

Section

4

Alzheimer's Disease

FACT SHEET

Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. In most people with Alzheimer's, symptoms first appear after age 60.

Alzheimer's disease is the most common cause of dementia among older people. Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—to such an extent that it interferes with a person's daily life and activities. Estimates vary, but experts suggest that as many as 5.1 million Americans may have Alzheimer's.

Alzheimer's disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and unpredictable behavior. After she died, he examined her brain and found many abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary tangles). Plaques and tangles in the brain are two of the main features of Alzheimer's disease. The third is the loss of connections between nerve cells (neurons) in the brain.

Changes in the Brain in Alzheimer's Disease

Although we still don't know what starts the Alzheimer's disease process, we do know that damage to the brain begins as many as 10 to 20 years before any problems are evident. Tangles begin to develop deep in the brain, in an area called the entorhinal cortex, and plaques form in other areas. As more and more plaques and tangles form in particular brain areas, healthy neurons begin to work less efficiently. Then, they lose their ability to function and communicate with each other, and eventually they die. This damaging process spreads to a nearby structure, called the hippocampus, which is essential in forming memories. As the death of neurons increases, affected brain regions begin to shrink. By the final stage of Alzheimer's, damage is widespread and brain tissue has shrunk significantly.

Very Early Signs and Symptoms

Memory problems are one of the first signs of Alzheimer's disease. Some people with memory problems have a condition called amnesic mild cognitive impairment (MCI). People with this condition have more memory problems than normal for people their age, but their symptoms are not as severe as



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National Institutes of Health
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those with Alzheimer's. More people with MCI, compared with those without MCI, go on to develop Alzheimer's.

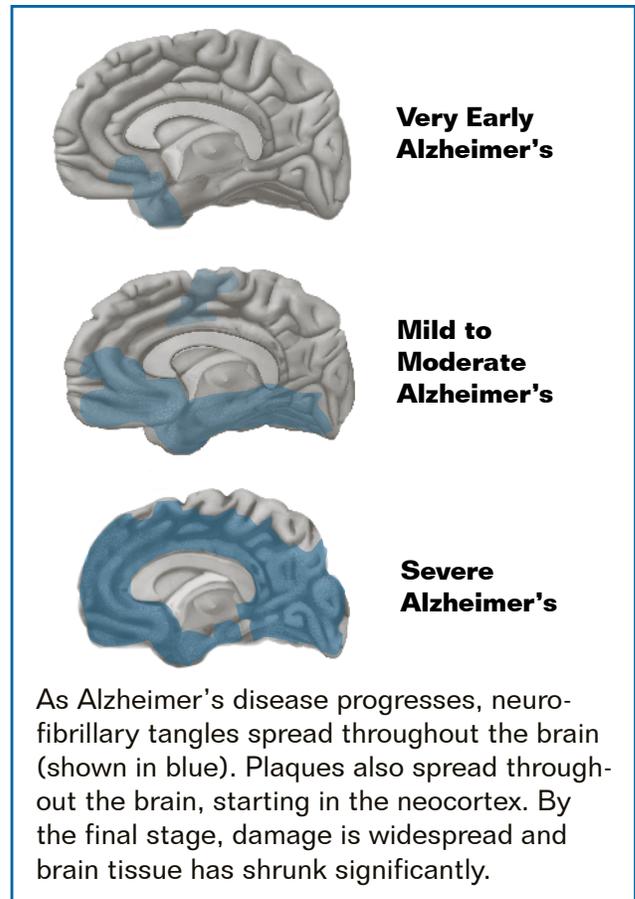
Other changes may also signal the very early stages of Alzheimer's disease. For example, brain imaging and biomarker studies of people with MCI and those with a family history of Alzheimer's are beginning to detect early changes in the brain like those seen in Alzheimer's. These findings will need to be confirmed by other studies but appear promising. Other recent research has found links between some movement difficulties and MCI. Researchers also have seen links between some problems with the sense of smell and cognitive problems. Such findings offer hope that some day we may have tools that could help detect Alzheimer's early, track the course of the disease, and monitor response to treatments.

Mild Alzheimer's Disease

As Alzheimer's disease progresses, memory loss continues and changes in other cognitive abilities appear. Problems can include getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, poor judgment, and small mood and personality changes. People often are diagnosed in this stage.

Moderate Alzheimer's Disease

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Memory loss and confusion increase, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out tasks that involve multiple steps (such as getting dressed), or cope with new situations. They may have hallucinations, delusions, and paranoia, and may behave impulsively.



