

alzheimer's association®

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Alzheimer's Atlas

Mapping and Navigating the Course of the Disease.

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Striving to know what lies ahead is a human characteristic that helps ensure we are adequately prepared for our future. It is a fundamental tendency to want to know the next turn or the next step. After we learn that a loved one has dementia, it is only natural to research the disease to better understand what can be expected and when to expect it. This helpful knowledge guides the caregivers in identifying how best to work with the behaviors associated with the progression of the disease.

Living with dementia is painful and confusing for all. You will find your loved one developing behaviors not necessarily typical of his/her normal personality—sometimes aggressive, or confused, disoriented or withdrawn. By mapping the route of key symptoms and behaviors that characterize the progression of the disease, one can have a better idea of how to support the patient. This awareness may contribute to a better quality of life for both the caregiver and the person living with dementia.

There are many diseases that can cause dementia and memory loss. Alzheimer's dementia, vascular dementia, Lewy Body, and frontotemporal dementia (FTD) all impact daily living through memory loss or other cognitive changes and usually increase slowly over time. It is important to note that *not* everyone living with dementia will experience the same symptoms or progress at the same rate. Dementia progresses from mild forgetfulness to widespread brain impairment. While there is not yet a cure, understanding the progression of these diseases may enhance the quality of an afflicted one's life.

In the early 1990s the New York University School of Medicine proposed a system to divide Alzheimer's disease into stages, starting with no symptoms at early onset to more severe symptoms as the disease progresses. *The*



purpose of identifying stages in the disease is to make sense of what may seem chaotic. Mapping the course of the disease informs caregivers so they can address symptoms, behaviors, and medical issues as they arise.

Early stage dementia is when problems with memory, thinking, and concentration may first become apparent. Gentle prompts and guidance from family members during social situations may prove helpful for the person with dementia. Medical issues related to dementia are not obvious to the treating physician at this time and often go unnoticed.

As the abilities and behaviors of the person with the disease change, in addition to normal age-related decline, the earliest signs of cognitive impairment may surface. Although a little bit of forgetfulness could be due to natural aging, there may be a tendency for a person with dementia to overly assist oneself with reminding clues like note taking. In addition, as a caregiver you may notice your loved one forgetting familiar words or names, misplacing keys, eyeglasses, or other everyday objects. This may be a good time to chat with a doctor, however, before doing this take some time to learn more about the 10 warning signs so that you can be specific when sharing your concerns.

Tips

While Navigating:

Keep the person's skills and abilities in mind.

A person with dementia may still be able to play simple songs on the piano. Bring these types of skills into daily activities.

Pay special attention to what the person enjoys.

Take note when the person seems happy, anxious, distracted or irritable.

Be aware of physical problems.

Does he or she get tired quickly or have difficulty seeing, hearing or performing simple movements?

Focus on enjoyment, not achievement.

Find activities that build on remaining skills and talents.

Encourage involvement in daily life.

Activities that help the individual feel like a valued part of the household.

Relate to past work life.

A former office worker might enjoy activities that involve organizing, like putting coins in a holder or making a to-do list.

Continued from previous page

In addition to memory loss—the hallmark of dementia—families may notice a range of additional symptoms. These may show up as performance issues in social or work settings, such as repeating questions or re-telling stories, difficulty in remembering names when introduced to new people, and difficulty with concentration. It may be time to arrange for a general physical exam and perhaps see a qualified neuropsychologist that has experience with diagnosing dementia. Be sure to schedule any and all of the tests suggested by this expert and follow through with all appointments

As the disease progresses, different regions of the brain will be affected and altered in various ways. Damage to the brain can make it difficult to perform more complete tasks, such as planning dinner for guests, paying bills, and remembering recent occasions. Your loved one may lose interest in activities, hobbies, and social gatherings. When this occurs, start simplifying and try to provide increased assistance with memory, organization, and socialization. Be clear with the doctor about how well the person performed various tasks that have now become difficult. Your doctor is likely to prescribe medication for memory and apathy.

People with dementia may gradually lose the ability to recall their own address or phone number and become confused about where they are or what day it is. They no longer recognize familiar faces, and perhaps not even their own. Caregivers will notice that some assistance with day-to-day living is now *essential*.

In the **middle stage** of dementia significant personality changes can emerge; the once calm person is suddenly combative, volatile, and possibly violent at times; loved ones

become inventive to outwit a caregiver. Safety issues arise for those who are still driving, and also for those prone to wandering—keeping them safe can be a constant challenge. A caregiver may witness increased paranoid or suspicious behavior. Hallucinations are not uncommon and compulsive behaviors (such as hand wringing or tissue shredding) may appear. Personal assistance with daily activities such as needing

help with meals, toileting, and personal hygiene may become necessary. It is at this time that doctors will rely heavily on information from *the caregiver* during medical examinations.

During the **final stage** of the disease the patient will lose the ability to speak and control movement. Your loved one will need help with eating and toileting. Reflexes become abnormal, swallowing is impaired, and families may become frantic when their loved one refuses to eat. Sometimes the body does not want food because the organs are shutting down. Your loved one will need 24/7 extensive assistance with all activities of living. Your doctor may recommend professional nursing care and hospice assistance.

Despite your personal frustration, as you provide increasing help, try to maintain your loved one's self-esteem, self-image, and independence as much as possible. This may be done by recognizing the person's limitations to recognizing his/her abilities. Although no map can trace or recover the many losses incurred by a person with dementia, it is important to remember that the "self" of the person is not lost. Self is more than memory—it is the core, the uniqueness, of the person who has been afflicted by the disease. Rest assured, you can continue to connect with your loved one by weaving the awareness of his/her "self"

The purpose of identifying stages in the disease is to make sense of what may otherwise seem chaotic.

Tools

Contact our 24/7 Helpline 1 800 272 3900 for information & referrals, education, support groups and care consultations.

Take the [Know the 10 Signs](https://www.training.alz.org) online course at: [training.alz.org](https://www.training.alz.org)

Safety MedicAlert® Call 1.888.572.8566 www.medicalert.org/safereturn and register online.