FAQ - Frequently Asked Questions re: Alzheimer’s Disease

What is Alzheimer’s disease?

First described by Dr. Alois Alzheimer in 1906, Alzheimer’s disease (pronounced Alts’-hi-merz) is a degenerative brain disease that usually begins gradually, causing a person to forget recent events or familiar tasks. How rapidly it advances varies from person to person, but the brain disease eventually causes confusion, personality and behavior changes, and impaired judgment. Communication becomes difficult as the affected person struggles to find words, finish thoughts, or follow directions. Eventually, most people with Alzheimer’s disease become unable to care for themselves.

What is dementia?

Dementia is an umbrella term used to describe the loss of cognitive or intellectual function. Many conditions can cause dementia. Dementia related to depression, drug interactions, and thyroid and other problems may be reversible if detected early. That’s one of the reasons it’s important to obtain a professional assessment, so that the actual cause can be identified and proper care provided. Several other diseases also cause dementia, such as Parkinson’s, Creutzfeldt-Jakob, Huntington’s, and multi-infarct or vascular disease, caused by multiple strokes in the brain.

Isn’t memory loss a natural part of aging?

Yes and no. Many healthy individuals are less able to remember certain kinds of information as they get older. But the symptoms of Alzheimer’s disease involve more than simple lapses in memory. People with Alzheimer’s experience difficulties in communicating, learning, thinking, and reasoning that can have an impact on a person’s work and social and family life. Alzheimer’s is a disease that destroys brain cells — which is not a normal part of aging.

How many people are affected by Alzheimer’s disease?

One in 10 persons over 65 and nearly half of those over 85 have Alzheimer’s disease. Today, four million Americans have Alzheimer’s disease. Unless a cure or prevention is found, that number will jump to 14 million by the year 2050. Worldwide, it is estimated that 22 million individuals will develop Alzheimer’s disease by the year 2025. Caregivers are affected by this disease, too. In a national survey, 19 million Americans said they have a family member with Alzheimer’s disease, and 37 million said they knew someone with the disease.

What are the warning signs?

The Alzheimer’s Association has developed a list of warning signs that include common symptoms of Alzheimer’s disease (some also apply to other dementias). Individuals who exhibit several of these symptoms should see a physician for a complete examination.

1. Memory loss that affects job skills. It’s normal to occasionally forget an assignment, deadline, or colleague’s name, but frequent forgetfulness or unexplainable confusion at home or in the workplace may signal that something’s wrong.
2. **Difficulty performing familiar tasks.** Busy people get distracted from time to time. For example, you might leave something on the stove too long or not remember to serve part of a meal. People with Alzheimer’s might prepare a meal and not only forget to serve it but also forget they made it.

3. **Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer’s disease may forget simple words or substitute inappropriate words, making his or her sentences difficult to understand.

4. **Disorientation to time and place.** It’s normal to momentarily forget the day of the week or what you need from the store. But people with Alzheimer’s disease can become lost on their own street, not knowing where they are, how they got there, or how to get back home.

5. **Poor or decreased judgment.** Choosing not to bring a sweater or coat along on a chilly night is a common mistake. A person with Alzheimer’s, however, may dress inappropriately in more noticeable ways, wearing a bathrobe to the store or several blouses on a hot day.

6. **Problems with abstract thinking.** Balancing a checkbook can be challenging for many people, but for someone with Alzheimer’s, recognizing numbers or performing basic calculations may be impossible.

7. **Misplacing things.** Everyone temporarily misplaces a wallet or keys from time to time. A person with Alzheimer’s disease may put these and other items in inappropriate places — such as an iron in the freezer or a wristwatch in the sugar bowl — and then not recall how they got there.

8. **Changes in mood or behavior.** Everyone experiences a broad range of emotions — it’s part of being human. People with Alzheimer’s tend to exhibit more rapid mood swings for no apparent reason.