Severe Alzheimer's Disease

By the final stage, plaques and tangles have spread throughout the brain and brain tissue has shrunk significantly. People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.

What Causes Alzheimer's

Scientists don't yet fully understand what causes Alzheimer's disease, but it is clear that it develops because of a complex series of events that take place in the brain over a long period of time. It is likely that the causes include genetic, environmental, and lifestyle factors. Because people differ in their genetic make-up and lifestyle, the importance of these factors for preventing

or delaying Alzheimer's differs from person to person.

The Basics of Alzheimer's

Scientists are conducting studies to learn more about plaques, tangles, and other features of Alzheimer's disease. They can now visualize plaques by imaging the brains of living individuals. They are also exploring the very earliest steps in the disease process. Findings from these studies will help them understand the causes of Alzheimer's.

One of the great mysteries of Alzheimer's disease is why it largely strikes older adults. Research on how the brain changes normally with age is shedding light on this question. For example, scientists are learning how age-related changes in the brain may harm neurons and contribute to Alzheimer's damage. These age-related changes include atrophy (shrinking) of certain parts of the brain, inflammation, and the production of unstable molecules called free radicals.

Genetics

In a very few families, people develop Alzheimer's disease in their 30s, 40s, and 50s. Many of these people have a mutation, or permanent change, in one of three genes that they inherited from a parent. We know that these gene mutations cause Alzheimer's in these "early-onset" familial cases. Not all early-onset cases are caused by such mutations.

Most people with Alzheimer's disease have "late-onset" Alzheimer's, which usually develops after age 60. Many studies have linked a gene called APOE to late-onset Alzheimer's. This gene has several forms. One of them, APOE ϵ 4, increases a person's risk of getting the disease. About 40 percent of all people who develop

late-onset Alzheimer's carry this gene. However, carrying the APOE ϵ 4 form of the gene does not necessarily mean that a person will develop Alzheimer's disease, and people carrying no APOE ϵ 4 forms can also develop the disease.

Most experts believe that additional genes may influence the development of late-onset Alzheimer's in some way. Scientists around the world are searching for these genes. Researchers have identified variants of the SORL1, CLU, PICALM, and CR1 genes that may play a role in risk of late-onset Alzheimer's. For more about this area of research, see the **Alzheimer's Disease Genetics Fact Sheet**, available at www.nia.nih.gov/Alzheimers/Publications/geneticsfs.htm.

Lifestyle Factors

A nutritious diet, physical activity, social engagement, and mentally stimulating pursuits can all help people stay healthy. New research suggests the possibility that these factors also might help to reduce the risk of cognitive decline and Alzheimer's disease. Scientists are investigating associations between cognitive decline and vascular and metabolic conditions such as heart disease, stroke, high blood pressure, diabetes, and obesity. Understanding these relationships and testing them in clinical trials will help us understand whether reducing risk factors for these diseases may help with Alzheimer's as well.

How Alzheimer's Disease Is Diagnosed

Alzheimer's disease can be definitively diagnosed only after death by linking clinical course with an examination of brain tissue and pathology in an autopsy. But doctors now have several methods

and tools to help them determine fairly accurately whether a person who is having memory problems has “possible Alzheimer’s disease” (dementia may be due to another cause) or “probable Alzheimer’s disease” (no other cause for dementia can be found). To diagnose Alzheimer’s, doctors:

- ask questions about the person’s overall health, past medical problems, ability to carry out daily activities, and changes in behavior and personality
- conduct tests of memory, problem solving, attention, counting, and language
- carry out medical tests, such as tests of blood, urine, or spinal fluid
- perform brain scans, such as computerized tomography (CT) or magnetic resonance imaging (MRI)

These tests may be repeated to give doctors information about how the person’s memory is changing over time.

Early diagnosis is beneficial for several reasons. Having an early diagnosis and starting treatment in the early stages of the disease can help preserve function for months to years, even though the underlying disease process cannot be changed. Having an early diagnosis also helps families plan for the future, make living arrangements, take care of financial and legal matters, and develop support networks.

In addition, an early diagnosis can provide greater opportunities for people to get involved in clinical trials. In a clinical trial, scientists test drugs or treatments to see which are most effective and for whom they work best. (See the box, at right, for more information.)

