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Patient information: Dementia (including Alzheimer disease)

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DEMENTIA OVERVIEW

Dementia is a general term used to indicate that a person has developed difficulties with reasoning, judgment, and memory. People who have dementia usually have some memory loss and difficulty with 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 multi-step tasks

In order to be considered dementia these changes 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 is Alzheimer disease. Alzheimer disease accounts for 60 to 80 percent of all cases of dementia.

This article will discuss the main causes of dementia, focusing primarily on Alzheimer disease. It will also review the most common treatments and self-care strategies that can help with dementia. More detailed information about dementia and Alzheimer disease are available by subscription. (See <u>"Evaluation of cognitive impairment and dementia"</u> and <u>"Treatment of dementia"</u>.)

CAUSES OF DEMENTIA

Dementia can be caused by several different brain disorders. These include:

Alzheimer disease — Alzheimer disease is associated with the death of nerve cells (neurons) in important parts of the brain. Scientists have not yet determined exactly why and how Alzheimer disease develops, but they do know that the brains of patients with Alzheimer disease develop deposits of a protein called beta amyloid (these deposits are also known as plaques), and that people also develop disorganized masses of protein fibers within the brain cells known as neurofibrillary tangles.

Vascular dementia — People with vascular dementia have lost or damaged areas of brain because of reduced blood flow. This can happen when the blood vessels in the brain get

clogged with blood clots or fatty deposits. This form of dementia is more common among people who have had strokes or are at risk for strokes, especially those with longstanding high blood pressure and diabetes. It can occur together with Alzheimer disease. (See <u>"Etiology, clinical manifestations, and diagnosis of vascular dementia"</u>.)

Dementia with Lewy bodies — Dementia with Lewy bodies is a form of dementia caused by abnormal protein structures called Lewy bodies forming within brain cells. It occurs with symptoms of Parkinson disease, such as trembling, stiffness, and slowness. This disorder often causes vivid and long-lasting hallucinations. (See <u>"Clinical features and diagnosis of dementia with Lewy bodies</u>" and <u>"Prognosis and treatment of dementia with Lewy bodies</u>".)

Parkinson disease dementia — Dementia can also occur later in the course of Parkinson disease and has symptoms that are very similar to dementia with Lewy bodies. (See <u>"Patient information: Parkinson disease symptoms and diagnosis"</u> and <u>"Parkinson disease dementia"</u>.)

Frontotemporal dementia (formerly called Pick's disease) — Like Alzheimer disease, frontotemporal dementia causes nerve cell loss in the brain, but frontotemporal dementia targets two specific parts of the brain, called the frontal and temporal lobes.

Frontotemporal dementia usually arises at an earlier age than Alzheimer disease. Three forms are more common than others: One causes personality changes and abnormal social behavior; one impairs speech and eventually leaves the patient unable to speak; another causes difficulty in understanding language. (See <u>"Frontotemporal dementia: Clinical features and diagnosis"</u>.)

Other causes of dementia — Dementia can also be caused by cumulative damage to the brain, which can occur in people with chronic alcoholism or repeated head injuries (eg, among former professional boxers or football players).

DEMENTIA RISK FACTORS

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 uncommon in people younger than 60 years old.

Family history — Some forms of dementia have a heritable 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, such as a parent or sibling, with Alzheimer disease have a 10 to 30 percent chance of developing the disorder. The risk is probably 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.

Scientists have discovered a particular gene, called APOE epsilon 4, that increases a person's risk of developing Alzheimer disease. But even among individuals with this gene, only about one-half develop Alzheimer disease by age 90, suggesting that other factors are also involved. The test is not currently recommended unless you are involved in a research study (www.alzheimers.org/clinicaltrials/search.asp).

Other factors — Studies indicate that high blood pressure, smoking, and diabetes may be risk factors for dementia, although experts are still not sure how treatment for these problems influence your risk of developing dementia.

