

DEMENTIA: A SURVIVAL GUIDE FOR FAMILY CAREGIVERS

Prepared by:

**Nebraska Medicine
The Home Instead Center for Successful Aging
730 S. 38th Ave., Omaha, Nebraska**

<https://www.nebraskamed.com/geriatrics>

DEMENTIA: CAUSES AND TREATMENTS

Dementia is not a specific disease. It is a term which describes a group of symptoms that causes a significant decline in intellectual functioning, impairing normal activities and changing relationships. While memory loss is a common symptom of dementia, by itself it does not mean that a person has dementia. Doctors diagnose dementia only if two or more brain functions - such as memory, orientation, learning or language skills, reasoning or judgment - are significantly impaired. Such impairments eventually decrease one's ability to perform everyday activities like driving, paying bills, housekeeping, preparing meals and even personal care skills like bathing and dressing. A person with dementia also may exhibit personality changes, loss of emotional control and behavioral problems such as agitation, paranoia and hallucinations.

Dementia is most common in older adults, but is not a normal part of aging. It is caused by a number of medical conditions. In some cases, dementia can be reversed or stopped from getting worse. In others, it is permanent and usually gets worse over time. As with any other medical condition, it is essential that a proper evaluation be made when the symptoms of dementia first appear, so that appropriate treatments can be offered. Common forms and causes of dementia include:

ALZHEIMER'S DISEASE is the most common cause of dementia in older persons. It is marked by the abnormally rapid death of brain cells. The precise cause of Alzheimer's Disease is unknown, but this is being aggressively studied worldwide by researchers. Alzheimer's is characterized by a progressive loss of intellectual and functional abilities. On average, persons with Alzheimer's Disease live for 8-10 years after they are diagnosed, with death often resulting from pneumonia and other infections that arise late in the disease. Current treatments focus on medications to prolong the functioning of still-living brain cells. These medications slow, but do not halt the progression of Alzheimer's Disease.

VASCULAR DEMENTIA is caused either by a severe narrowing or blockage of arteries that carry blood to the brain, or from strokes caused by an interruption of blood flow to the brain. The first symptoms of vascular dementia usually start suddenly, and progression is often marked by abrupt "step downs" of cognitive abilities. But vascular dementia may also slowly and progressively worsen over time. Treatment involves preventing additional strokes by addressing underlying diseases, such as high blood pressure and high cholesterol, and by use of blood-thinning medications. There is some evidence that use of medications commonly prescribed to treat Alzheimer's Disease may also slow the progression of vascular dementia.

PARKINSON'S DEMENTIA. Persons with late-stage Parkinson's Disease or "Parkinson's Plus" Diseases (such as Progressive Supranuclear Palsy) may develop a dementia with symptoms and a progressive course similar to those of Alzheimer's Disease.

LEWY BODY DEMENTIA is marked by small protein deposits found in deteriorating nerve cells in the brain. These often appear in areas of the brain that are associated with the tremor and rigidity of Parkinson's Disease. When these Lewy bodies are spread throughout the brain, they may produce symptoms similar to those of Alzheimer's Disease as well as hallucinations and major fluctuations in alertness.

FRONTO-TEMPORAL DEMENTIA is marked by a deterioration of nerve cells in the frontal and temporal lobes of the brain. Initial symptoms include behavioral and personality changes, such as poor judgment and impulsiveness. It then progresses to impairments of language and cognitive skills. Frono-Temporal Dementia is not curable, and usually does not respond to the medications used to treat Alzheimer's Disease. Mood and behavioral problems can be treated using standard anti-psychotic and anti-depressant medications.

HEAD TRAUMA Dementia may result from a single, significant head injury, or from a series of head blows, such as those suffered by professional boxers. A single traumatic brain injury may produce an immediate dementia, but symptoms vary depending on which part of the brain was damaged. Dementia from repeated head blows may appear many years after the trauma ends, and is often marked by symptoms of Parkinsonism.

