

## Early Stage Alzheimer's Disease

*\*This information is supplemental to the NIH/NIA documents, p.4:*  
**Caring for a Person with Alzheimer's Disease (English) or  
Cómo cuidar a una persona con la enfermedad de Alzheimer (Spanish)**

If you (or your loved one) are dealing with a diagnosis of Alzheimer's disease, you may have been provided with information on the stages of Alzheimer's disease. Although each person's journey is unique, having a general understanding of the progression of Alzheimer's symptoms can be helpful in terms of coping on a day to day basis as well as, planning ahead.

An early diagnosis helps people receive treatment for symptoms and gain access to support to assist them in living with Alzheimer's disease. Unfortunately there is no cure. Taking advantage of available treatment and support options can enhance your quality of life. The information below provides some suggestions to assist those with early-stage Alzheimer's disease as well as, their family members, and friends.

### Symptoms in early-stage Alzheimer's

Symptoms are usually mild in the early stage of the disease, allowing most people to continue with simple daily routines. Typically there is an awareness of the changes that are occurring, including difficulty with:

- Recalling recent events (remembering appointments or conversations)
- Making decisions and judgments (in response to an emergency)
- Managing routine chores
- Expressing thoughts and feelings (finding the right word, writing letters, or e-mails)
- Processing what was said by others (and understanding what you have read)
- Handling tasks such as balancing a checkbook or taking medications as prescribed
- Behavior and mood (loss of interest in activities and socializing, feelings of anxiety and depression)

It is important to note that time in each stage varies from person to person, and not everyone will experience all Alzheimer's symptoms. A person recently diagnosed is not necessarily in the early stage of Alzheimer's disease as some individuals are further advanced at the time of the diagnosis.

### Reactions to a diagnosis

Emotional reactions are a normal response to news of a diagnosis of Alzheimer's disease. People may experience a range of emotions that vary in intensity, including:

- Denial
- Depression
- Anger – why me?
- Anxiety and fear – worry about a loss of independence, will I be a burden to my family? How do I tell my family/friends?
- Isolation and loneliness,
- Embarrassment and shame
- Feelings of loss
- A sense of relief knowing what is wrong

#### Tips for addressing reactions to the diagnosis:

- **Give yourself some time to adjust.** As with any major change in life, don't expect that you will "snap" into this new transition. Acknowledge your feelings. You may feel like you are on a 'roller coaster ride' of emotional ups and downs. You may feel alright and then suddenly feel stressed and overwhelmed again. Allow yourself time.

If your loved one has been diagnosed with Alzheimer's, you will also experience a range of emotions.

- **Reach out for support.** Living with Alzheimer's is not easy, but there is help in this journey. The more you reach out to others and get support, the more you will be able to cope with Alzheimer's symptoms while continuing to enrich and find meaning in your life.
- **Make your wishes known.** While it's not easy to think about, planning how you want your finances and healthcare managed gives you power over your future. Talk with your family and let them know what is important to you. Who do you trust to make decisions for you when you are no longer able to do so?
- **Focus on the four pillars of brain health.** Engage in physical exercise, eat a balanced diet, manage your stress and exercise your brain.
- **Educate yourself.** Understanding what to expect will help you plan for care and transitions. Knowledge will help you both honor a loved one's strengths and capabilities throughout each stage, and make sure you have the strength and resources to continue.
- **Don't take on the care giving journey alone.** Despite your dedication, at some point you will need some help in care giving. No one can be awake and alert 24 hours a day. You have your own health and other obligations to consider. Care giving support is critical.

#### Changes in relationships

Alzheimer's disease can cause stress in relationships between the loved one diagnosed, caregivers, family, friends and colleagues.

#### Individuals in the early stages of Alzheimer's disease may experience:

- Feelings of people trying to help too much or too little
- Role changes in relationships with family and friends
- Anxiety over who to tell about the diagnosis
- Increased or decreased desire for intimacy
- Feelings of not being understood by others
- Problems trusting their own decisions
- Family and friends withdrawing or avoiding them
- Difficulty interacting in social settings
- Increased anxiety over legal and financial issues

**Caregivers may experience:**

- Role changes within the relationship
- Anxiety over who to tell about the diagnosis
- Changes in the intimate relationship
- Feeling misunderstood by friends and family, which may lead to isolation

**Tips for addressing relationship issues:**

- Include your loved one in decision-making as much as possible.
- Encourage openness with friends and family about the changes that are taking place.
- Encourage family and friends to learn about Alzheimer's disease so that they will better understand what you are going through and how to provide support.
- Continue to explore ways for intimacy and closeness
- You may need to talk about the changes you are experiencing and how you feel. Counseling and/or Alzheimer's support groups may assist.

**Changes in lifestyle**

Your daily routine will change in response to disease progression.

**Individuals with Alzheimer's may experience:**

- Increased or decreased concern about safety
- Difficulty performing daily routines without assistance
- Frustration due to need for assistance with meals, medications, finances and self care
- Anger and grief due to loss of independence such as living alone or driving

**Caregivers may experience:**

- Difficulty assessing your loved one's capacity to manage things such as finances or personal care
- Loss of independence due to added care giving responsibilities
- A need for seeking socialization with others
- Anger and grief due to loss of their loved one and their relationship as they know it

**Tips for addressing lifestyle changes:**

- Focus on your/your loved one's abilities and develop strategies to compensate for declining abilities
- Establish a daily routine for you/your loved one that provides structure, consistency, physical exercise, as well as, mental and social stimulation.
- Evaluate home safety
- Plan for what will happen when it is no longer safe for your loved one to remain at home for any period of time or live alone?

- Consider community resources to provide support such as home care, adult day services, social clubs, and support groups.
- Create a list of practical things others can do to assist
- Keep a journal as a way of acknowledging feelings
- Familiarize yourself with the “Caregiver’s 10 Commandments”

### **Plan for the future**

In the early stages, you can play an active role in making decisions about treatment options, housing preferences, financial and legal issues. Planning for the future facilitates decision-making for the caregiver and assures your wishes are known. Families may not initiate planning due to denial. It may be difficult for some families to discuss these issues based on their history of communication, status of relationship and fears about the future.

### **Tips for families planning for the future:**

- Complete advance directives for health care and financial planning as soon as possible
- An Elder Law attorney can provide legal advice and assist with advanced care planning
- Develop a day to day care plan
- Identify community resources that can provide assistance

### **Challenges for those who live alone**

Not all individuals with early-stage Alzheimer’s disease have a caregiver living with them. If your loved one lives alone, he/she may need more frequent home safety assessments and help with managing medications. Watch for changes that would indicate the need for additional supervision or care.