times because they do not wish or are afraid to divulge sensitive information. The individual’s evasiveness may be due to the fear of revealing an abusive situation. This evasiveness would most likely appear in discussions regarding finances, relationships, falls, fractures, or other medical issues.

If you suspect any of the above causes, work with the caregiver and physician to obtain an appropriate medical evaluation. Ensuring proper nutrition, removal of toxins from the environment, or counseling could alleviate many of the symptoms.
SECTION 2

ALZHEIMER’S DISEASE

Alzheimer’s disease (pronounced Allz-high-merz) is a progressive and degenerative disease of the brain (large numbers of nerve cells in the brain die). It is the most common type of dementia, accounting for approximately 60-80% of dementia cases. There is no known cause or cure. The disease progresses gradually from forgetfulness to total disability. The disease causes changes in personality, memory, and function, thereby, affecting families as much as the person who has the disease.

The disease was first identified in 1907 by Dr. Alois Alzheimer. During an autopsy of a 56 year old patient, Dr. Alzheimer noticed “structural changes in the brain of a demented patient. Plaques and tangles had formed on the outside of the nerve cells which scientists believed are degenerated ends of nerve fibers.” (Leschied, p. 27). There is also an accumulation of an abnormal form of the protein tau inside neurons (called tau tangles). The unique structural changes isolated the disease from other dementias. Significant research on the disease did not begin until the 1960’s because Alzheimer’s disease was thought to be a rare disease of middle aged adults.

To see how the brain is affected by Alzheimer’s disease, open this hyperlink to view a short National Institute of Health video:

“Inside the Brain: Unraveling the Mystery of Alzheimer’s disease.  
https://www.youtube.com/watch?v=x-ntCl=850276366v=0pTq4R9RztA&x-yt-ts=1422503916&feature=player_embedded

Another short video by the Alzheimer’s Association also describes the changes in the brain due to Alzheimer’s disease:

“A Quick Look at Alzheimer’s: Four Pocket Films—Film One”
https://www.youtube.com/watch?v=3G0uwOgn8M

The symptoms of Alzheimer’s Disease usually begin with the individual experiencing memory loss and having difficulty performing tasks that were once done with ease such as managing money, driving, or preparing meals. Caregivers can often look back and identify when the individual started having difficulty completing tasks. As symptoms worsen, the individual may become more disoriented about time and place, misplacing items and not being able to
backtrack to locate them, demonstrate poor judgment, and/or have mood and personality changes.

Note: To learn more about symptoms of Alzheimer’s disease (AD), visit www.alz.org/10signs

**Incidence**

- Today, every 67 seconds, someone in America develops AD; by 2050, it will occur every 33 seconds
- Approximately 5.2 million Americans have AD with a projected 11-16 million Americans with AD by 2050
- One third of all seniors who die in a given year have been diagnosed with Alzheimer’s or another dementia.
- About 70% of all nursing home residents have cognitive impairment, 50% of assisted living residents have AD or another dementia, over 50% of adult day service participants have AD or another dementia, as well as about 25% of all elderly hospital patients.
- The greatest risk factor for developing AD is age. While most individuals with AD are 65 years of age or older, the likelihood of developing AD doubles about every five years after age 65. After the age of 85, the risk is nearly 50 percent.
- Individuals who have a parent, brother or sister with Alzheimer’s Disease are more likely to develop AD than those who do not. The more family members that have AD, the greater the risk of developing the disease.
- Genetics also play a role in whether an individual gets AD. Those that inherit a copy of the APOE-e4 (Apolipoprotein E) gene have a greater risk of developing the disease.

(Alzheimer’s Association, e27-e82)

**Normal Memory Problems vs. Alzheimer’s**

Many people report increased difficulty with names, dates, or appointments as they age, but continue to remain active in the community and with their families. Normal aging will allow us to eventually remember what was forgotten. Individuals with Alzheimer’s disease or other dementias will not remember that s/he forgot something or remember how to backtrack to locate a misplaced item.