Doctors have identified other conditions that can cause dementia or dementia-like symptoms. In the following conditions, cognitive problems may sometimes be reversed with appropriate treatment.

HYPOXIA occurs when there has been a significant disruption in the flow of oxygen to the brain. This can cause serious impairments of physical, cognitive and psychological skills. The rate and extent of recovery are unpredictable and largely depend on which parts of the brain have been affected, and how severe the injury is.

BRAIN TUMOR A tumor may press on and damage brain cells, and other structures in the brain. Medical or surgical treatment of the tumor can sometimes reverse the symptoms of dementia however, depending upon the degree of brain injury sustained because of pressure on brain cells and structures, a person may be left with some degree of permanent cognitive disability.

SUBDURAL HEMATOMA is a collection of blood, a hematoma, that forms on the surface of the brain. It often results from head injury but can occur spontaneously in older persons, especially those who take blood thinning medications. Symptoms may include numbness and weakness, slurred speech, drowsiness and mental confusion. Cognitive changes occur and progress quickly or slowly depending upon the size and location of the hematoma. This condition requires emergency treatment that may include medications and/or surgery to drill a small hole in the skull to allow the blood to drain and relieve pressure on the brain. Depending upon the degree of brain injury caused by pressure from the hematoma, a person may be left with some degree of permanent cognitive disability.

NORMAL PRESSURE HYDROCEPHALUS (NPH) is a condition that arises when the flow of spinal fluid in and out of the brain is obstructed, causing it to backup into areas of the brain and creating increased pressure that can damage brain tissue. NPH often results from a prior brain injury or infection, and also produces symptoms of walking difficulties and loss of bladder control. NPH may often be corrected with surgery to install a small tube (a "shunt") into the brain to drain off the excess fluid. The degree of cognitive improvement after such treatment, however, varies among patients.

ALCOHOL DEPENDENCE can lead to symptoms of dementia. Long term and/or heavy use of alcohol can damage brain cells, causing them to deteriorate and die off more rapidly than they otherwise would. Alcohol abuse also contributes to nutritional and vitamin deficiencies and liver diseases which can cause dementia symptoms. Abstaining from alcohol can often improve all of these problems.

INFECTIONS of the brain and central nervous system, from disorders such as meningitis, encephalitis Lyme Disease or late-stage syphilis, will cause inflammation that damages brain cells if not properly treated

HORMONE DISORDERS involve body glands that secrete and/or regulate hormones. These include the thyroid, parathyroid, pituitary and adrenal glands. Severe and/or prolonged imbalances in such hormones can lead to dementia if not corrected.

METABOLIC DISORDERS such as kidney, liver and pancreas diseases, can cause symptoms of dementia, and may be progressive and irreversible if left untreated.

WHAT CONDITIONS ARE NOT DEMENTIA?

DEPRESSION can make an older person appear to be demented because it can cause inattention, apathy and impair one's ability to learn and remember new things. Persons with a significant depression, but without any underlying dementia, should regain cognitive skills if their mood is successfully treated. However, depression can also be a symptom of dementia. In such cases, treating depression is still important but does not fully restore cognition.

DELIRIUM causes confusion and rapidly fluctuating mental states. The person may also be disoriented, drowsy or incoherent, and may have personality changes. Delirium is usually caused by a treatable physical illness, such as a poisoning or an infection, and persons will often, though not always, make a complete recovery after the underlying illness is treated.

MEDICATION EFFECTS Misuse or abuse of some prescription and over-the-counter medications can produce a delirium that mimics symptoms of dementia. Medications which can produce such side effects include sleeping pills, tranquilizers and anti-anxiety drugs, antihistamines and other cold medications. When such medications are stopped or decreased, the delirium and symptoms of dementia usually lessen or stop.

AGE-RELATED COGNITIVE DECLINE is marked by very mild memory impairment and a slowing in the rate in which the brain processes new information. These changes are considered normal and are not considered signs of dementia.