9. **Changes in personality.** People’s personalities may change somewhat as they age. But a person with Alzheimer’s can change dramatically, either suddenly or over a period of time. Someone who is generally easygoing may become angry, suspicious, or fearful.

10. **Loss of initiative.** It’s normal to tire of housework, business activities, or social obligations, but most people retain or eventually regain their interest. A person with Alzheimer’s disease may remain uninterested and uninvolved in many or all of his usual pursuits.

**What causes Alzheimer’s disease?**

Scientists still are not certain. Age and family history have been identified as potential risk factors. Researchers are exploring the role of genetics in the development of Alzheimer’s, but most agree the disease is likely caused by a variety of factors. Each year, scientists are uncovering important new clues about potential causes of the disease, which is helping to generate more accurate diagnostic tests and better treatment options for affected individuals.

**How is Alzheimer’s disease diagnosed?**

There is no single, comprehensive diagnostic test for Alzheimer’s disease. Instead, physicians or other specialists rule out other conditions through a process of elimination. They usually conduct physical, psychological, and neurological exams and take a thorough medical history. A diagnosis of probable Alzheimer’s disease can be obtained through evaluation with approximately 90 percent accuracy. The only way to confirm a diagnosis of Alzheimer’s disease is through autopsy.

**How does Alzheimer’s disease progress?**

Alzheimer’s disease causes the formation of abnormal structures in the brain called plaques and tangles. As they accumulate in affected individuals, nerve cell connections are reduced. Areas of the brain that influence short-term memory tend to be affected first. Later, the disease works its way into sections of the brain that control other intellectual and physical functions.
Alzheimer’s disease affects people in different ways, making it difficult for medical professionals to predict how an individual’s disease will progress. Some experts classify the disease by stage (early, middle, and late). But specific behaviors and how long they last vary greatly, even within each stage of the disease. As more is learned about the progression of the disease, new assessment scales are being developed to help physicians track, predict, and treat symptoms of Alzheimer’s disease.

Does Alzheimer’s disease run in families?

The evidence is not clear. Cases where several members of a single family have been diagnosed with Alzheimer’s are rare (except in families who have a history of early-onset Alzheimer’s, a form of the disease that typically strikes middle-aged members of the same family). Much more common is the situation where a single family member is diagnosed with Alzheimer’s disease late in life.

Can Alzheimer’s disease occur in younger adults?

Yes, though less frequently. The disease can occur in people in their 30s, 40s, and 50s. However, most people diagnosed with Alzheimer’s are older than 65. The early onset form of the disease that strikes younger people accounts for less than 10 percent of all reported cases. Scientists believe this variation of the disease may be genetically transmitted across multiple generations of the same family.

What treatment is available?

There is no medical treatment currently available to cure or stop the progression of Alzheimer’s disease. Four FDA-approved drugs — tacrine (Cognex®), donepezil (Aricept®), and rivastigmine (Exelon®), and galantamine (Reminyl®) — may temporarily relieve some symptoms of the disease. Many other new promising drugs are now being developed — some which may be available within the next few years. Medication and nondrug therapies are also available to reduce some of the behavioral symptoms associated with Alzheimer’s, such as depression, sleeplessness, and agitation.

What is being done to find a cure or prevention?

Alzheimer research is being tackled from many sides. Pharmaceutical companies, the U.S. federal government, and the Alzheimer’s Association are funding research to learn more about the disease process and to find compounds that will alleviate symptoms and prevent or cure the disease.

What should I do if I feel overwhelmed by my diagnosis?

1. **Contact the Alzheimer’s Association.** Nearly 200 Association chapters nationwide provide programs and services for people with Alzheimer’s and their families. When talking with a chapter representative, ask the following questions:
   - What kind of information do you have available?
   - What kind of support groups do you offer?
   - What other programs and services are available in the area?
   - Who can help us plan for the future?