Benign (or normal) forgetfulness is a part of the normal aging process and usually begins in early middle age. It is common for all of us to be more forgetful when we’re depressed, grieving, overworked, or running in a dozen directions. Most people have some experience
misplacing their keys, glasses or their car in a parking lot. We all forget names or occasional appointments.

**Key differences between early signs of Alzheimer’s disease and normal aging include:**

<table>
<thead>
<tr>
<th>Alzheimer’s Disease</th>
<th>Normal Aging</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making poor judgments and decisions a lot of the time</td>
<td>Making a bad decision once in a while</td>
</tr>
<tr>
<td>Problems taking care of monthly bills</td>
<td>Missing a monthly payment</td>
</tr>
<tr>
<td>Losing track of the date or time of year</td>
<td>Forgetting which day it is and remembering it later</td>
</tr>
<tr>
<td>Trouble having a conversation</td>
<td>Sometimes forgetting which word to use</td>
</tr>
<tr>
<td>Misplacing things often and being unable to find them</td>
<td>Losing things from time to time</td>
</tr>
</tbody>
</table>

(NIH Publication No. 11.5441)
Vascular dementia is the second most common type of dementia accounting for 10-20 percent of cases. It is most often due to a stroke or infarct (a blockage or injury to vessels supplying blood to the brain) and attacks a different part of the brain than other dementias. Initial indicators of vascular dementia may be seen as trouble planning and making decisions whereas individuals with Alzheimer’s disease typically experience memory loss first. There may be a sudden on-set followed by the individual exhibiting a more “step-wise” pattern of decline due to multiple smaller strokes.

Other symptoms may include: memory problems, trouble speaking or understanding speech, becoming disoriented with difficulty recognizing sights and sounds that used to be familiar, becoming confused or agitated, changes in personality or mood, difficulty walking and an increased number of falls.

Age is a risk factor for vascular dementia. This dementia is rare before age 65 but the risk rises substantially after age 80. Risk factors for heart disease and stroke raise the risk of getting vascular dementia. Atherosclerosis results from deposits of cholesterol and other substances (plaques) that build up in the arteries and narrow the blood vessels. The reduction of the flow of blood to the brain may increase the risk of vascular dementia and possibly the risk of Alzheimer’s Disease, (Mayo Clinic Health System website).

To decrease chances of developing vascular disease:

- Don’t smoke (smoking damages blood vessels which increases risk of vascular dementia).
- Keep your blood pressure within recommended limits (the extra stress on blood vessels everywhere including your brain, increases risk of vascular issues in the brain).
- Keep cholesterol within recommended limits. Elevated limits of LDL or “bad” cholesterol increases risk of vascular dementia.
- Keep blood sugar within recommended limits (high glucose levels damage blood vessels and damage to blood vessels in the brain increase risk of stroke and vascular dementia).
- Eat a healthy diet
- Exercise.
- Maintain a healthy weight (obesity is a risk factor for vascular diseases and therefore increases risk for vascular dementia)
- Limit alcohol consumption

Cognition may improve slightly after a stroke during rehabilitation. Individuals who develop vascular dementia after a stroke survive approximately three more years. (Alzheimer’s Association website.)
SECTION 4

DEMENTIA WITH LEWY BODIES

Lewy Body Disease (named for Dr. Friederich Lewy) is a progressive disease affecting approximately 1.3 million individuals in the United States and accounts for up to 20% of people with dementia worldwide. Lewy bodies are abnormal clumps of a protein (alpha-synuclein) in the brain. These deposits form in the neurons (nerve cells) in the brain. The deposits cause neurons, especially at synapses (where brain cells communicate with each other) to work less effectively. When the brain changes as a result of these proteins, problems with thinking, behavior, movement or mood occur. Common mood changes may include depression or apathy, anxiety, agitation, paranoia, or delusions such as believing that a spouse is having an extramarital affair. There is currently no cure for this condition.

Symptoms of Lewy Body Disease (LBD) typically begin for individuals in their early 50’s and appear to affect more men than women. Early symptoms in this dementia are often confused with symptoms of Alzheimer’s disease. LBD can occur by itself or can occur with Alzheimer’s disease or Parkinson’s disease. Due to the similarity of symptoms of Alzheimer’s or Parkinson’s, Lewy Body dementia is often misdiagnosed. As the condition progresses, individuals have difficulty managing their activities of daily living and instrumental activities of daily living.