MILD COGNITIVE IMPAIRMENT is a condition in which cognitive and memory problems are more pronounced than the cognitive changes associated with normal aging, but are not severe enough to be diagnosed as dementia. Many persons with Mild Cognitive Impairment, however, eventually go on to develop a dementia.

MEDICATIONS TO TREAT DEMENTIA

Approximately ¾ of all cases of dementia are caused by Alzheimer's Disease or vascular brain disease, or by a combination of both disorders. Medications are available that help to stabilize mental function in persons with Alzheimer's Disease, vascular dementia, and with mixed Alzheimer's and vascular dementia. These medications are also being used more frequently to treat a condition known as Mild Cognitive Impairment. None of these medications stop the progression of cognitive decline, but they appear to slow down the rate at which such decline occurs. This can help ease the burden of family caregivers and delay placement in a long-term care facility.

WHAT MEDICATIONS ARE CURRENTLY BEING PRESCRIBED?

There are two classes of medications currently being prescribed to treat Alzheimer's Dementia: "Cholinesterase Inhibitors" such as **Donepezil** (the generic form of Aricept), **Rivastigmine** (the generic form of Exelon), **Galantamine** (the generic form of Razadyne), and an "NMDA Receptor Antagonist", **Memantine** (the generic form of Namenda). **Namzaric** (a brand-name combination of Donepezil and Memantine) can also be prescribed.

The generic forms of these medications are usually less expensive and equally as effective as their brand-name counterparts.

HOW DO THESE MEDICATIONS WORK?

Cholinesterase Inhibitors: Acetylcholine is a substance manufactured by nerve cells in the brain. It helps transmit “messages” between cells, allowing a person to think and perform tasks. Both Alzheimer’s Disease and vascular brain disease destroy some of the brain cells that make acetylcholine. Cholinesterase inhibitors temporarily boost the levels of acetylcholine in the brain, thereby preserving memory and cognitive function.

NMDA Receptor Antagonists regulate the activity of glutamate, another “messenger” chemical in the brain. Glutamate triggers NMDA receptors in the brain to allow a controlled amount of calcium to flow into nerve cells to help the brain process, store and retrieve information. Excess amounts of glutamate cause NMDA receptors to allow too much calcium into nerve cells, leading to disruption and death of cells. Namenda (memantine) may protect cells against excess glutamate by partially blocking the NMDA receptors.

WHAT CAN I EXPECT THESE MEDICATIONS TO DO FOR MY LOVED ONE?

Cholinesterase Inhibitors: From 30%-50% of those taking cholinesterase inhibitors experience a mild but noticeable improvement in attention, concentration and in the ability to perform daily activities. The average improvement was comparable to “rolling back” the disease symptoms anywhere from 6-12 months. Cholinesterase Inhibitors appear to be most effective in the early to middle stages of dementia.

NMDA Receptor Antagonists: In US clinical studies, memantine has proven modestly effective in improving functional performance in persons with moderate to late-stage dementia. Studies fail to show an advantage to using memantine along with a cholinesterase inhibitor.

WHAT SHOULD BE CONSIDERED WHEN USING THESE MEDICATIONS?

Dementia medications differ in the number of daily doses required and the types of potential side effects. Some are taken once daily and others are taken twice daily. All come in tablet or capsule form, and **Rivastigmine** also comes in a once-daily transdermal patch form.

The most common side effects of all cholinesterase inhibitors are nausea, vomiting, loss of appetite and diarrhea. The most common side effects of **Namenda** and **Memantine** are dizziness, headache and constipation. When they occur, these symptoms tend to be mild and get better with time. Side effects may be avoided by starting with the smallest possible dose of medication, then gradually increasing it to the higher dose. When side effects do appear, they may be able to be overcome by reducing the dose for a week or so, and then increasing it again. These medications may not be appropriate for persons with certain medical conditions. Your physician can determine whether a person has any medical conditions or potential risk factors that would preclude them using these medications.