Lifestyle factors have also been implicated in dementia. For instance, it seems as though people who remain physically active, socially connected, and mentally engaged seem less likely to fall prey to dementia (or develop dementia later) than people who do not do these things.

DEMENTIA SYMPTOMS

Each form of dementia can cause difficulty with memory, language, reasoning, and judgment, but the symptoms are often slightly different. These differences are usually noticeable only to skilled healthcare providers who have experience working with people with dementia.

Since Alzheimer disease is the most common cause of dementia, and the symptoms of other forms of dementia often overlap, the sections below will focus on the symptoms of Alzheimer disease.

Is memory loss normal? — Many people worry that memory problems are caused by early Alzheimer disease. Normal age-related changes usually cause minor difficulties in short term memory and a slowed ability to learn and process information. These changes are usually mild and do not worsen over time, nor should they interfere with a person's day-to-day functioning.

Sometimes people with memory difficulty are labeled as having mild cognitive impairment (MCI). Some people with MCI, although not all, develop dementia over time. While people with MCI can often function normally, they are monitored closely for signs of dementia and Alzheimer disease. (See <u>"Mild cognitive impairment: Epidemiology, pathology, and clinical assessment"</u>.)

Early changes — The earliest symptoms of Alzheimer disease are gradual and often subtle. Many people and their families first notice difficulty remembering recent events or information. Other changes can include one or more of the following:

- Confusion
- Difficulties with language (eg, 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 personality and behavioral symptoms are more likely to appear. These can include:

- Increased anger or hostility, sometimes aggressive behavior; alternatively some people become very passive
- Hallucinations and/or delusions
- Disorientation
- Needing help with basic tasks (eating, bathing, dressing)
- Incontinence (leaking urine or feces)

The number of symptoms and speed with which symptoms progress can vary widely from one person to the next. In some people, severe dementia occurs within five years of the diagnosis; for others, the process can take more than 10 years. Most people with Alzheimer disease do not die from the disease itself, but instead die from a secondary illness such as pneumonia, bladder infection, or complications of a fall.

DEMENTIA DIAGNOSIS

Brain scans and other laboratory tests are not usually useful in diagnosing dementia or in identifying the type of dementia. For this, healthcare providers typically rely on the information they can gather by interacting with the person and speaking with his or her family members. The provider will typically perform memory and other cognitive (thinking) tests to assess the person's degree of difficulty with different types of problems. The results of these tests can be monitored over time.

Brain scans (either CT or MRI) are usually performed in people with dementia to rule out other problems. Blood tests may also be performed to see if a chemical or hormonal imbalance or vitamin deficiency is contributing to the person's difficulties.

SAFETY AND LIFESTYLE ISSUES FOR PEOPLE WITH DEMENTIA

A major issue for caregivers of people with dementia is being sure the person 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 patient or others.

The following information applies specifically to people with Alzheimer disease, but much of it is also relevant to people with other forms of dementia. (See <u>"Safety and societal issues related to dementia"</u>.)

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. Over time, everyone with dementia will reach a point where driving is too dangerous.

Losing the ability to drive is hard to face because it represents independence for many people. The person may resist limits on driving because he or she does not completely appreciate his/her impairments in mental functioning or reaction 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, their ability to drive needs to be reassessed every six months, with the expectation that driving will eventually no longer be possible.

Cooking — Cooking is another area that can lead to serious safety concerns and may require supervision. Symptoms such as distractibility, forgetfulness, and difficulty in following directions can lead to burns, fires, or other injuries.

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 "safe return" program with ID tags and 24-hour assistance (www.alz.org/we_can_help_safe_return.asp).

Regular exercise may decrease the restlessness that can lead to wandering. For those who continue to wander, alarm systems are available that alert caretakers when the wearer leaves the home.

Falls — For all types of dementia, including Alzheimer disease, falls are a safety concern. To reduce the risk of falls, eliminate potential hazards such as loose electrical cords, slippery rugs, and so forth.