There are two types of LBD—dementia with Lewy bodies and Parkinson’s disease dementia. Though both are the result of the same biological changes in the brain, the initial signs are different.

Individuals with dementia with Lewy bodies develop cognitive problems within a year of parkinsonian movement problems. Visual hallucinations may occur in the early stage for up to 80% of individuals with LBD. Images of children or animals are common. Other common symptoms include:

- Fluctuations in thinking, attention and alertness
- Difficulty in movement—slowness, difficulty walking, and rigidity
- REM sleep behavior disorder wherein individuals physically act out their dreams. Also difficulty getting to sleep or excessive daytime sleepiness.
- Difficulty with complex thinking rather than memory problems

In Parkinson’s Disease dementia, movement symptoms (muscle stiffness, tremor, shuffling gait) are evident first. It takes years longer for the cognitive symptoms to appear.
Over time, individuals with either of these two dementias may develop similar symptoms, however, not all individuals with Parkinson’s Disease develop Parkinson’s disease dementia.

### Main Symptoms of Lewy Body Dementia

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Dementia with Lewy Bodies</th>
<th>Parkinson’s Disease Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>❖ Appears within a year of movement problems</td>
<td>❖ Appears later in the disease, after movement problems</td>
</tr>
<tr>
<td>Movement Problems (parkinsonism)</td>
<td>❖ Appear at the same time as or after dementia</td>
<td>❖ Appear before dementia</td>
</tr>
<tr>
<td>Fluctuating cognition, attention, alertness</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Visual hallucinations</td>
<td>❖</td>
<td>❖</td>
</tr>
<tr>
<td>REM sleep behavior disorder</td>
<td>✓ May develop years before other symptoms</td>
<td>✓ May develop years before other symptoms</td>
</tr>
<tr>
<td>Extreme sensitivity to antipsychotic medications</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Changes in personality and mood (depression, delusions, apathy)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Changes in autonomic (involuntary) nervous system (blood pressure, bladder and bowel control)</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

❖ Primary symptom  
✓ Common symptom  

(Lewy Body Dementia Association website, Diagnostic Criteria)
Management of Symptoms

One of the most effective approaches to managing symptoms is to work with a team of professionals, each with their own expertise, to coordinate their efforts to develop a comprehensive plan of care.

- A neurologist can prescribe medications which may help symptoms.
- Physical Therapy can help with strengthening and ambulation.
- Speech Therapists can provide assistance with swallowing difficulty and voice projection (voice tends to get soft and low).
- Occupational Therapists can provide tips on how to better complete activities of daily living.
- Counselors (from a mental health center or from a caregiver program) can help families learn to manage difficult emotions (such as depression, anxiety, etc.) and provide support and planning for the future.

Without coordinating their efforts, they may unknowingly be working at cross purposes. For example, knowing that physical therapy is scheduled for late afternoons may help the physician prescribe a more effective scheduling of medication use. Or, knowing the individual has greater difficulty in the late afternoon, physical therapy may be more advised in the morning. Increasing each professional’s awareness of the total plan of care and coordinating with each other significantly increases the odds of a positive outcome for the individual.
SECTION 5

FRONTOTEMPORAL DEMENTIA

Frontotemporal disorders affect the frontal and temporal lobes of the brain. The frontal lobes are located above the eyes and behind the forehead on the right and left sides of the brain. This area of the brain affects executive function (planning and sequencing, multi-tasking, monitoring and correcting errors). When there is damage or degeneration in these regions, the damage causes difficulty in thinking. Other symptoms such as unusual behaviors, difficulty with work or difficulty walking may result (NIH Publication, No. 14-6361 p. 2).

The temporal lobes are located below and to the side of the frontal lobes. Memory is contained in this area as well as having responsibility for language and emotions.

