

UNDERSTANDING THE DIAGNOSIS

Major Neurocognitive Disorder, due to Alzheimer's disease

“Major Neurocognitive Disorder” is the clinical term used by professionals to identify a dementia. "Dementia" is a general term for when a person has developed difficulties with reasoning, judgment, and memory. People who have dementia usually have some memory loss as well as difficulty in at least one other area, such as:

- Speaking or writing coherently (or understanding what is said or written)
- Recognizing familiar surroundings
- Planning and carrying out complex or multi-step tasks

In order to be considered dementia these issues must be severe enough to interfere with a person's independence and daily activities.

Dementia can be caused by several diseases that affect the brain. The most common cause of dementia is Alzheimer disease. Scientists have not yet determined exactly why or how it develops, but most agree that a combination of genetic, lifestyle, and environmental factors influence when the disease develops and how it progresses. We do know that Alzheimer disease produces specific changes in the brain. These changes include deposits (plaques) of a protein called "beta amyloid," loss of nerve cells (neurons) in important parts of the brain, and disorganized masses of protein fibers within the brain cells (these are known as "neurofibrillary tangles").

Risk Factors:

There is no way to predict with certainty who will develop dementia. Each form of dementia has its own risk factors, but most forms have several risk factors in common.

Age: The biggest risk factor for dementia is age: dementia is rare in people younger than 60 years and becomes very common in people older than 80. For example, dementia affects approximately one in six people between 80 and 85 years old, one in three above 85 years, and almost half of people over age 90.

Family history: Some forms of dementia have a genetic component, meaning that they tend to run in families. Having a close family member with Alzheimer disease increases your chances of developing it. People with a first-degree relative (parent or sibling) with Alzheimer disease have a greater chance of developing the disorder. The risk is highest if the family member developed Alzheimer disease at a younger age (less than 70 years old) and is lower if the family member did not get Alzheimer disease until late in life.

Other factors: Studies indicate that high blood pressure, smoking, and diabetes may be risk factors for dementia. Lifestyle factors have also been implicated in dementia. For instance, people who remain physically active, socially connected, and mentally engaged seem less likely to develop dementia than people who do not. These activities may produce more cognitive (mental) reserve or resilience, delaying the emergence of symptoms until an older age.

Alzheimer's disease Symptoms:

Early changes: The earliest symptoms of Alzheimer disease are gradual and often subtle. Many people and their families first notice difficulty recalling recent events or information. This often emerges as a tendency to repeat

stories or questions or to request or require repetition of material to be able to remember. Other changes can include one or more of the following:

- Confusion
- Difficulties with language (e.g., not being able to find the right words for things)
- Difficulty with concentration and reasoning
- Problems with complex tasks like paying bills or balancing a checkbook
- Getting lost in a familiar place

Late changes: As Alzheimer disease progresses, a person's ability to think clearly continues to decline, and any or all of the changes listed above may be more disruptive. In addition, personality and behavioral symptoms can become quite troublesome. These can include:

- Increased anger or hostility, sometimes aggressive behavior; alternatively, some people become depressed or exhibit little interest in their surroundings (called "apathy")
- Sleep problems
- Hallucinations and/or delusions
- Disorientation
- Needing help with basic tasks (such as eating, bathing, and dressing)
- Incontinence (difficulty controlling the bladder and/or bowels)

The number of symptoms, the functions that are impaired, and the speed with which symptoms progress can vary widely from one person to the next. Most people with Alzheimer disease do not die from the disease itself, but rather from a secondary illness such as pneumonia, bladder infection, or complications of a fall.

Over time, people with dementia have trouble doing their regular daily activities, which can lead to safety issues.

Safety and Lifestyle Issues:

A major issue for caregivers is making sure the person with dementia stays safe. Because many people with dementia do not realize that their mental functioning is impaired, they try to continue their day-to-day activities as usual. This can lead to physical danger, and caregivers must help to avoid situations that can threaten the safety of the person or others.

Medications: People with Alzheimer disease often have trouble remembering to take medications they are prescribed for other conditions, or they become confused about which medications to take. They are also at increased risk for potentially dangerous side effects from certain medications. It is important to develop a plan for medication monitoring and safety. People with dementia often need help taking their medications. It is a good idea to throw away old pill bottles and other medications that are no longer needed.