DEMENTIA TREATMENT

The treatment for dementia depends in part on the type of dementia. People with vascular dementia should focus on getting their blood pressure and cholesterol under control to reduce the risk of further damage to the brain. People with dementia with parkinsonism, meanwhile, sometimes need medications used to manage Parkinson disease (See <u>"Patient information: Parkinson disease treatment options — medications"</u>.)

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. The section below addresses treatment for Alzheimer disease, but these treatments are also being used in people with other forms of dementia.

These include medications to manage memory as well as behavioral problems. (See <u>"Treatment of dementia"</u>.)

Treatment of memory problems — There are three medicines currently available for treating memory disturbances in Alzheimer disease:

- Donepezil (Aricept®)
- Rivastigmine (Exelon®)
- Galantamine (Razadyne®)

These are called cholinesterase inhibitors and allow more of a chemical called acetylcholine to be active in the brain, thus making up for Alzheimer disease-related drops in acetylcholine levels. Cholinesterase inhibitors can cause nausea, vomiting, and diarrhea in some people. In some patients, these medicines cause fainting spells, which should be discussed with a doctor or nurse. When taken at bedtime, these medicines can cause very vivid dreams.

Memantine (Namenda®) 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.

Typically, one of these medicines will be tried for a period of about eight weeks while the person is monitored for side effects and response. If there is no improvement or side effects are bothersome, the medicine is usually stopped. Sometimes the person will worsen after the medicine is stopped; if this happens, the medicine may be started again. The medicines can be taken for as long as needed as long as the person benefits from their use.

It is important to have realistic expectations about the potential benefits of these medicines. None of these medicines cures Alzheimer disease, and over time the patient will continue to worsen. When these medicines are effective, the hope is that the patient and their family will have an improved quality of life for a longer period.

Treatment of behavioral symptoms — The behavioral symptoms of Alzheimer disease are often more troubling than the cognitive symptoms. Even in mild cases, agitation, anxiety, and irritability can occur, and generally worsen as Alzheimer disease advances. A combination of medicines and behavioral therapy may be helpful. (See <u>"Treatment of behavioral symptoms related to dementia"</u>.)

Depression — If depression is suspected in a person with Alzheimer disease, the first step may be to try an antidepressant medicine. A group of medicines known as selective serotonin reuptake inhibitors, or SSRIs, are usually preferred. SSRIs include fluoxetine (Prozac®), sertraline (Zoloft®), paroxetine (Paxil®), citalopram (Celexa®), and escitalopram (Lexapro®).

Other treatments, especially behavioral therapy, are often helpful and may be recommended for depression. Behavioral therapy involves changing the environment (eg, encouraging exercise, socializing with others).

Anxiety 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. In addition, some caregivers become so frustrated that they themselves begin to behave abusively.

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

- Confusion or misunderstanding, disorientation
- Frightening or paranoid delusions or hallucinations
- Depression
- Sleep disorders, reduced sleep or altered sleep/wake cycles
- Medical conditions such as difficulty urinating or severe constipation, other causes of physical pain or discomfort

Delusions 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.

Family members should discuss any concerns regarding aggressive behavior with a healthcare provider, and arrange for help if necessary. 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 medicine.

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, a sleeping medicine may be recommended, although these medicines do have side effects (worsened confusion).

LIFE WITH DEMENTIA

Being diagnosed with any form of dementia can be overwhelming both for patients and for their 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 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 wellbeing.

Another issue to consider is how to tell family and friends about the diagnosis of dementia. Explaining the disease can help others to understand what to expect and how they can help, now and in the future. This can be especially helpful for children and grandchildren, who may not be familiar with the condition.

You may live alone in the early stages in the early stages of dementia, but you may need help with tasks such as housekeeping, cooking, transportation, and paying bills. If possible, ask a friend or family member for help to develop 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.