The cause of frontotemporal degeneration is not known in most cases, although 15 to 40 percent of people have genetic mutations in certain genes (Tau gene, PGRN gene, C9ORF72 gene, and VCP, CHMP2B, TARDBP and FUS genes). There is no cure for this progressive disease which can last up to 10 years. Approximately 60 percent of people with FTD are 45-64 years old. (NIH Publication, No. 14-6361, p. 2)

The three types of frontotemporal disorders are described in the chart on the next page. Note that symptoms may overlap within FTD as well as with other types of dementia. It is for this reason that a thorough evaluation be completed so that an accurate diagnosis can inform appropriate interventions.
### Types of Frontotemporal Disorders

<table>
<thead>
<tr>
<th>Diagnostic Terms</th>
<th>Main Early Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Progressive Behavior/Personality Decline</strong></td>
<td></td>
</tr>
<tr>
<td>• Behavioral variant Frontotemporal dementia (bvFTD)</td>
<td>• Apathy, reduced initiative</td>
</tr>
<tr>
<td>• Temporal/frontal variant FTD (tvFTD, fvFTD)</td>
<td>• Inappropriate and impulsive behaviors</td>
</tr>
<tr>
<td>• Pick’s disease</td>
<td>• Emotional flatness or excessive emotions</td>
</tr>
<tr>
<td></td>
<td>• Memory generally intact</td>
</tr>
<tr>
<td><strong>Progressive Language Decline</strong></td>
<td></td>
</tr>
<tr>
<td>• Primary progressive aphasia (PPA)</td>
<td>• Semantic PPA (also called semantic dementia) can’t understand words or recognize familiar people and objects</td>
</tr>
<tr>
<td>• Progressive nonfluent aphasia</td>
<td>• Agrammatic PPA (also called progressive nonfluent aphasia): omits words that link nouns and verbs (such as to, from, the)</td>
</tr>
<tr>
<td>• Semantic dementia</td>
<td>• Logopenic PPA: trouble finding the right words while speaking, hesitation, and/or pauses in speech</td>
</tr>
<tr>
<td><strong>Progressive Motor Decline</strong></td>
<td></td>
</tr>
<tr>
<td>• Corticobasal syndrome (CBS)</td>
<td>• Muscle rigidity</td>
</tr>
<tr>
<td></td>
<td>• Difficulty closing buttons, operating simple appliances; difficulty swallowing</td>
</tr>
<tr>
<td></td>
<td>• Language or spatial orientation problems</td>
</tr>
<tr>
<td>• Progressive supranuclear palsy (PSP)</td>
<td>• Progressive problems with balance and walking</td>
</tr>
<tr>
<td></td>
<td>• Slow movement, falling, body stiffness</td>
</tr>
<tr>
<td></td>
<td>• Restricted eye movements</td>
</tr>
<tr>
<td>• FTD with parkinsonism</td>
<td>• Movement problems similar to Parkinson’s disease, such as slowed movement and stiffness</td>
</tr>
<tr>
<td></td>
<td>• Changes in behavior or language</td>
</tr>
<tr>
<td>• FTD with amyotrophic lateral sclerosis (FTD-ALS)</td>
<td>• Combination of FTD and ALS (Lou Gehrig’s disease)</td>
</tr>
<tr>
<td></td>
<td>• Changes in behavior and/or language</td>
</tr>
<tr>
<td></td>
<td>• Muscle weakness and loss, fine jerks, wiggling in muscles</td>
</tr>
</tbody>
</table>

(NIH, Pub. No. 14-6361, Frontotemporal Disorders, p. 6)
SECTION 6

COMMUNICATION

Communication with an individual with dementia requires patience. Individuals may become frightened or embarrassed by their failure to communicate effectively. Show respect in your methods of communication and never assume that the individual cannot understand you.