Participating in Clinical Trials

People with Alzheimer’s disease, those with MCI, those with a family history of Alzheimer’s, and healthy people with no memory problems and no family history of the disease may be able to take part in clinical trials. Study volunteers help scientists learn about the brain in healthy aging as well as what happens in Alzheimer’s. Results of clinical trials are used to improve prevention and treatment approaches. Participating in clinical trials is an effective way to help in the fight against Alzheimer’s disease.

NIA, which is part of the National Institutes of Health (NIH), leads the Federal Government’s research efforts on Alzheimer’s. NIA-supported Alzheimer’s Disease Centers located throughout the United States conduct many clinical trials and carry out a wide range of research, including studies of the causes, diagnosis, and management of Alzheimer’s. NIA also sponsors the Alzheimer’s Disease Cooperative Study (ADCS), a consortium of leading researchers throughout the U.S. and Canada who conduct clinical trials on promising Alzheimer’s treatments.

To find out more about Alzheimer’s clinical trials, talk to your health care provider or contact NIA’s ADEAR Center at 1-800-438-4380. Or, visit the ADEAR Center clinical trials database at www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials. You also can sign up for email alerts that let you know when new clinical trials are added to the database. More information about clinical trials is available at www.ClinicalTrials.gov. Also see **Participating in Alzheimer’s Disease Clinical Trials and Studies** at www.nia.nih.gov/Alzheimers/Publications/trials-studies.htm.

How Alzheimer's Is Treated

Alzheimer's disease is a complex disease, and no single “magic bullet” is likely to prevent or cure it. That's why current treatments focus on several different aspects, including helping people maintain mental function; managing behavioral symptoms; and slowing, delaying, or preventing the disease.

Helping People with Alzheimer's Maintain Mental Function

Four medications are approved by the U.S. Food and Drug Administration to treat Alzheimer's. Donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®) are used to treat mild to moderate Alzheimer's (donepezil can be used for severe Alzheimer's as well). Memantine (Namenda®) is used to treat moderate to severe Alzheimer's. These drugs work by regulating neurotransmitters (the chemicals that transmit messages between neurons). They may help maintain thinking, memory, and speaking skills, and help with certain behavioral problems. However, these drugs don't change the underlying disease process and may help only for a few months to a few years.

Managing Behavioral Symptoms

Common behavioral symptoms of Alzheimer's include sleeplessness, agitation, wandering, anxiety, anger, and depression. Scientists are learning why these symptoms occur and are studying new treatments—drug and non-drug—to manage them. Treating behavioral symptoms often makes people with Alzheimer's more comfortable and makes their care easier for caregivers.

Slowing, Delaying, or Preventing Alzheimer's Disease

Alzheimer's disease research has developed to a point where scientists can look beyond treating symptoms to think about addressing the underlying disease process. In ongoing

clinical trials, scientists are looking at many possible interventions, such as cardiovascular and diabetes treatments, antioxidants, immunization therapy, cognitive training, and physical activity.

Supporting Families and Caregivers

Caring for a person with Alzheimer's disease can have high physical, emotional, and financial costs. The demands of day-to-day care, changing family roles, and difficult decisions about placement in a care facility can be hard to handle. Researchers are learning a lot about Alzheimer's caregiving, and studies are helping experts develop new ways to support caregivers.

Becoming well-informed about the disease is one important long-term strategy. Programs that teach families about the various stages of Alzheimer's and about flexible and practical strategies for dealing with difficult caregiving situations provide vital help to those who care for people with Alzheimer's.

Developing good coping skills and a strong support network of family and friends also are important ways that caregivers can help themselves handle the stresses of caring for a loved one with Alzheimer's disease. For example, staying physically active provides physical and emotional benefits.

Some Alzheimer's caregivers have found that participating in a support group is a critical lifeline. These support groups allow caregivers to find respite, express concerns, share experiences, get tips, and receive emotional comfort. The Alzheimer's Association, Alzheimer's Disease Centers, and many other organizations sponsor in-person and online support groups across the country. There are a growing number of groups for people in the early stage of Alzheimer's and their families. Support

networks can be especially valuable when caregivers face the difficult decision of whether and when to place a loved one in a nursing home or assisted living facility. For more information about at-home caregiving, see **Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging** at www.nia.nih.gov/Alzheimers/Publications/CaringAD.