Driving: Driving is often one of the first safety issues that arises in people with Alzheimer disease. In people with Alzheimer disease, the risk of having a car accident is significantly increased, especially as the disease progresses. It is best to discuss the issue of driving early, before the symptoms become advanced.

Losing the ability to drive can be hard to accept because it represents independence for many people. It can also be challenging if the person does not completely appreciate the impairments in mental functioning or reaction time. Many people with mild but worrisome impairments will insist that they can safely drive locally or in the daytime. However, they may forget about these limitations, and their ability to drive even in these restricted settings will deteriorate over time.

A roadside driving test is often recommended if there is disagreement or uncertainty about a person's ability to drive. However, if a person with newly diagnosed, mild Alzheimer disease is deemed still able to drive, they should be reassessed often, with the understanding that driving will eventually no longer be possible.

Cooking: Cooking is another area that can lead to serious safety concerns and may require help or supervision. Symptoms such as distractibility, forgetfulness, and difficulty following directions can lead to burns, fires, or other injuries. The use of gas cooking appliance raises a particular concern. A family member may have to ask the utility company to disconnect gas stoves if there is potential for accident or injury. Newer induction electric stoves do not change color when on and may carry an inadvertent burn risk if a person forgets what they are doing.

Wandering: As dementia progresses, some people with Alzheimer disease begin to wander. Because restlessness, distractibility, and memory problems are common, a person who wanders may easily become lost. Identification bracelets can help ensure that a lost wanderer gets home. The Alzheimer's Association provides a "Wandering Support" program that provides ID tags and 24-hour assistance to patients who are preregistered for this program (<https://www.alz.org/help-support/caregiving/safety/medicalert-with-24-7-wandering-support>). There are many "locator" applications that allow the person with dementia to wear or carry a GPS device that a family member can track with their cell phone.

Regular exercise may decrease the restlessness that can lead to wandering. Exercise is also just good practice to maintain strength, good sleep, and overall health. If wandering continues, wearable alarm systems are available that alert caretakers when the person leaves the home.

Falls: For all types of dementia, including Alzheimer disease, falls are a safety concern. Commonly used medications also increase risk of falls and injuries. In fact, falls and injuries are one of the most important causes of additional disability in people with dementia. Hip fracture is a particular concern in older people, as it can lead to serious complications and sometimes even death.

To reduce the risk of falls, eliminate potential hazards such as loose electrical cords, slippery rugs, and clutter that could be trip hazards. Review medications with a doctor to identify those that might increase the risk of falling. Regular exercise, especially early in the course of dementia, and use of assistive devices like canes can also help.

Treatments for Alzheimer's disease:

Although scientists are learning more about Alzheimer disease all the time, there is currently no cure. There are a number of medications that may help to control some of the symptoms of Alzheimer disease. These include medications to manage memory as well as behavioral problems.

Treatment of memory problems: There are several medicines currently available for treating the memory problems associated with Alzheimer disease. Three of these medications are cholinesterase inhibitors:

- Donepezil (brand name: Aricept)
- Rivastigmine (brand name: Exelon)
- Galantamine (brand name: Razadyne)

These medications allow more of a chemical called acetylcholine to be active in the brain, making up for drops in acetylcholine levels that happen in Alzheimer disease. Cholinesterase inhibitors can cause side effects such as nausea, vomiting, and diarrhea in some people. They also seem to cause weight loss in many people. In some cases, these medicines can cause a slow heart rate and even fainting spells. When taken at bedtime, cholinesterase inhibitors can cause very vivid dreams.

Memantine (brand names: Namenda, Ebixa) is a unique medicine that works differently than cholinesterase inhibitors. It may protect the brain from further damage caused by Alzheimer disease. Dizziness is the most common side effect, and aggression and hallucinations may worsen in some people. It is usually used along with a cholinesterase inhibitor.

Many people with Alzheimer disease will have the option of trying one of these medications. Unfortunately, few people will experience measurable benefit. If there is no improvement in symptoms or side effects are bothersome, the medication should be stopped. Sometimes the person's symptoms will worsen after treatment is stopped; if this happens, the medication may be started again. A health care provider should periodically review all medications to see if they are providing any benefit.

