Information Sheet: **ALZHEIMER'S DISEASE (AD)**

Definition: Alzheimer's disease (AD) is a degenerative brain disease and it is the most common cause of dementia. All forms of dementia result in memory and thinking changes severe enough to affect a person's ability to function safely and independently. Over time, the ability to remember new information, to learn new things, communicate, and to reason and exercise good judgement is lost. As AD progresses and the person loses the ability to remain independent, they may experience changes in orientation; behavioral and personality changes may occur along with false beliefs, paranoid thinking, and hallucinations. New research criteria for the stages of AD is now focused on the continuum from Pre-Clinical to Mild Cognitive Impairment to fully expressed disease when an evaluation and diagnosis of dementia is made. At this time, no cure for Alzheimer's disease is available but research is advancing to identify better ways to delay or slow down the onset of AD.

There are many issues faced by people with dementia and those who care for them, BUT every person with AD is different and will need a tailored plan of care.

Statistics: According to the Alzheimer's Association, 5.3 million Americans have dementia, including 1 in 9 people over 65 and 1 in 3 people over 85.

- By 2050, it is expected that 13.8 to 16 million Americans will have the disease.
- AD makes up about 60% of all types of dementia (conditions that cause cognitive loss to the point that a person's ability to function independently is impaired).
- Fewer that 50% of those with AD have the diagnosis written on their medical records, and therefore may not be getting the care they need.

Risk Factor: AD is characterized by a protein "plaque" (amyloid) that deposits *between* cells in the brain and another protein that breaks down *inside* the cells and forms a "tangle" (tau), as well as nerve cell damage and death in the brain. Though scientists do not yet have a clear understanding of how or why theses plaques and tangles form, there are risk factors that may contribute to the disease.

Established Risk Factors:

- Age is the number one risk factor for AD.
- Women are a greater risk of AD than men.
- Family history may contribute:
    - Having a brother, sister, parent or child with AD increases risk.
    - Having an Apo-E4 allele, a gene you may inherit from your parents.
    - <1% of people with AD have an inherited, familial form of the disease that is usually diagnosed at a younger age than non-familial AD.

Healthy habits that may lower your risk:

- Moderately brisk aerobic exercise most days of the week.
- Diet with plenty of fresh fruits and vegetables and low in fat.
- Lifelong learning activities.
- Social engagement.
- Good control of other conditions that affect brain health, such as high blood pressure, diabetes, high cholesterol, mid-life obesity, and sleep apnea.
- Protect against head injuries: wear a helmet!

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Symptoms/Warning Signs: At early stages, the signs of AD can be difficult to distinguish from normal brain aging. With normal aging, a person's speed of thinking, processing information and shifting between tasks may slow, but their ability to learn new information and do the things they have always done stays intact. The following is a list of ten warning signs of dementia prepared by the Alzheimer's Association. These items can be problems if they are a *change* from how the person has always been:

1. **Memory loss that disrupts daily life.**
2. **Challenges with planning/problem solving.**
3. **Difficulty performing familiar tasks.**
4. **Confusion with time or place.**
5. **Trouble understanding visual images and spatial relationships.**
6. **Problems with language.**
7. **Misplacing things.**
8. **Decreased or poor judgement.**
9. **Withdrawal from work or social activities.**
10. **Changes in mood and personality.**

If you or a loved one experiences these problems, see a physician trained to care for those with memory disorders who can provide appropriate diagnosis and treatment.

Why Get a Diagnosis?

Though there is not yet a cure for AD, there are benefits to having an early diagnosis:

- Opportunity for the person to be involved in future planning for personal and business affairs.
- Time to address other illnesses that may have a negative impact on the brain.
- Time to maximize the value of available medications which have greatest benefit if started early in the disease process.
- Time to make adaptations for a longer period of "supported" independence.
- Opportunity to educate caregivers about the disease which can lessen their stress as they face difficult behaviors.
- Opportunity for families to enjoy the time they have together.

Diagnosis: This is an intense area of research with new strategies being developed to use imaging technologies and disease biomarkers that can be tested in the spinal fluid. The hope is to diagnose AD earlier and with more accuracy. Given a year to follow a person, a clinical diagnosis approached 95% accuracy. For diagnosis, a physician needs to:

- Talk with others who know the person well and can provide reliable history about changes they may have seen in the person's thinking and ability to do day to day activities.
- Obtain blood work to rule out reversible causes of memory loss such as infections, electrolyte or endocrine abnormalities, vitamin deficiencies, other illnesses.
- Review medications and do a physical exam.
- Perform cognitive tests.
- Consider CT, MRI, or other brain scan.

Treatment options: Treatment guidelines are aimed at slowing symptom progression, managing symptoms caused by the disease, and treating other health conditions that might affect the person's cognitive health. Currently there is no cure for dementia.

Medications available include:

- Cholinesterase inhibitors such as donepezil (Aricept), galantamine (Razadyne) and rivastigmine (Exelon).
    - Used to prevent the breakdown of acetylcholine, one of the chemicals in our brains used for memory.

- NMDA receptor antagonist, memantine (Namenda).
    - May be protective to injured nerve cells.
- Medications for symptom management or behavioral difficulties. Depression, anxiety, insomnia, hallucinations, delusions, paranoia, agitation, sundowning, or other behaviors.
- Treatment of other health conditions that impact a person's memory such as diabetes, high blood pressure, heart disease, or sleep disorders.
- If medication is started, ask the doctor:
    - How long will it be taken? Is there an appropriate time to consider stopping the medication?
    - How do you know if it is working?
    - Are there side effects?
    - How much does it cost? Is there help available to pay for it?

Other Treatment Consideration:

AD is a "family disease" because as a person loses their ability to function independently, others around them help to provide care. Treatment plans are best when they involve the entire family and include education and support services with medical care.

- **Consider Safety Issues** such as driving, finances, medications, fire hazards, nutrition, accessing help in an emergency, or the potential to get lost. Enlist your family and your doctor's help to address these concerns.
- **Obtain Advance Directives** Including a living will, Healthcare Power of Attorney, and Durable Power of Attorney (for financial affairs). This helps facilitate an understanding of a person's wishes and a means for them to be honored when they can no longer express them.
- **Participation in Support Groups** can be valuable for the support provided and to learn strategies others have found useful.
- **Counseling** with emotional and practical support can prolong a caregiver's ability to care for a loved one at home and help avoid isolation.
- **Access to Educational Materials** about the disease's progression can ease caregiver stress.
- **Utilization of Respite Options** may preserve a caregiver's health, prolong the time a person can live in the home setting, and facilitate a caregiver's ability to remain employed.
- **Develop a Network of Family, Friends, Community Services, and Local Care Facilities.** Having support at all stages of a progressive dementia is invaluable. It is critical to develop a back-up plan in the event the primary caregiver is no longer able to provide care.

What to Expect Long Term?

Alzheimer's disease progresses through various stages and as yet there is no cure. If a person does not die of some other cause such as a heart attack, stroke, or an accident, AD is ultimately fatal when the damaged brain tissue can no longer control basic bodily functions. The specific course of the disease varies from person to person and can last up to 20 years with the average time from diagnosis to death being 4 – 8 years.

Long-term planning helps caregivers face many difficult choices over the course of the disease. While every person's course is unique, knowing your choices and having support available will help ease your stress.

- Have a knowledgeable attorney to advise you about legal and financial issues related to long-term care planning.
- Have a health care team you rely on.
- Making realistic plans with routine breaks from caregiving is important.
- Maintain a routine that includes a healthy diet, regular physical exercise, and participation in activities you enjoy.

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