As a rule of thumb, if a person is taking one of these medications - and is doing well - they should not switch to another. If they are not doing well on a particular medication (ie. having side effects, or showing no benefit after 6 months of use), it would be reasonable to stop that drug and to then start another, either in the same or a different class. If a person cannot take, or does not benefit from, any of these currently prescribed medications, it would be reasonable to enroll them in a clinical research trial for medications that are still being tested.

WHAT DO THESE MEDICATIONS COST?

In 2019, a 30-day supply of Donepezil retails for up to \$220, Rivastigmine capsules retail for about \$50 and Rivastigmine patches retail for up to \$500. Galantamine retails for about \$200. Memantine retails for up to \$460, and Namzaric retails for about \$555. These medications are covered by many of the Medicare-approved prescription drug plans, and the website: <https://www.goodrx.com> allows you to compare prices between pharmacies, and print coupons that can provide substantial cost savings.

Additionally: the pharmaceutical companies that make these medications may offer them free of charge or at a discount to persons of limited means, and without prescription drug coverage. Speak to your physician or pharmacist about these Patient Assistance Programs, or go online to Benefits Checkup: www.benefitscheckup.org

HOW DO I OBTAIN A PRESCRIPTION FOR THESE MEDICATIONS?

Any medical doctor may prescribe them. However, it is essential that an accurate diagnosis for the cause of cognitive problems be made first. To do this, the physician must perform a thorough physical examination, blood tests and a brain scan. The physician should also administer basic cognitive tests, and should review all the medication the person currently takes to look for possible side effects. It is important that the physician gather from the family a detailed history of the type of onset and progression of the cognitive and functional decline, and the type of symptoms they have observed. Such a thorough evaluation will help the physician identify and treat other medical conditions that may be mistaken for Alzheimer's or vascular dementia.

ARE NEWER MEDICATIONS CURRENTLY BEING TESTED?

Clinical research studies are part of a careful, scientific process to see whether new treatment approaches are safe and effective. After first being tested in the laboratory, and then with animals, treatments that appear promising are then tested on humans in carefully designed clinical trials.

Interested persons are first screened to see if they are candidates to participate in a clinical trial. Those selected for a trial will be divided into two groups: one group will receive the trial medication and another will receive a "placebo", a pill or patch with no active medication. Study participants agree to a series of follow-up appointments and phone calls to track their progress and the effects of the study treatment over time. The cost of study medications, physical and cognitive examinations and lab tests are covered by the research sponsor.

For information about clinical trials in the Omaha area, contact the UNMC Neurology AD Trials staff at (402) 552-6241.

The Alzheimer's Association sponsors a program called "TrialMatch" which can match people to clinical trials around the country. To access this service, call (800) 272-3900 or go online to https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials

TIPS FOR CARING FOR A MEMORY- IMPAIRED PERSON

MEMORY AIDS (clocks, calendars and written notes) help a person stay oriented.

Much of what you say to the person may soon be forgotten. Be prepared to **REPEAT** yourself sometimes often.

Speak in a **CALM VOICE**. Make brief, simple statements. Try using touch and **DIRECT EYE CONTACT** when responding to emphasize what you say.

Avoid presenting the person with more than one thought at a time, and **LIMIT CHOICES** ("Either/or", rather than "multiple choice").

DISTRACT the person from an irritating or repetitive topic by using a word from the conversation to **RE-DIRECT** them or change the subject. Try such pleasurable distractions as taking a walk or drive, looking at family photos, playing music or giving the person a simple, repetitive task to perform, such as folding towels.

If distractions fail, try to **IGNORE** repeated questions. This may initially anger or agitate the person, but the questions may stop if they are not reinforced by your behavior. Ignoring is an especially good tactic when you are irritated. It may prevent the person from picking up on your irritation.

