

# Understanding Dementia: A Clinician's Overview

By PHILIP McCALLION, PhD, ACSW

**D**ementia is an overall term for a number of diseases, including Alzheimer's disease, the most common type. Alzheimer's accounts for an estimated 60 to 80 percent of dementia cases, and the numbers continue to increase. A 2013 estimate counts about 5 million people age 65 and older, and another 200,000 individuals under age 65, with Alzheimer's disease.

People with diagnosed or diagnosable dementia have memory, thinking and behavioral symptoms that impair their ability to function in daily life. As the disease progresses, these individuals are increasingly unable to live independently or to manage their affairs — including their health care. Though researchers are striving to better understand causes of dementias, accurately diagnose them as early as possible and develop effective treatment plans, the number of affected individuals already is large and will increase as the population ages.

Realistically speaking, the challenge for health service providers is to develop a stage-based approach to treatment, target services to needs and prepare the means to connect people with dementia-capable services.

## ALZHEIMER'S DISEASE

Physiologically, individuals with Alzheimer's develop hallmark brain abnormalities of deposits of the protein fragment beta-amyloid (also called plaques) and twisted strands of the protein tau (also called tangles), as well as evidence of nerve cell damage and

ongoing death in the brain.

Common symptoms are difficulty remembering names and recent events, apathy and depression. Over time, there are more pronounced symptoms of impaired judgment, disorientation, confusion, behavioral changes, difficulty speaking, swallowing and walking, and difficulty in adjusting to changes in routines.

There is a lot of ongoing research into the causes of Alzheimer's disease, focusing on understanding the gene that produces a protein believed to be influential in the formation of plaques, investigating oxidative damage that may occur from free radical

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molecules and studying the contributions of amino acids and inflammation. To gather clues about possible causes, researchers have assembled groups of people for long-term studies of their characteristics, lifestyles and disease rates. The researchers survey the participants annually regarding their physical and mental status, and the participants agree to donate their brains for study at autopsy.

Researchers also are working to develop new treatments, including drugs to treat symptoms, vaccines and preventive measures, though it is still too early to judge the results.

## OTHER DEMENTIAS

Though Alzheimer's disease is by far the most common, there are a number of other types of dementia with different causes and often with a different sequence of symptoms.

**Vascular dementia**, called multi-infarct or post-stroke dementia, is the second most common dementia. Here, impaired judgment or inability to make plans is more likely the initial symptom, as opposed to memory problems. Communication difficulties are common. Vascular dementia appears to occur because of brain injuries such as microscopic bleeding and blood vessel blockage; the location of the brain injury determines how it affects the individual's thinking and physical func-



tioning. Vascular dementia often coexists with Alzheimer's disease. When any two or more types of dementia are present at the same time, the individual is considered to have "mixed dementia."

**Dementia with Lewy Bodies**, also called DLB, has some symptoms in common with Alzheimer's, but initial or early symptoms are more likely to be sleep disturbances, well-formed visual hallucinations, increased personal care needs and muscle rigidity or other Parkinsonian movement features. Lewy Bodies are abnormal aggregations or clumps of the protein alpha-synuclein, and when they develop in the cortex of the brain, dementia can result. Alpha-synuclein also aggregates in the brains of people with Parkinson's disease, but it has a different pattern. The brain changes of DLB alone can cause dementia, but DLB can occur at the same time as brain changes of Alzheimer's disease and/or vascular dementia.

**Frontotemporal lobar degeneration** or FTL D involves a group of dementias. Among them, a rare but very concerning form called behavior variant dementia generally develops at a younger age — about age 60 — than Alzheimer's, and individuals typically have a shorter survival span. Symptoms include changes in personality and behavior and difficulty with language. Nerve cells in the front and side regions of the brain are especially affected, but there is no distinguishing abnormality in all cases. Also, brain changes of behavioral variant FTL D may be present at the same time as the brain changes of Alzheimer's.

**Parkinson's disease** occurs about one-tenth as often as Alzheimer's, but advocacy by public figures such as Michael J. Fox has increased public awareness. Problems with movement often are an early symptom, and the disorder can impair memory, coordination and cause behavior changes. Compared to Alzheimer's disease, symptoms often occur in reverse order, but as Parkinson's disease symptoms progress, they may result in a severe dementia similar to DLB or Alzheimer's.