Advancing Our Understanding

Thirty years ago, we knew very little about Alzheimer's disease. Since then, scientists have made many important

advances. Research supported by NIA and other organizations has expanded knowledge of brain function in healthy older people, identified ways we might lessen normal age-related declines in mental function, and deepened our understanding of the disease. Many scientists and physicians are now working together to untangle the genetic, biological, and environmental factors that, over many years, ultimately result in Alzheimer's. This effort is bringing us closer to the day when we will be able to manage successfully or even prevent this devastating disease.

For More Information

To learn about support groups, services, research centers, research studies, and publications about Alzheimer's disease, contact the following resources:

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380 (toll-free)
www.nia.nih.gov/Alzheimers

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. The ADEAR website provides free, online publications in English and Spanish; email alert and online *Connections* newsletter subscriptions; an Alzheimer's disease

clinical trials database; the Alzheimer's Disease Library database; and more.

Alzheimer's Association

225 N. Michigan Avenue, Floor 17
Chicago, IL 60601-7633
1-800-272-3900 (toll-free)
1-866-403-3073 (TDD/toll-free)
www.alz.org

Alzheimer's Foundation of America

322 Eighth Avenue, 7th Floor
New York, NY 10001
1-866-AFA-8484 (1-866-232-8484; toll-free)
www.alzfdn.org

Eldercare Locator

1-800-677-1116 (toll-free)
www.eldercare.gov

Family Caregiver Alliance

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
1-800-445-8106 (toll-free)
www.caregiver.org

NIH Senior Health

www.nihseniorhealth.gov/alzheimersdisease/toc.html

Alzheimer's Disease Medications

FACT SHEET

Several prescription drugs are currently approved by the U.S. Food and Drug Administration (FDA) to treat people who have been diagnosed with Alzheimer's disease. Treating the symptoms of Alzheimer's can provide patients with comfort, dignity, and independence for a longer period of time and can encourage and assist their caregivers as well.

It is important to understand that none of these medications stops the disease itself.

Treatment for Mild to Moderate Alzheimer's

Medications called cholinesterase inhibitors are prescribed for mild to moderate Alzheimer's disease. These drugs may help delay or prevent symptoms from becoming worse for a limited time and may help control some behavioral symptoms. The medications include Razadyne® (galantamine), Exelon® (rivastigmine), and Aricept® (donepezil). Another drug, Cognex® (tacrine), was the first approved cholinesterase inhibitor but is rarely prescribed today due to safety concerns.

Scientists do not yet fully understand how cholinesterase inhibitors work to treat Alzheimer's disease, but research indicates that they prevent the breakdown of acetylcholine, a brain chemical believed to be important for memory and

thinking. As Alzheimer's progresses, the brain produces less and less acetylcholine; therefore, cholinesterase inhibitors may eventually lose their effect.

No published study directly compares these drugs. Because they work in a similar way, switching from one of these drugs to another probably will not produce significantly different results. However, an Alzheimer's patient may respond better to one drug than another.

Treatment for Moderate to Severe Alzheimer's

A medication known as Namenda® (memantine), an N-methyl D-aspartate (NMDA) antagonist, is prescribed to treat moderate to severe Alzheimer's disease. This drug's main effect is to delay progression of some of the symptoms of moderate to severe Alzheimer's. It may allow patients to maintain certain daily functions a little longer than they would without the medication. For example, Namenda® may help a patient in the later stages of the disease maintain his or her ability to use the bathroom independently for several more months, a benefit for both patients and caregivers.

Namenda® is believed to work by regulating glutamate, an important brain chemical. When produced in excessive amounts, glutamate may lead to brain cell death. Because NMDA antagonists

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National Institutes of Health
U.S. Department of Health and Human Services



Medications to Treat

This brief summary does not include all information important for professional medical advice. Consult the prescribing information for any other medications or supplements. Drugs are listed

DRUG NAME	DRUG TYPE AND USE	HOW IT WORKS	COMMON SIDE EFFECTS
Namenda® (memantine)	N-methyl D-aspartate (NMDA) antagonist prescribed to treat symptoms of moderate to severe Alzheimer's	Blocks the toxic effects associated with excess glutamate and regulates glutamate activation	Dizziness, headache, constipation, confusion
Razadyne® (galantamine)	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate Alzheimer's	Prevents the breakdown of acetylcholine and stimulates nicotinic receptors to release more acetylcholine in the brain	Nausea, vomiting, diarrhea, weight loss, loss of appetite
Exelon® (rivastigmine)	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate Alzheimer's	Prevents the breakdown of acetylcholine and butyrylcholine (a brain chemical similar to acetylcholine) in the brain	Nausea, vomiting, diarrhea, weight loss, loss of appetite, muscle weakness
Aricept® (donepezil)	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate, and moderate to severe Alzheimer's	Prevents the breakdown of acetylcholine in the brain	Nausea, vomiting, diarrhea

*Available as a generic drug.