It is important to have realistic expectations about the potential benefits of medication therapy in Alzheimer disease. None of these medications cure the disease, and the reality is that over time the person will continue to worsen. When medication does have an effect, the goal is not to stop progression of the disease, but to improve quality of life for the person and their family to the extent possible. For patients who do benefit symptomatically from these medications, the benefit may be long-lasting.

Treatment of behavioral symptoms: The behavioral symptoms of Alzheimer disease are often more troubling than the cognitive (mental) symptoms. Even in mild cases, agitation, anxiety, and irritability can occur, and generally worsen as Alzheimer disease advances. This can be stressful for the person as well as for his or her family and caregivers. A combination of medications and behavioral therapy may be helpful. Non-medication therapies are preferred.

Depression: Depression is common, especially in the early phases of dementia. It may be treated with behavioral therapy and/or with medications. The key is to recognize that depression may be playing a role in the person's symptoms. If depression is causing distress, it is worth treating. Potentially helpful medicines include a group of medicines known as selective serotonin reuptake inhibitors, or SSRIs, which are usually preferred over other choices in patients with dementia. Widely used SSRIs include fluoxetine (brand name: Prozac), sertraline (brand name: Zoloft), paroxetine (sample brand names: Brisdelle, Paxil), citalopram (brand name: Celexa), and escitalopram (brand names: Lexapro, Cipralex).

A variety of behavioral therapies are often helpful, do not have the side effects often seen with medications, and may be recommended for depression. Behavioral therapy involves changing the person's environment (e.g., regular exercise, avoiding triggers that cause sadness, socializing with others, engaging in pleasant activities that a person enjoys).

Agitation and aggression: One of the most difficult issues for caregivers and people with Alzheimer disease is aggressive behavior. Fortunately, this behavior is not common. However, many family members are reluctant to report aggressive behavior. In some cases, the behavior becomes physically abusive as dementia progresses.

Agitation and aggression can be caused by a number of factors, including:

- Confusion, misunderstanding, or disorientation (doctors use the term "delirium" as a general term to describe a state of confusion in which a person does not think or behave normally)
- Frightening or paranoid delusions or hallucinations
- Depression or anxiety
- Sleep disorders, such as reduced sleep or altered sleep/wake cycles
- Certain medical conditions that can cause delirium, such as urinary tract infection or pneumonia
- Being in physical pain or discomfort
- Side effects of certain medications

Delusions: Delusions (i.e., believing something that is not real or true) are common in patients with dementia, occurring in up to 30 percent of those with advanced disease. Paranoid delusions are particularly distressing to both the patients and the caregivers: these often include beliefs that someone has invaded the house, that family members have been replaced by impostors, that spouses have been unfaithful, or that personal possessions have been stolen.

The best treatment for these symptoms depends upon what triggers them. As an example, a person who becomes aggressive during periods of confusion might best be treated by talking through the problem, while someone who becomes aggressive during delusions might require medication. Often, behavior improves once an underlying medical condition is treated.

Sleep problems: Sleep disorders can be treated with either medicine or behavior changes or both: for example, limiting daytime naps, increasing physical activity, avoiding caffeine and alcohol in the evening. In some people, medication to help with sleep may be recommended, although these medications almost always have side effects (e.g., worsened confusion and increased risk of falls). Maintaining daily rhythms, using artificial lighting when needed during the day, and avoiding bright light exposures during the night may help maintain normal wake-sleep cycles.

Coping with Alzheimer's disease:

Being diagnosed with any form of dementia can be distressing and overwhelming for the person affected as well as his or her loved ones.

For people with dementia: It is important for people with early dementia to care for their physical and mental health. This means getting regular checkups, taking medicines if needed, eating a healthy diet, exercising regularly, getting enough sleep, and avoiding activities that may be risky.

It is often helpful to talk to others through support groups or a counselor or social worker to discuss any feelings of anxiety, frustration, anger, loneliness, or depression. All of these feelings are normal and dealing with these feelings can help you to feel more in control of your life and health. It can also help to talk to other people who are going through a similar experience.

While many people are able to live alone in the early stages of dementia, you may need help with tasks such as housekeeping, cooking, transportation, and paying bills. If possible, ask a friend or family member for help making plans to deal with these and other issues as dementia progresses. Occupational therapists, and sometimes speech pathologists, can help to set up your home to minimize confusion and keep you independent for as long as possible.

It is also important to establish Power of Attorney and Health Care Proxy statuses early, before a financial or health care crisis happens. This involves completing paperwork to determine who can make decisions on your behalf if needed.