**Creutzfeldt-Jakob disease** is a rare, rapidly fatal brain disorder. According to the National Institutes of Health, it is one of a family of diseases in humans and animals in which an infectious misfolded protein (prion) appears to cause other proteins throughout the brain also to misfold and malfunction. A form of it is known to be

related to mad cow disease, which has received considerable media attention. Early Creutzfeldt-Jakob symptoms include impaired memory, thinking and judgment, personality changes and difficulties with muscular coordination. As the disease progresses, mental deterioration becomes pronounced.

**Korsakoff syndrome** is not overly common, but it also belongs on the list of dementias. The syndrome is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1), most commonly caused by alcohol misuse. Poor nutrition also may raise risk. Common symptoms are problems learning new information, inability to remember recent events and long-term memory gaps. Memory problems may be strikingly severe while other thinking and social skills are relatively unaffected. Unlike many other dementias where cure is not yet possible, with treatment, about 25 percent of those who develop Korsakoff syndrome eventually recover; about half improve but don't recover completely; and about 25 percent remain unchanged.

Differentiating the type of disease often helps caregivers to better understand the progression and may suggest more effective and sensitive approaches to symptom management. However the majority of dementia cases appear to be

## ALZHEIMER'S DISEASE WARNING SIGNS

There is a growing concern that Alzheimer's disease is not being recognized and responded to early enough. The Alzheimer's Association and others highlight these 10 warning signs:

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work or at leisure
- Confusion with time and place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

Alzheimer's disease, or occur with Alzheimer's.

It is an increasing concern that Alzheimer's may occur earlier than once thought. Research has found measurable changes in the brain, cerebrospinal fluid and/or blood (biomarkers) that indicate the earliest signs of disease, even when there are no developed symptoms such as memory loss. These findings reflect current thinking that Alzheimer's-related brain changes may begin 20 years or more before symptoms occur. This is sometimes referred to as preclinical Alzheimer's disease, but there are no established diagnostic criteria for such a preclinical stage.

More established are criteria for mild cognitive impairment. Such individuals have mild but measurable changes in thinking abilities that are noticeable to the person affected and to family and friends. Symptoms usually do not affect the individual's abil-

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ity to carry out everyday activities. Further cognitive decline is more likely among individuals whose mild cognitive impairment involves memory problems.

### **PROVIDERS BECOMING DEMENTIA CAPABLE**

The Administration for Community Living, a federal agency created by the U.S. Department of Health and Human Services, recommends that all service providers and community and government agencies focus on becoming dementia capable, which includes the ability to:

- Identify those with a possible dementia and have procedures and expectations for staff to recommend follow-up with a physician.
- Train staff members who interact with people with dementia on effective communication and on the unique needs and services available for such people.
- Provide quality, person-centered services that help people with dementia remain independent and safe in their communities.
- Involve family caregivers when they are available and it is appropriate, such as when the person agrees to their help, or seems unable to manage the

information being shared.

- Provide linkages to other organizations that can help or provide the services that people with dementia and their caregivers need and want.

### **A STAGE-BASED APPROACH**

Dementia capability is also about the delivery of services and approaches to care that begin with an understanding of dementia's progression.

**Early stage:** The person becomes aware that she is not thinking and remembering as she did in the past. Yet people are often pretty good at covering up gaps and lapses in memory. Family members and others may see lapses once in a while, but will likely attribute it to having a bad day or to the normal memory changes in aging. However, the ability to manage day-to-day life is affected. A formerly neat person may become messy. Hobbies previously enjoyed may be abandoned. Concerns also may arise regarding driving, living alone and managing medications. This stage may last from two to four years or longer.

**Middle stage:** Memory lapses and confusion become more obvious, and the person can no longer hide memory gaps from family and friends. Short-term memory is very impaired and the person tends to ask a lot of repetitive questions and be anxious about when events are happening. Ability to manage day-to-day life is more greatly affected. The person may withdraw socially, finding group situations uncomfortable. This is also the stage where there may be restlessness, often in the evening hours, which is called sundowning; and individuals may be emotionally changeable, cycling quickly between being happy and sad. There may also be increased incidences of wandering, which is often difficult for caregivers to manage and can present serious safety concerns. Assistance with day-to-day care and access to respite and day programs are frequent needs in this stage. The stage may last two to 10 years or longer.