Alzheimer's Disease

ant for patient use and should not be used as a substitute doctor and read the package insert before using these or in order of FDA approval, starting with the most recent.

MANUFACTURER'S RECOMMENDED DOSAGE	FOR MORE INFORMATION
<ul style="list-style-type: none"> • Tablet: Initial dose of 5 mg once a day • May increase dose to 10 mg/day (5 mg twice a day), 15 mg/day (5 mg and 10 mg as separate doses), and 20 mg/day (10 mg twice a day) at minimum 1-week intervals if well tolerated • Oral solution: same dosage as above • Extended-release tablet: Initial dose of 7 mg once a day; may increase dose to 14 mg/day, 21 mg/day, and 28 mg/day at minimum 1-week intervals if well tolerated 	<p>For current information about this drug's safety and use, visit www.namenda.com. Click on "Prescribing Information" to see the drug label.</p>
<ul style="list-style-type: none"> • Tablet*: Initial dose of 8 mg/day (4 mg twice a day) • May increase dose to 16 mg/day (8 mg twice a day) and 24 mg/day (12 mg twice a day) at minimum 4-week intervals if well tolerated • Oral solution*: same dosage as above • Extended-release capsule*: same dosage as above but taken once a day 	<p>For current information about this drug's safety and use, visit www.razadyneer.com. Click on "Important Safety Information" to see links to prescribing information.</p>
<ul style="list-style-type: none"> • Capsule*: Initial dose of 3 mg/day (1.5 mg twice a day) • May increase dose to 6 mg/day (3 mg twice a day), 9 mg (4.5 mg twice a day), and 12 mg/day (6 mg twice a day) at minimum 2-week intervals if well tolerated • Patch: Initial dose of 4.6 mg once a day; may increase to 9.5 mg once a day after minimum of 4 weeks if well tolerated • Oral solution: same dosage as capsule 	<p>For current information about this drug's safety and use, visit www.fda.gov/cder. Click on "Drugs@FDA," search for Exelon, and click on drug-name links to see "Label Information."</p>
<ul style="list-style-type: none"> • Tablet: Initial dose of 5 mg once a day • May increase dose to 10 mg/day after 4-6 weeks if well tolerated • Orally disintegrating tablet: same dosage as above 	<p>For current information about this drug's safety and use, visit www.fda.gov/cder. Click on "Drugs@FDA," search for Aricept, and click on drug-name links to see "Label Information."</p>

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work very differently from cholinesterase inhibitors, the two types of drugs can be prescribed in combination.

The FDA has also approved Aricept® for the treatment of moderate to severe Alzheimer's disease.

Dosage and Side Effects

Doctors usually start patients at low drug doses and gradually increase the dosage based on how well a patient tolerates the drug. There is some evidence that certain patients may benefit from higher doses of the cholinesterase inhibitors. However, the higher the dose, the more likely are side effects. The recommended effective dosages of drugs prescribed to treat the symptoms of Alzheimer's and the drugs' possible side effects are summarized in the table (see inside).

Patients should be monitored when a drug is started. Report any unusual symptoms to the prescribing doctor right away. It is important to follow the doctor's instructions when taking any medication, including vitamins and herbal supplements. Also, let the doctor know before adding or changing any medications.

Testing New Alzheimer's Drugs

Clinical trials are the best way to find out if promising new treatments are safe and effective in humans. Volunteer participants are needed for many Alzheimer's trials conducted around the United States. To learn more, talk with your doctor or visit the ADEAR Center's listing of clinical trials at www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials. More information is available at www.ClinicalTrials.gov.

For More Information

To learn about support groups, research centers, research studies, and publications about Alzheimer's disease, contact the following resources:

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380 (toll-free)
www.nia.nih.gov/Alzheimers

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and professionals on Alzheimer's disease research, diagnosis, treatment, patient care, caregiver needs, long-term care, education, and training. Staff members answer telephone, email, and written requests and make referrals to local and national resources. The ADEAR website

offers free, online publications in English and Spanish; email alert and online newsletter subscriptions; an Alzheimer's clinical trials database; the Alzheimer's Disease Library database; and more.