Most memory-impaired persons function best when following a **FAMILIAR ROUTINE** in **FAMILIAR SURROUNDINGS**. Avoid abrupt or frequent changes of routine, activities and location. Avoid discussing plans for non-routine activities/appointments with the person until just prior to the event to avoid agitation and repeated questions days in advance.

PRAISE and POSITIVE REINFORCEMENT helps a person maintain dignity and self-care skills. When correcting or directing them, avoid negative commands ("Don't do that"). Use a positive focus ("Let's do this").

If the person's cognitive skills continue to worsen, closely monitor their ability to perform tasks and be prepared to **LOWER YOUR EXPECTATIONS** for their performance. Allow the person to do as much for themselves as they possibly can, even if they are slower and less efficient. Take over a task completely only when they cannot perform it even with step-by-step instructions or help. Complex or risky tasks (such as driving, using appliances or managing financial affairs) may have to be assumed by others sooner.

To include the person in social conversations, refer to positive memories of the past. **ENCOURAGE REMINISCENCE**, as the person is able to remember past events better than present.

Suggest a word or name the person is searching for in conversation, but **AVOID CORRECTING MISTAKES** already made. Contradicting or arguing with the person may only cause upset and humiliation.

ANTICIPATE and avoid activities and discussions that will provoke anger or agitation. Prevention is the most effective approach to reduce behavior problems.

LOOK FOR A REASON BEHIND TROUBLESOME BEHAVIOR. Is the person frightened, in pain, hungry or needing to toilet? Respond to the need or emotion you feel the person is trying to express.

If the person becomes extremely agitated or aggressive, **REMOVE THEM FROM THE STRESSFUL SITUATION** or place. Avoid quick gestures and try to calm the person with a soothing and reassuring voice and gentle touch. Do not try to reason with the person, as their ability to understand logic and reason is impaired. If you feel threatened, remove sharp or dangerous objects from the area and stay out of reach. Leave and seek help if needed.

Make note of when a catastrophic reaction occurs. Is there a pattern (ie. time of day, type of activity, interaction with a specific person) that can be identified? **SIMPLIFY THE ENVIRONMENT** by reducing extra people, clutter, noise and activity. Soft music, or holding a doll or a stuffed animal may ease agitation and calm fears in a severely impaired person.

While use of medication to control behavior should be a last resort, **MEDICATIONS MAY BE NECESSARY** to control depression, hallucinations, paranoia, sleeplessness and extreme agitation. Discuss this with your doctor.

Honestly **ACKNOWLEDGE TO THE PERSON THAT THEY HAVE A MEMORY PROBLEM**, but confronting them with their loss of ability may lessen their sense of dignity and self esteem. Try to remind the person how much they can still do for themselves. Reassure them that they are still loved and valued. Try to discuss openly the person's memory and behavior problems with family, friends, neighbors and others who will have regular contact with him/her. People tend to respond more appropriately and offer assistance when they understand the situation.

Emotional support and **RESPITE** from care giving responsibilities are essential to helping you cope. Arrange for someone else to assume your care giving duties for several hours at a time on a regular basis so you can get out and "recharge your batteries". You cannot provide good care for your loved one if you neglect your own needs.

Consider joining a self-help or **SUPPORT GROUP**. These offer an excellent setting in which to express your feelings and learn creative approaches to solve the challenges you face in providing care. Your local Area Agency on Aging or regional chapter of the Alzheimer's Disease Association can direct you to such groups.

BE PATIENT WITH YOURSELF. Recognize that you will make mistakes and will become angry and impatient at times. Know your own limits and try not to feel guilty when you have to say "no" to others. Remember, you are only human!

HELPFUL RESOURCES FOR CAREGIVERS

CAREGIVER CALENDARS

Easy to use, on-line, interactive "Help Calendars" enable family members to schedule and sign up for tasks such as meals, rides to medical appointments, and visits. A primary caregiver can post tasks that require help so volunteers can easily see what's needed. Regular reminders are sent to volunteers so that no one forgets their commitments.

