

# Mapping a Better Care Plan for Dementia Patients and Their Families

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**W**hile age is not synonymous with dementia, dementia is more common in those 75 and older. The Centers for Disease Control and Prevention reports there are more than 6 million Americans living with dementia, and it affects more women largely due to their longer lifespan.<sup>1</sup> The symptoms of dementia affect people's memory, thinking and social abilities, and greatly interfere with their daily lives. Dementia-related illnesses can dramatically change and shorten the lives of patients and negatively affect their families and communities.

Alzheimer's is the most common manifestation of dementia. People often think that Alzheimer's disease, a degenerative brain disease, is a synonym for dementia. It is not. Several diseases cause dementia. Among them are Lewy body dementia, often associated with parkinsonism, vascular dementia, frontotemporal dementia and Huntington's disease.<sup>2</sup> Although each disease has its unique pattern, all dementias are characterized by loss of cognitive functions and the ability to carry out activities of independent living. People can also have more than one disease that causes dementia, which is known as mixed dementia.

Because of the complex manifestations of dementia, it is not easy to recognize or diagnose, especially in its early stages. Although no single test can diagnose dementia, there are tools, resources and educational materials available to help providers recognize it, along with supportive services and recommended plans of action they can encourage patients and their families to follow. There is a growing understanding of the pre-clinical phase of dementia, and the importance of early detection, but one key step for many care providers is understanding and recognizing chronic

illnesses that include dementia symptoms.

## Alzheimer's Disease

Scientists know that signs of Alzheimer's disease are present in the brain years before symptoms appear. The early presence of plaques and the ability to detect their presence drives the search for drugs that may delay the onset of active disease. There are also patterns that alert health care providers that their patients may be displaying symptoms or comorbidities associated with Alzheimer's disease. These symptoms alert providers that a self-amplifying inflammatory response may be damaging the central cortex.<sup>3</sup>

## Lewy Body Dementia

The third most prevalent type of dementia, Lewy body dementia, is difficult to diagnose<sup>4</sup> because its symptoms overlap with Alzheimer's and other mental illnesses.<sup>5</sup> Men ages 60 and older are most at risk for Lewy body dementia.<sup>6</sup> People with Lewy body dementia have memory loss and diminished visual-spatial awareness. Difficulty in moving is an early symptom of the illness; memory problems appear later.



Parkinson's disease dementia, a subtype of Lewy body dementia, while easier to diagnosis, is more difficult to treat than Lewy body disease because medicines to treat parkinsonism — for example, carbidopa-levodopa — cause confusion.<sup>7</sup> Movement disorders constitute the main difference between Lewy body dementia and Alzheimer's. Difficulty moving appears early in Lewy body disease, while memory problems develop later; however, it may not cause short-term memory loss.

People with Alzheimer's or Lewy body dementia have trouble thinking, being alert and paying attention. In Lewy body disease, these symptoms come and go. Hallucinations may also be present among people with it early in the illness, unlike those with Alzheimer's who do not hallucinate until the later stages of the disease. While there is no cure for Lewy body dementia, its symptoms can be managed.

#### Vascular Dementia

Vascular dementia, or multi-infarct dementia, is the second most common cause of dementia. It typically affects people between the ages of 55 and 75.<sup>8</sup> Slightly more men than women have this condition. Those affected have mini-strokes, which block small blood vessels in the brain and injure cortical cells. As more cerebral vessels are damaged, symptoms of dementia appear. Risk factors for it include diabetes, atherosclerosis, hypertension, smoking and previous strokes.

#### Frontotemporal Dementia

Frontotemporal dementia is an umbrella term for a group of brain diseases that mainly affect the frontal and temporal lobes of the brain. In frontotemporal dementia, parts of the frontal and temporal brain areas atrophy. Symptoms of this disease depend on the part of the brain that is most affected. Some people with it have personality changes, and become socially inappropriate, impulsive or emotionally unstable. Others lose

their ability to use language.

Often diagnosed in people between the ages of 40 and 65, it causes 10% to 20% of dementias,<sup>9</sup> and is often misdiagnosed as Alzheimer's disease.

#### Huntington's Disease

Huntington's disease, a rare genetic disease, destroys neurons in the brain affecting a person's thinking ability, planning and the person's ability to focus on what is being said. People with this condition have uncontrolled and inappropriate movements and symptoms of mental disease.

Huntington's disease has an early onset, and often people with the disease show symptoms in their early 30s or 40s. When the disease develops before age 20, the condition is called juvenile Huntington's disease. Huntington's disease causes perseveration, lack of impulse control and changes in sexual drive, including hypersexuality for some, and lack of awareness of behavior. It is as if they no longer know themselves. Patients may be slow to process thoughts, find words or learn new information.

Movement disorders associated with Huntington's disease include chorea and other involuntary movements that affect the muscles, specifically those in the arms, legs, face and tongue. It also causes muscle rigidity and contracture. Huntington's disease patients have difficulty in speaking, swallowing, walking or maintaining posture and balance.