*Keep in mind that the person is doing the best that they can.*

Some techniques for effective communication include:

- Identifying yourself if the individual does not recognize you or to avoid initial confusion, say your name before the individual feels they have to figure it out.
- Call the individual by his/her preferred name.
- Stand/sit in front of the person and maintain eye contact equal to their eye level if possible. Watch for nonverbal reactions particularly as related to how close or far away you are from the person.
- Use touch appropriately to reassure them and ask permission to touch first.
- Reduce environmental distractions, particularly extraneous noise or visual movement such as from a television, flickering lights, radio, nearby conversations, etc.
- Understand that the individual may prefer to talk about the past because those memories can be retrieved. Let the individual have some time to talk about the past to build rapport.
- Use empathy and validation
- Speak slowly and allow ample time for reply. Pose questions slowly, reduce distractions, and be sensitive to hearing or vision impairments.
- If you do not understand, ask the individual to show you.
- If the person has difficulty speaking, it is okay to ask questions for clarification but be sure to ask the individual if the “guess” was correct. Look for body language to affirm that you guessed correctly, (the individual nods their head or moves on in topic.)
- Be aware that disruptive behavior from the individual with dementia may just be their way of trying to communicate an unmet need.
- Use repetition. Phrase your message several different ways. Use the same words the individual has used previously as this indicates some understanding.
- Use several modes of input such as facial expressions, gestures, or pictures, in addition to verbal communication. Act out words, if possible. Be concrete. Abstract ideas like
hypothetical situations may confuse the individual. ("You look sad, can you show me what you are thinking about?" rather than “What is worrying you right now?” or “How do you feel?”)

- Use simple sentences with short words. Don’t elaborate. Ask yes or no questions.
- Avoid pronouns. Repeating the name of a person or thing may help them remember.
- Give instructions one step at a time.
- Limit choices.
- Let speech reflect sincerity. Do not speak in an overly enthusiastic voice as it may cause confusion.
- Try to pick out meaningful comments if the person’s speech is rambling or incoherent. Furnish missing words if you can.
- Respond to the person’s emotional needs. For instance, if a person seems anxious over the absence of a caregiver, do not get in to a lengthy explanation about their absence and don’t use “therapeutic fibbing”. Not all individuals with dementia have memory loss and may not trust you if you “fib”. If the individual with dementia is looking for or worried about their little children, focus on the individual’s strengths as a mother rather than telling them that her children are in school and okay.
- Do not argue with the individual. Stop and let the person relax if s/he becomes very agitated or aggressive. Wait awhile and try to communicate again.
- Use common sense and try to maintain a sense of humor.
- Most importantly….try to make the interaction a pleasant experience.
Plans of care should be “person centered”, keeping the person with dementia as the focal point. The plan of care should honor the values and preferences of the person with dementia while addressing safety factors as the symptoms become more severe. The professional developing the plan of care must keep in mind that the person with dementia can help in the decision making process well into the disease.

“Person-centered care emphasizes the importance of not just diagnoses and physical and medical needs, but of social, mental, emotional, and spiritual needs as well. Components of person-centered and directed care include respecting personhood, striving to maintain personhood in spite of declining cognitive ability, treating people as individuals, seeing the world from the perspective of the person with dementia,” (Lines, p. 5).

Services should not be imposed on an individual or their family even though the need for a service is apparent. The individual/family must understand they have the right to accept or reject any or all parts of the plan. It is crucial to include the individual’s family in the planning process because the family will have an active role in the plan and will need support and/or respite. Individuals with dementia usually have preference for family members to complete all of the tasks that s/he needs. Offer support to the family member by discussing the need for additional assistance in the home.

When family members do not exist or are unavailable, the individual with dementia may still be supported at home. Services should be evaluated routinely as the person with dementia becomes more impaired. The care coordinator would also play a greater role to monitor the situation for changes and reassess the on-going safety of the plan of care. Consultations with a supervisor, the primary physician, the Alzheimer’s Association or the regional testing site are all critical to gain a fuller perspective and identify other care options.