Alzheimer's Association

225 North Michigan Avenue, Floor 17
Chicago, IL 60601-7633
1-800-272-3900 (toll-free)
1-866-403-3073 (TDD/toll-free)
www.alz.org

The Alzheimer's Association is a national nonprofit association with a network of local chapters that provide education and support for people diagnosed with Alzheimer's, their families, and caregivers. The Association also supports research on Alzheimer's.

Dementia - different types

Dementia is a broad term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning. Dementia symptoms include loss of memory, intellect, rationality, social skills and normal emotional reactions.

Dementia is not a normal part of ageing

Most people with dementia are older, but it is important to remember that most older people do not get dementia. It is not a normal part of ageing. Dementia can happen to anybody, but it is more common after the age of 65 years. People in their 40s and 50s can also have dementia.

There are many forms of dementia

There are many different forms of dementia and each has its own causes. Dementia may also be a symptom that develops in the later stages of some illnesses. Some of the most common forms or causes of dementia include:

- Alzheimer's disease
- Vascular dementia
- Parkinson's disease
- Dementia with Lewy bodies
- Huntington's disease
- Alcohol related dementia – Korsakoff's syndrome
- AIDS related dementia
- Fronto Temporal Lobar Degeneration (FTLD)
- Creutzfeldt-Jakob disease.

Alzheimer's disease

Alzheimer's disease is the most common form of dementia and accounts for between 50 and 70 per cent of all cases. It is a progressive degenerative illness that attacks the brain. As brain cells shrink or disappear, abnormal material builds up as 'tangles' in the centre of the cells and 'plaques' form outside the cells. These disrupt messages within the brain, damaging connections between brain cells.

The cells eventually die and this means that information cannot be recalled or assimilated. As Alzheimer's disease progressively affects different areas of the brain, certain functions or abilities are lost.

Vascular dementia

Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain. It is the second most common form of dementia. There are a number of different types of vascular dementia. Two of the most common are:

- **Multi-infarct dementia** – caused by a number of small strokes, called mini-strokes or transient ischaemic attacks (TIA). This is probably the most common form of vascular dementia.
- **Binswanger's disease** (also known as subcortical vascular dementia) – associated with stroke-related changes to the brain. It is caused by high blood pressure, thickening of the arteries and inadequate blood flow.

Vascular dementia may appear similar to Alzheimer's disease. A mixture of Alzheimer's disease and vascular dementia can occur in some people.

Parkinson's disease

Parkinson's disease is a progressive disorder of the central nervous system, characterised by tremors, stiffness in limbs and joints, speech impediments and difficulty in initiating physical movements. Late in the course of the disease, some people may develop dementia. Drugs may improve the physical symptoms, but can have side effects including hallucinations, delusions and a temporary worsening of confusion and abnormal movements.

Dementia with Lewy bodies

Dementia with Lewy bodies is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal spherical structures called Lewy bodies inside the cells – it is thought these may contribute to the death of brain cells. People who have dementia with Lewy bodies tend to see things (visual hallucinations) or experience stiffness or shakiness (parkinsonism), and their condition tends to fluctuate quite rapidly, often from hour to hour or day to day. These symptoms make it different from Alzheimer's disease.

Dementia with Lewy bodies sometimes occurs along with Alzheimer's disease and/or vascular dementia. It may be hard to distinguish dementia with Lewy bodies from Parkinson's disease and some people who have Parkinson's disease develop a dementia similar to that seen in dementia with Lewy bodies.

Huntington's disease

Huntington's disease is an inherited degenerative brain disease that affects the mind and body. It usually appears between the ages of 30 and 50, and is characterised by intellectual decline and irregular involuntary movement of the limbs or facial muscles. Other symptoms include personality change, memory disturbance, slurred speech, impaired judgement and psychiatric problems.

There is no treatment available to stop the progression of the disease, but medication can control movement disorders and psychiatric symptoms. Dementia occurs in the majority of Huntington's cases.

Alcohol related dementia – Korsakoff's syndrome

Too much alcohol, particularly if associated with a diet deficient in thiamine (vitamin B1), can lead to irreversible brain damage. If drinking stops there may be some improvement.

This type of dementia is preventable. The National Health and Medical Research Council of Australia's recommendations for the safe use of alcohol are that men should drink no more than four standard drinks daily and women should drink no more than two standard drinks daily. Development of alcohol related dementia and Korsakoff's syndrome has not been reported in people drinking regularly at or below these levels.