<https://www.carecalendar.org>

<https://www.alz.org/help-support/caregiving/care-options/care-team-calendar>

RECOMMENDED READINGS:

Books, brochures and videos recommended by the Alzheimer's Association for family members, professional caregivers, and for those experiencing dementia are available through your local Alzheimer's Association chapter, at public libraries and book stores. Items not in stock can be special-ordered.

Internet book sellers such as www.amazon.com and www.barnesandnoble.com will send items to you, or direct you to out-of-print book providers. Their web sites offer detailed descriptions of the focus and content of most books. They also sell downloadable e-book versions.

RECOMMENDED VIDEOS:

Dementia in Long Term Care

This website created by an Omaha geriatrician and geriatric psychiatrist offers short videos, power point presentations and care tips for professional and family caregivers.

<https://www.unmc.edu/intmed/divisions/geriatrics/education/resources/dementia.html>

UCLA Alzheimer's and Dementia Care Video Series: Seven videos highlighting problematic behaviors, and strategies for caregivers to assess and respond to them.

<https://www.uclahealth.org/dementia/caregiver-education>

INTERNET WEBSITES

Alzheimer's Disease Association <https://www.alz.org>

Alzheimer's Foundation of America <https://alzfdn.org>

Caregiver Action Network <https://caregiveraction.org>

Dementia Society of America <https://www.dementiasociety.org>

Family Caregiver Alliance <https://www.caregiver.org>

Frontal-Temporal Dementia	https://www.theaftd.org
Hydrocephalus Association	https://www.hydroassoc.org
Lewy Body Dementia	https://www.lbda.org
Medline Plus	https://medlineplus.gov/alzheimerscaregivers.html
National Alliance for Caregiving	https://www.caregiving.org
National Institute on Aging	https://www.nia.nih.gov/alzheimers/topics/caregiving#pubs

ALZHEIMER'S DISEASE & RELATED DISORDERS ASSOCIATION

National Alzheimer's Association <https://www.alz.org>
 225 N. Michigan Ave. Floor #17
 Chicago, IL 60601
 (800) 272-3900 (24 Hour Help Line)

Local Chapters/Satellite Offices: All are reachable toll-free at (800) 272-3900

Nebraska Chapter
 11711 Arbor St., Suite 110
 Omaha, NE 68144
 (402) 502-4300
<https://www.alz.org/nebraska>

Satellite Offices
 Lincoln: 1500 S. 70th St., Suite 201 (68506)
 Kearney: 4009 6th Ave., Suite 11 (68845)

ALZHEIMER'S DISEASE & RELATED DISORDERS ASSOCIATION (continued)

Iowa Chapter
 1730 28th St.
 West Des Moines, IA 50266
 (515) 440-2722
<https://www.alz.org/iowa>

Satellite Offices
 Burlington: (319) 237-4900
 Cedar Rapids: (319) 294-9699
 Council Bluffs: (712) 308-8946
 Davenport: (563) 293-8058
 Dubuque: (319) 238-7783
 Fort Dodge: (515) 212-3226
 Sioux City: (712) 454-5034
 Waterloo: (319) 277-4100

Heart of America Chapter (Northwest Missouri & Northeast Kansas)

3846 W. 75th St.

Prairie Village, KS 66208

(913) 831-3888

<http://www.alz.org/kansascity>

Satellite Offices

St. Joseph, MO: 927 Faraon St. (64501)

(816) 364-4467

Topeka, KS: 3625 SW 29th St., Suite 102 (66614)
(785) 271-1804

South Dakota Chapter

(800) 272-3900 (24 Hour Help Line)

You may download and print a copy of this and other patient education documents from the resources link on our Internet web site: <https://www.nebraskamed.com/geriatrics/resources>

(2019)