2. **Talk to your physician.** As Alzheimer’s disease progresses, you may experience physical and behavioral changes. Some of these changes may be treatable, so ongoing communication with a physician who understands the disease is important. When talking with a doctor, ask:
   - Are additional tests needed to confirm the diagnosis?
   - Can symptoms be treated?
   - How much do these treatments cost? Are there side effects? Are the treatments reimbursable?
   - What else can be done to alleviate symptoms?
   - Are there clinical drug trials being conducted in the area?

3. **Plan for the future.** Soon after learning the diagnosis, it is important to start putting legal and financial documents, such as a living will and power of attorney, into place. Ask legal and financial professionals:
• What documents are used for persons with dementia?
• What is legal capacity, and how do you determine it?
• What long-term care services are covered by Medicare or health insurance policies?

4. Locate care services. At some point, you may need assistance in the home or be interested in alternative care options. Case managers and social workers from the Association or the Area Agency on Aging can help you learn more about local services and offer guidance in making decisions. They can help you address the following issues:
• What services could help?
• What additional care options are available in this community?
• Is assistance available to help pay for these services?
• How do you find a facility/program that provides quality care?

How can I participate in clinical drug trials?

You should consider a variety of factors before volunteering to participate in a clinical drug study. Here is some practical information about what may be involved and what to expect.
• If your physician agrees that enrolling might be beneficial, read about the drugs in clinical trials and the eligibility requirements for participation.
• Be prepared to answer questions about your condition. When you or your caregiver contacts a study center, the initial conversation with researchers usually will include a phone interview to determine eligibility for the study. You may need to report when a diagnosis of Alzheimer’s was made, if you are generally good health, and whether you reside at home or in a facility. The researchers also will want to know if a caregiver will be available to assist you throughout the duration of the study.
• Additional testing may be needed to determine eligibility. You and your caregiver may receive an invitation to the study site for further screening, including an assessment of medical and psychiatric history, physical and neurological examinations, an imaging exam (usually a CT scan or MRI), and blood and urine tests. Most drug studies provide these initial screening examinations, along with the medication used during the study, and routine follow-up examinations free of charge to the participant.
• Be aware of the responsibility involved in participating. Volunteering requires a serious time commitment from participants and caregivers. Researchers expect drugs to be administered according to schedule, regular follow-up visits to the study site, and reports on any changes seen in the participant’s condition or behavior.
• Understand that clinical studies determine the effectiveness and safety of a drug. Volunteering may involve some risk since the treatments being tested are still considered experimental. There is a chance the drug being tested will be helpful, and if the drug causes discomfort, a participant can drop out of the study at any time.
• Know that not all participants are given the medication being tested. In almost every study, participants are divided into two groups — an experimental group (which receives the active drug) and a control group (which receives a placebo, or “sugar pill”). Neither the participants nor the researchers know who is taking the active drug and who is in the placebo group.

Can I continue to live independently?

Whether you can continue to live independently depends on the progression of the disease and your remaining abilities. Some of these include your ability to handle money, do routine chores, make decisions, work, and drive and live safely. You may be able to live alone or with some assistance for some time. However, as the disease progresses, your care needs will increase, and you will need to rely on others for more help.

How do I handle my anger?

It’s normal to get angry. Your anger may arise from having the disease or from daily frustrations. The hard
part is eventually letting go of that anger so it does not consume you. The best way to deal with your anger is to acknowledge that what you are feeling is anger and that it’s okay. Then talk about it with your family, friends, or counselor; in an on-line chat room; or at a support group. Try to specify who or what is making you angry. Your local chapter of the Alzheimer’s Association can refer you to counselors and support groups.

**Why should I participate in a support group?**

Alzheimer’s creates many challenges in your daily life, and a support group allows you to hear how others have coped or are coping with similar situations. Support groups are safe places to talk openly about difficult issues and feelings. And you may find that other group members will become a great source of comfort and encouragement. To find a support group near you, contact your local chapter of the Alzheimer’s Association.