The most vulnerable parts of the brain are those used for memory and for planning, organising and judgement, social skills and balance. Taking thiamine appears to help prevent and improve the condition.

AIDS related dementia

AIDS related dementia, or AIDS dementia complex (ADC), is a complication that affects some people with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). It is uncommon in people in the early stages of HIV/AIDS, but may increase as the disease advances. Not everyone who has HIV/AIDS will develop ADC. It is thought to affect around seven per cent of people with HIV/AIDS who are not taking anti-HIV drugs.

ADC is a complicated syndrome made up of different nervous system and mental symptoms. There are particular issues that may need to be addressed with this type of dementia, as it often affects young people. Issues to be addressed may include employment, identity and sexuality issues.

Fronto temporal lobar degeneration (FTLD)

This is the name given to a group of dementias that involve degeneration in one or both of the frontal or temporal lobes of the brain. It includes fronto temporal dementia, progressive non-fluent aphasia, semantic dementia and Pick's disease. About 50 per cent of people with FTLD have a family history of the disease. Those who inherit it often have a mutation in the tau protein gene on chromosome 17, leading to abnormal tau protein being produced. No other risk factors are known.

Creutzfeldt-Jakob disease

Creutzfeldt-Jakob disease is an extremely rare and fatal brain disorder caused by a protein particle called prion. It occurs in one in every million people per year. Early symptoms include failing memory, changes of behaviour and lack of coordination. As the disease progresses – usually very rapidly – mental deterioration becomes pronounced, involuntary movements appear and the person may become blind, develop weakness in the arms or legs and, finally, lapse into a coma.

Deciding if it is dementia

There are a number of conditions that have symptoms similar to those of dementia. By treating these conditions, the symptoms will often disappear.

These include:

- Some vitamin deficiencies and hormone disorders
- Depression
- Medication clashes or overmedication
- Infections
- Brain tumour.

It is essential that a medical diagnosis is obtained at an early stage, when symptoms first appear, to make sure that a person who has a treatable condition is diagnosed and treated correctly. If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information and medication (should it be available).

How to know if dementia is inherited

This will depend on the cause of the dementia, so it is important to have a firm medical diagnosis. If there are concerns about the risk of inheriting dementia, consult with your doctor or contact Alzheimer's Australia to speak with a counsellor. Most cases of dementia are not inherited.

The early signs of dementia

The early signs of dementia are subtle and vague, and may not be immediately obvious. However, common symptoms include:

- Progressive and frequent memory loss
- Confusion
- Personality change
- Apathy and withdrawal
- Loss of ability to do everyday tasks.

Symptoms may be reduced with medication

At present there is no prevention or cure for most forms of dementia. However, some medications have been found to reduce some symptoms.

Support is vital for people with dementia and the help of families, friends and carers can make a positive difference to managing the condition.

Where to get help

- Your doctor
- Your local community health service
- Your local council
- National Dementia Helpline Tel. 1800 100 500
- Dementia Behaviour Management Advisory Service (DBMAS) Tel. 1800 699 799 – for 24-hour telephone advice for carers and care workers
- Carer Respite Centre Tel. 1800 059 059
- Carer Resource Centres Tel. 1800 242 636
- Aged Care Assessment Services – contact your regional Department of Health office
- Aged Care Information Line Tel. 1800 500 853

Things to remember

- Dementia describes a broad range of symptoms, such as loss of memory, intellect, rationality, social skills and normal emotional reactions.
- There are different forms of dementia and each has its own causes.
- There is currently no prevention or cure for most forms of dementia; however, symptoms may be reduced with medication.

This page has been produced in consultation with, and approved by:

Alzheimer's Australia Victoria

This Better Health Channel fact sheet has passed through a rigorous approval process. The information provided was accurate at the time of publication and is not intended to take the place of medical advice. Please seek advice from a qualified health care professional.

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KNOW^{the} 10 SIGNS

EARLY DETECTION MATTERS

Have you noticed any of these warning signs?

Please list any concerns you have and take this sheet with you to the doctor.

Note: This list is for information only and not a substitute for a consultation with a qualified professional.

____ 1. **Memory changes that disrupt daily life.** One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. **What's typical?** Sometimes forgetting names or appointments, but remembering them later.

____ 2. **Challenges in planning or solving problems.** Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. **What's typical?** Making occasional errors when balancing a checkbook.