At some point, a nursing home may become necessary for both the safety of the individual with dementia and for an overwhelmed caregiver. Up until that point, supportive services can keep individuals with dementia at home as long as possible. For the individual with dementia, usually a combination of family, informal supports, and formal services are needed in the plan of care.
Care Coordinators or Case Managers from Care Coordination Units, Managed Care Organizations, Supportive and Assisted Living Facilities, or located in home care agencies, along with Adult Protective Service Case Workers often serve as the eyes and ears for physicians and for long-distance caregivers. As a result of the information gathered in the completion of a comprehensive assessment, appropriate services can be implemented. A Care Coordinator can assist the individual and family to:

1.) Increase or maintain the independence of the individual with dementia as long as possible.
2.) Facilitate the least restrictive environment by securing supports and coordinating care plans.
3.) Defend the individual’s rights by being an advocate.
4.) Support families so that services supplement and extend their care.
5.) Assure that services are at an appropriate level and accomplish the plan of care.

Continuum of Care

A continuum of services and treatment interventions are available to assist individuals with dementia. Check the Illinois Department on Aging website (in Resource Section) to find the Aging and Disability Resource Center in your geographic area. Also listed are Care Coordination Units who can complete a comprehensive needs assessment and work with the person with dementia and their family to jointly develop a plan of care. Broad categories of supportive services include home care, legal and financial assistance, various types of socialization including adult day services, caregiver programs, and environmental evaluations.

When the person with dementia needs more support and supervision than can be provided in the home setting, but are not ready for long term care, assisted living facilities and supportive living facilities (assisted living facilities that will accept Medicaid payment) are an excellent option. Check with the individual facility to determine if they provide care to individuals with dementia.

Medication: There are medicines that can treat the symptoms of Alzheimer’s disease but there is no cure. Most of these medicines work best for individual in the early or middle stages of the disease. They may keep memory loss from getting worse for a time.

One should use much precaution before deciding to use medication to address undesirable behaviors. Older adults metabolize drugs differently than when they were young which leads to unpredictable side effects and possible mismanagement of medications. A mild dose may cause exaggerated side effects such as drowsiness or agitation. It is especially difficult to
determine the appropriate drug or the proper dosage with an individual with AD. It takes careful monitoring to find something that will achieve and maintain the desired results.

Caregivers may seek out medication to reduce catastrophic reactions, combative behavior, and sleep disturbances; however, medication becomes dangerous when it is used only for the convenience of the caregiver. In an attempt to gain relief from the behavior, the caregiver may overdose the individual leaving them in a haze. They become “easier to manage” for the caregiver but this can produce potential health and safety hazards for the individual.

Environmental Adjustments
The more impaired the individual with Alzheimer’s disease or another dementia becomes, the greater their chances of having an accident or being injured in an unsafe environment. Since individuals with AD or another dementia are not responsible for their actions, it is up to the individual who is caring for them to make the environment as safe as possible.

Three important principles are: keep the environment SIMPLE, UNCLUTTERED, and UNCHANGED. Further modification may be necessary as the individual’s condition worsens. Work with the family and provider agencies to accomplish a safe environment.
Caring for an individual with dementia may make the caregiver feel good because they are providing love and comfort. At times, the amount of care may become overwhelming and it’s important for those in the aging and disability network to provide the caregiver with the resources that can help reduce stress. The well-being of the caregiver correlates to the well-being of the care receiver.

Caregivers may experience feelings of guilt, anger, frustration, and/or depression in their role. Learning more about the disease and progression can be empowering for the caregiver to reduce the fear of the unknown.

Encourage the caregiver to take care of themselves first so they can care for the care receiver. By accepting help from family members, friends or formal support services on a regular basis, caregivers can receive enough of a break to keep them going in their caregiving journey. Caring for self also includes maintaining healthy practices such as exercising and eating nutritious meals. Getting sufficient sleep is essential, particularly for those whose care receiver is up in the night with disrupted sleep cycles. Encourage caregivers to sleep when the care receiver sleeps.

Maintaining a sense of humor can reduce stress not only for the caregiver but in turn can help with the mood of the person with dementia. Keeping a consistent routine for the person with dementia can reduce agitation. Encourage the caregiver to seek support through Caregiver Support Programs offered through Area Agencies on Aging (See Resource Section), mental health providers, or support groups offered through adult day centers, hospitals, or the Alzheimer’s Association.