**Severe stage:** Dementia symptoms are even more advanced. Individuals can't recognize family or friends, have little capacity for self-care and can't communicate with words. There often is progressive loss of bladder and bowel control and difficulties with swallowing. There also may be seizures and an increase in infections, and, with increased immobility, skin breakdown may occur. Persons with severe-



stage dementia need to be connected with increased levels of supports, and their caregivers are likely to need supports too. This stage may last one to three years.

### DEMENTIA-CAPABLE APPROACHES

In the care and service arena, dementia capability is about building capacity for proactive approaches to management of such stage-based symptoms. Critical issues include person-centered care, communication strategies, enjoyed activities, palliative care, medication management and caregiver support.

**Person-centered care:** In supporting care of persons with Alzheimer's disease and other dementias, programming and responses should be tailored to each person. Alzheimer's disease robs people of their personalities and individuality, and care response must reinforce and maintain recognition of that individuality. Person-centered care is an individualized process that responds to an individual's personal goals, preferences, desires and needs. It recognizes that each individual has strengths and the ability to determine personal goals, express preferences and make choices, and it works to ensure that an individual's choices and preferences are honored and considered. Person-centered care also importantly recognizes and values a person's cultural background in the planning process and beyond.

**Communication:** Both staff and family caregivers need help in how best to communicate with a person with Alzheimer's disease. As dementia progresses, communication becomes harder, but it is still possible. Here are some tips:

- Speak to a person with dementia only when you are visible; be sure you are in his or her line of sight
- When speaking, use the person's name and identify yourself with your name
- Avoid asking questions like "Do you know who I am?"
- When talking, also use overemphasis, gestures, facial expressions and pointing to familiar objects to give more clues and to visually illustrate what you mean
- Try to make sure that you have been understood
- Always wait for the person with dementia to respond to anything you say or ask
- Validate, don't deny or minimize feelings

**Valued Activities:** Caregivers will find that life for the person with dementia — and for the caregivers — is less stressful when they focus on the activities the

individual values. People with dementia retain the capacity to enjoy life, and short time periods should be set aside each day for activities they enjoy. These activities are important; caregivers need to ensure that phone calls, appointments and the chores of care don't interrupt them. A good approach is to have a menu of things to choose from that the person enjoys doing. The Alzheimer's Association ([www.alz.org](http://www.alz.org)) has a long list of suggestions for caregivers seeking activities for people with Alzheimer's.

**Palliative Care:** Alzheimer's disease and other dementias ultimately are terminal conditions. Dementia care should incorporate and plan for a palliative care approach at the time the disease reaches the late stage. Advance care planning should be encouraged; it should be guided by the person, his or her family or proxy where appropriate. An important step is to review the living will and health care proxy designations. Whether care is at home or in a hospice program, plans for support are needed for all aspects of the person's final days and for the support of family, friends and caregivers.

**Medication:** A number of medications have been developed for use in managing Alzheimer's disease symptoms, and approved available medications may address different stages of dementia. People with dementia — and their caregivers — should consult the individual's physician about all medication use. Caregivers in particular should understand what to watch for in terms of potential side effects.

**PHILIP McCALLION** is co-director of the Center for Excellence in Aging & Community Wellness at the University at Albany, part of the State University of New York system. He is a distinguished professor in the university's School of Social Welfare.

### RESOURCES FOR CAREGIVER SUPPORT

Quality care is enhanced when caregivers (staff or family) feel supported and valued. These resources may help:

[www.alz.org/care/overview.asp](http://www.alz.org/care/overview.asp)

Caregiving Tip Sheets and Resource List — [www.nia.nih.gov/alzheimers/topics/caregiving#pubs](http://www.nia.nih.gov/alzheimers/topics/caregiving#pubs)

The latest research information — [www.nia.nih.gov/alzheimers/](http://www.nia.nih.gov/alzheimers/)

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