____ 3. **Difficulty completing familiar tasks at home, at work or at leisure.** People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. **What's typical?** Occasionally needing help to use the settings on a microwave or to record a television show.

____ 4. **Confusion with time or place.** People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. **What's typical?** Getting confused about the day of the week but figuring it out later.

____ 5. **Trouble understanding visual images and spatial relationships.** For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. **What's typical?** Vision changes related to cataracts.

____6. **New problems with words in speaking or writing.** People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a "watch" a "hand-clock"). **What's typical?** Sometimes having trouble finding the right word.

____7. **Misplacing things and losing the ability to retrace steps.** A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. **What's typical?** Misplacing things from time to time, such as a pair of glasses or the remote control.

____8. **Decreased or poor judgment.** People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. **What's typical?** Making a bad decision once in a while.

____9. **Withdrawal from work or social activities.** A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. **What's typical?** Sometimes feeling weary of work, family and social obligations.

____10. **Changes in mood and personality.** The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. **What's typical?** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you have questions about any of these warning signs, the Alzheimer's Association recommends consulting a physician. Early diagnosis provides the best opportunities for treatment, support and future planning.

For more information, go to www.alz.org/10signs or call 877-IS IT ALZ (877.474.8259).

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Preparing for Your Doctor's Visit

Fill out the information below to the best of your ability. Share it with your doctor. Be open and honest in answering any questions your doctor may ask you about the changes you've been experiencing.

Has your health, memory or mood changed?

How did it change?

When did you first notice the change?

How often does it happen?

When does it happen? Is it always at a certain time of day?

What do you do when it happens?

What behaviors are the same?

Do you have problems with any of the following?

Please check the answer.

Repeating or asking the same thing over and over?

- Not at all Sometimes Frequently Does not apply

Remembering appointments, family occasions, holidays?

- Not at all Sometimes Frequently Does not apply

Writing checks, paying bills, balancing the checkbook?

- Not at all Sometimes Frequently Does not apply

Shopping independently (e.g., for clothing or groceries)?

Not at all

Sometimes

Frequently

Does not apply

Taking medications according to the instructions?

Not at all

Sometimes

Frequently

Does not apply

Getting lost while walking or driving in familiar places?

Not at all

Sometimes

Frequently

Does not apply

Medications and medical history

List medications (dosage, frequency) including over-the-counter and prescription:

List vitamins and herbal supplements:

List current medical conditions:

List past medical conditions:

Questions to ask the doctor

What are the tests I need to take and how long will it take to get a diagnosis?

Will you refer me to a specialist?

Could the medicines I'm taking be causing my symptoms?

Do I have any other conditions that could be causing my symptoms or making them worse?

What should I expect if it is Alzheimer's?

Which treatments are available for Alzheimer's? What are the risks and benefits and possible side effects?

What about participating in a clinical trial? What are the risks and benefits?

Is there anything else I should know?

When should I come back for another visit?

Some information in this tool was developed for the Chronic Care Networks for Alzheimer's Disease (CCN/AD) project and is the joint property of the Alzheimer's Association and the National Chronic Care Consortium.

principles for a dignified diagnosis

Principles for a Dignified Diagnosis is the first statement of its kind written by people with dementia on the subject of the Alzheimer diagnosis experience.

In the 2008 report *Voices of Alzheimer's Disease: A Summary Report on the Nationwide Town Hall Meetings for People with Early Stage Dementia*, the Alzheimer's Association identified diagnostic challenges and dissatisfying interactions with the medical community as two major challenges articulated by people living with the disease. These principles are their insights on how to make that experience better.

Talk to me directly, the person with dementia.

I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.

Tell the truth.

Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.

Test early.

Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.

Take my concerns seriously, regardless of my age.

Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.

Deliver the news in plain but sensitive language.

This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.

❑ ***Coordinate with other care providers.***

I may be seeing more than one specialist — it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don't have to repeat any tests unnecessarily.

❑ ***Explain the purpose of different tests and what you hope to learn.***

Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

❑ ***Give me tools for living with this disease.***

Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.

❑ ***Work with me on a plan for healthy living.***

Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

❑ ***Recognize that I am an individual and the way I experience this disease is unique.***

This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

❑ ***Alzheimer's is a journey, not a destination.***

Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

The Alzheimer's Association is the leading voluntary health care organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

For reliable information and support, contact the Alzheimer's Association:

1.800.272.3900
www.alz.org

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