For those individuals who develop early onset dementia, there is a process to obtain Social Security Disability Insurance (SSDI) benefits in a faster manner:
Compassionate Allowances
Historically, persons with young-onset dementia have had a very arduous and lengthy SSDI application process with multiple denials and appeals. The Social Security Administration (SSA) rolled out its Compassionate Allowances program in an effort to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards. Due to successful advocacy efforts by the Association for Frontotemporal Dementias, in March 2009, Frontotemporal Dementia was one of the first fifty conditions named in SSA’s Compassionate Allowances List. With the support of the Alzheimer’s Association, early onset Alzheimer’s Disease and Primary Progressive Aphasia were two of the 38 conditions subsequently added in 2010 (Social Security Administration, 2010). Other dementias included in the Compassionate Allowances Program now include: Adult Onset Huntington Disease, Creutzfeldt - Jakob disease, Lewy Body Dementia, Mixed Dementias, Progressive Supranuclear Palsy, The ALS/Parkinsonism Dementia.

Call the Social Security Administration at 1-800-722-1213 or see www.ssa.gov/compassionateallowances for more information and a list of other conditions covered through Compassionate Allowances.

Planning for the future becomes even more important for the caregiver who is caring for a person with dementia. Assuring that a Durable Power of Attorney is in place before the person with dementia is incapable of making decisions is critical as well as providing information about Prevention of Spousal Impoverishment guidelines. Professionals in the aging and disability network, can also help provide other planning information: local elder law attorneys, local legal aid agency, and the Social Security Administration. The Illinois Department on Aging website can also provide the names of specific agencies in a specific geographic location.
SECTION 9

RESOURCES/LINKS

Alzheimer’s Association
    National www.alz.org
    Central Illinois Chapter www.alz.org/illinoiscentral
    Greater Illinois Chapter www.alz.org/illinois
    Greater Iowa Chapter www.alz.org/greateriowa
    St. Louis Chapter www.alz.org/stl

Alzheimer’s Reading Room www.alzheimersreadingroom.com

Alzheimer’s Disease Assistance Centers
    Northwestern University Feinberg School of Medicine—
    Cognitive Neurology & Alzheimer’s Disease Center www.brain.northwestern.edu

    Rush University Medical Center—
    Rush Alzheimer’s Disease Center www.rush.edu/radc

    Southern Illinois University School of Medicine—
    Center for Alzheimer’s Disease & Related Disorders www.siumed.edu/alz

Alzheimer’s Disease Education and Referral Center (ADEAR)
    www.nia.nih.gov/age...s

Aging Network:
Illinois Department on Aging www.state.il.us/aging
    Area Agencies on Aging
    Aging & Disability Resource Centers
    Care Coordination Units

Administration on Aging www.aoa.gov

American Society on Aging www.asaging.org

Association for Frontotemporal Degeneration www.theaftd.org
Eldercare Locator  www.eldercare.gov

Healthy Brain Initiative:

Huntington’s Disease Society of America  www.hdsa.org

Lewy Body Disease Association  www.lbda.org

Memory Bridge  www.memorybridge.org

National Stroke Association  www.stroke.org

Terra Nova Films  www.terranova.org

**Caregiver Resources:**

AARP  www.aarp.org/families

Association for Frontotemporal Degeneration Support Groups
www.theaftd.org/support-resources/finding-support/caregiver-support-groups

Family Caregiver Alliance  www.caregiver.org

National Caregiver’s Library  www.caregiverslibrary.org

National Family Caregiver Association  www.thefamilycaregiver.org

Safe Return  www.alz.org/SafeReturn
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Mayo Clinic Health Systems, www.mayoclinic.org/diseases-conditions


National Institutes of Health:
NIH Publication No. 11-5441, June 2011, Understanding Alzheimer’s Disease
NIH Publication No. 13-7907, September 2013, Lewy Body Dementia
NIH Publication No. 14-6361, June 2014, Frontotemporal Disorders


RTI International, The Alzheimer’s Voice: Person-Centered and Person-Directed Dementia Care, RTI Project Number 0212050.035.000.001.001. September 2014.