In addition, you should discuss your preferences regarding issues that are likely to become important as your dementia worsens, including:

- Is health insurance available, and what does it cover?
- Where will I live?
- Who will make health care and end-of-life decisions if I can't make them for myself?
- Who will pay for care?

For caregivers: Dementia can also impose an enormous burden on families and other caregivers. People with dementia become less able to care for themselves as the condition progresses. If you are caring for someone with dementia, the following may help:

1. Make a daily plan and prepare to be flexible if needed.
2. Try to be patient when responding to repetitive questions, behaviors, or statements.
3. Try not to argue or confront the person with dementia when he or she expresses mistaken ideas or facts. Change the subject or gently remind the person of an inaccuracy. Arguing or trying to convince a person of "the truth" is a natural reaction but it can be frustrating to all and can trigger unwanted behavior and feelings.
4. Use memory aids such as writing out a list of daily activities, phone numbers, and instructions for usual tasks (i.e., the telephone, microwave, etc.).
5. Establish calm and consistent nighttime routines to manage behavioral problems, which are often worst at night. Leave a night light on in the person's bedroom.
6. Avoid major changes to the home environment (for example, rearranging furniture).
7. Employ safety measures in the home, such as putting locks on medicine cabinets, keeping furniture in the same place to prevent falls, removing electrical appliances from the bathroom, installing grab bars in the bathroom, and setting the water heater below 120°F.
8. Help the person with personal care tasks as needed. It is not necessary to bathe every day, although a health care provider should be notified if the person develops sores in the mouth or genitals related to hygiene problems (e.g., ill-fitting dentures, urine leakage).
9. Speak slowly, present only one idea at a time, and be patient when waiting for responses.
10. Encourage physical activity and exercise. Even a daily walk can help prevent physical decline and improve behavioral problems.
11. Consider respite care. Respite care can provide a needed break and give you a chance to recharge. This is offered in many communities in the form of in-home care or adult day care. Caregiving can be an all-consuming experience, and it is essential to take time for yourself, take care of your own medical problems and arrange for breaks when you need them.
12. See if your area has a support group for people caring for loved ones with dementia. It can help to talk with other people who understand what you are going through.

Additional Resources:

1. **National Institute on Aging:** provides free information on aging and dementia: nia.nih.gov
2. **Alzheimer's Association:** provides resources for those with Alzheimer's and their caregivers: alz.org
3. **Up to Date:** provides diagnosis details and is an online tool for patients to learn more about their symptoms: uptodate.com/patients
4. **A Place for Mom:** website with a long list of additional dementia resources including caregiver support, awareness, ongoing research, videos, books, nonprofit organizations, blogs, etc.: <https://www.aplaceformom.com/blog/list-of-alzheimers-resources-3-06-2013/>
5. **Leading Age:** provides a searchable database of aging services, including assisted living, nursing care, and home meal delivery: www.leadingage.org
6. **National Adult Day Services Association:** provides a searchable database of adult day activities: www.nadsa.org
7. **National Center for Assisted Living:** contains information for consumers on assisted living: www.ncal.org
8. **National Hospice and Palliative Care Organization:** Provides free resources to help people make decisions about end-of-life care and services before a crisis. Topics include advanced directives, and hospice and palliative care, among others: www.caringinfo.org
9. **AngelSense:** The AngelSense solution provides caregivers a comprehensive view of their loved one's activities, comings and goings: www.angelsense.com

10. **The Alzheimer's Store:** Products for people with Alzheimer's disease and for those caring for them: www.alzstore.com
11. **Home Instead Senior Care:** Some of the services offered include personal care, hospice care, and memory care training in collaboration with experts on Alzheimer's disease and dementia. While the tasks of each service might differ, the goal for all types of care remains the same: enhancing the lives of seniors and their families: www.homeinstead.com/alzheimers
12. **MedicAlert Foundation International:** Offers emblems and chains engraved with the person's membership number, primary medical conditions, and the toll-free 24-hour Emergency Response Center number. MedicAlert allows the person to be identified, and can relay key medical facts and notify family contacts: www.medicalert.org
13. **Project Lifesaver:** The program is comprised of components specifically designed to protect "at risk" individuals and offers wearable locating technology: <https://projectlifesaver.org>