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

- Is health insurance available?
- Where will I live?
- Who will make healthcare and end of life decisions?
- Who will pay for care?

A number of resources are available to assist in this type of planning. (See <u>'Where to get</u> <u>more information'</u> below.) In some communities there are support groups specifically for people with frontotemporal dementia. These may be a better fit than groups for anyone with dementia since people with FTD are often younger and may have more bothersome behavioral problems.

For caregivers — Dementia is debilitating and can impose an enormous burden on patients and families or other caregivers. People with dementia become less able to care for themselves as the condition progresses. Some tips that may help caregivers include the following:

- Make a daily plan and prepare to be flexible if needed.
- Try to be patient when responding to repetitive questions, behaviors, or statements. This type of behavior is common, and often related to feeling insecure or nervous.
- Use memory aids such as writing out a list of daily activities, phone numbers, and instructions for usual tasks (ie, the telephone, microwave, etc).

- Establish calm nighttime routines to manage behavioral problems, which are often worst at night. Leave a night light on in the person's bedroom.
- Avoid major changes to the home environment.
- Employ safety measures in the home, such as locks on medicine cabinets, keep furniture in the same place to prevent falls, remove electrical appliances from the bathroom, install grab bars in the bathroom, and set the water heater below 120°F.
- Help the patient perform personal care as they are willing and able. It is not necessary to bathe every day, although a healthcare provider should be notified if the person develops sores in the mouth or genitals related to hygiene problems (eg, urinary leakage, ill-fitting dentures).
- Speak slowly, present only one idea at a time, and be patient when waiting for responses.
- Encourage physical activity and exercise. A daily walk can help prevent physical decline and improve behavioral problems.
- Consider respite care. Respite care can provide a needed break for family and can strengthen the family's ability to provide care in the future. This is offered in many communities in the form of in-home care or adult day care. Caregiving can be an all-consuming experience. Be sure to take time for yourself, take care of your own medical problems, and arrange for breaks when you need them.

WHERE TO GET MORE INFORMATION

Your healthcare provider is the best source of information for questions and concerns related to your medical problem.

This article will be updated as needed every four months on our web site (<u>www.uptodate.com/patients</u>).

Related topics for patients, as well as selected articles written for healthcare professionals, are also available. Some of the most relevant are listed below.

Patient Level Information:

Patient information: Parkinson disease symptoms and diagnosis Patient information: Parkinson disease treatment options — medications

Professional Level Information:

Cholinesterase inhibitors in the treatment of dementia Clinical features and diagnosis of dementia with Lewy bodies Diseases of the central nervous system caused by prions Epidemiology, pathology, and pathogenesis of dementia with Lewy bodies Etiology, clinical manifestations, and diagnosis of vascular dementia Evaluation of cognitive impairment and dementia Frontotemporal dementia: Clinical features and diagnosis Mild cognitive impairment: Epidemiology, pathology, and clinical assessment Mild cognitive impairment: Prognosis and treatmentParkinson disease dementiaPrevention of dementiaPrognosis and treatment of dementia with Lewy bodiesRisk factors for dementiaSafety and societal issues related to dementiaTreatment and prevention of vascular dementiaTreatment of behavioral symptoms related to dementiaTreatment of dementia

The following organizations also provide reliable health information.

National Institute of Neurological Disorders and Stroke

(www.ninds.nih.gov)

• Administration on Aging (Department of Health and Human Services)

(www.aoa.gov)

• The American Geriatrics Society

(www.americangeriatrics.org)

Alzheimer's Association

(www.alz.org)

• The Associate of Frontotemporal Dementias

(www.ftd-picks.org)

• Alzheimer's Disease Education and Referral (ADEAR) Center (National Institute on Aging)

(www.nia.nih.gov/alzheimers)

• Eldercare Locator (Administration on Aging)

(www.eldercare.gov)

• Family Caregiver Alliance

(www.caregiver.org)

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