People with Huntington's disease may not be able to control voluntary movements. Many with this condition are unable to work, perform daily activities, communicate with others or live independently. They may be depressed, irritable and withdrawn. They may have concerns that they passed the gene that causes the disease to their children before they had a diagnosis. They sleep poorly and feel tired. The depression seen in persons with Huntington's disease is thought to be related to brain atrophy rather than mental illness. As the disease progresses, the person loses weight.

### An Aging Population

The U.S. Census Department reports that the number of Americans aged 65 and older is projected to increase from 58 million in 2022 to 82 million by 2050, which means their share of the population is projected to increase from 17% to 23% by 2050.

Source: <https://www.prb.org/resources/fact-sheet-aging-in-the-united-states/>

### Mixed Dementia

When a person has more than one disease causing dementia, it is known as mixed dementia. Symptoms may be similar to or indistinguishable from single diseases. While it is estimated that more than 50% of those with dementia have coexisting pathology, only a small percentage of patients get dually diagnosed.<sup>10</sup>

### WAYS TO ASSIST

Health professionals should help patients and families find supportive, community-based services. Initially, most families opt to keep their loved ones at home.

As people with dementia spend a lot of time in the house, their homes should be attractive and safe. Their family may decide to move into a one-story home with accessible bathrooms, if possible. Ideally, there should be a nice view from the porch and windows.

Most older people want to stay in their own homes. If their spouses are living, they want to live together. Often, children or relatives no longer live down the street. For those who remain in their own residences, homes need to be assessed for safety. Visiting nurses are skilled at these assessments, and their suggestions may be received better than those offered by children or other relatives.

However, it is very difficult to care for a person 24 hours a day, seven days a week, especially if the person is awake at night, wanders or engages in unsafe or combative behaviors. The decision to place a parent, spouse or loved one in a nursing home or memory care unit is very difficult. It may be one of the most difficult decisions that a family makes.

There are many programs supporting home care that can improve the lives and well-being of the person with dementia and ease the burden on families: Meals on Wheels, congregate eating centers, senior centers, senior day care, home health care, personal attendants and audiobooks or podcasts. People with dementia should exercise regularly to maintain their mobility and improve their safety. They should be encouraged to participate in organizations and clubs. If they live in senior

apartment complexes, they should aim to attend the facility's programs. Activity and engagement with people and other pastimes prevent loneliness and may help delay the progression of dementia.<sup>11</sup>

Because the rate of progression of the disease is not predictable, families need to be attentive to their loved one's safety, rest, nutrition, skin care, infection and pain management. As the disease progresses, those with dementia need care 24 hours a day. Health care providers can alert families to the resources in the community to assist patients and families to manage dementia.

Because early manifestations of dementia may not be obvious, and its symptoms such as forgetfulness, losing objects, like cell phones or car keys, or getting lost can initially seem like absent-mindedness or routine aging, it is important to determine the diagnosis early. Persons with signs of

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dementia should have comprehensive neurological examinations, such as cognitive assessments and CAT and PET scans which can reveal amyloid plaques. A new blood test that measures the level of amyloid in the blood is about 90% effective in identifying Alzheimer's disease.<sup>12</sup>

Complete physical exams are important to distinguish routine aging from dementia symptoms. Identifying ways to lessen symptoms can improve quality of life and may even slow disease progression. Consider factors that may make it harder for people to communicate or to voice their concerns. For example, people with dementia should have eye and hearing tests. Cataract surgery, hearing aids and walkers can significantly improve their lives. These aids are important because loss of vision and hearing and a lack of physical activity increases dementia risk and, as of today, there is no medicine to cure any of the diseases causing dementia.<sup>13</sup> Of critical importance is the identification of the type of dementia for developing a care plan.

Home care nurses can help caregivers and



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families as the condition of the patient changes with finding others to assist with food procurement and preparation, cleaning, laundry and patient care. If or when care becomes overwhelming, nurses can help families select a memory care unit or another long-term care setting.

### **MEDICAL AND NURSING MANAGEMENT**

Health care professionals can encourage conversation about the impact that dementia has on patients and families. Many people want to deny early signs of dementia. They are unwilling to talk about it or seek help until the disease can no longer be denied. Nurses and others can encourage patients and families to become familiar with research.

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Catholic health systems can also invite state and federal lawmakers to tour their memory care units and encourage them to support funding for dementia research. Health care providers can work with professional and other organizations, like dementia associations; medical, nursing and social work organizations; and AARP. Families of persons with dementia can advocate members of Congress and the pharmaceutical industry to fund research and support clinical trials of drugs to manage dementia. It is also important for families and the public to learn to identify early signs of dementia.

Patients with dementia and their families need a plan of care. This includes the person with dementia making plans for a will. They also need to name a person with durable power of attorney. The patient and his or her family must talk about what they want as their disease progresses and what they want to happen at the end of their lives. These conversations are hard, but they may reduce family conflict and guilt.

Catholic health care can offer those with dementia spiritual care and support. A diagnosis of dementia may allow a person to address symptoms, settle their affairs and prepare for their end of life and death. Through spiritual care, patients can spiritually and emotionally close any unresolved matters, providing them with a sense of peace and comfort.

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### **NOTES**

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