

Information for those just Diagnosed

I Have Alzheimer's disease Living with the disease

Finding out that you have memory loss or Alzheimer's disease may bring many emotions, fear disbelief, anxiety and relief. It is our hope that here you will find information to help you cope and understand what is happening to you and some tips on how to make life easier.

One of the most important things that you can do is to learn what you can about Alzheimer's disease and how it progresses. Knowing what to expect may help you to adjust to the changes that you are experiencing.

Encourage your family and friends to also learn about Alzheimer's disease. Contact your local resource the Alzheimer's Support Center for support and information. Your physician and nurse will also be someone who will provide support and be able to answer any questions that you might have.

What is Alzheimer's disease?

It is not a normal part of aging. Some symptoms include having difficulty with remembering, personality changes, depression, having difficulty doing familiar tasks; you may also notice that you have a hard time in making decisions. All of these changes have an impact on how the person will act and feel.

Currently there is no cure for Alzheimer's disease but there is medications that slow down the process of the disease. Talk to your doctor about what treatment that will be best for you. These medications do not stop the disease.

Researches are working hard and there are several studies being done all over the United States. The hope is that they will find a cure.

What Causes Alzheimer's disease?

We do not know what causes Alzheimer's disease but researchers have identified some possible risk factors.

Age: Your risk of developing Alzheimer's disease increases, as you age especially for those over the age of 65. This does not mean that Alzheimer's disease only affects those over the age of 65, there are individuals at younger ages being diagnosed.

Family History: People with a parent or sibling with Alzheimer's disease have a greater chance of developing the disease when compared to someone with no family history.

Other: Researches are looking at environmental causes, education level, diet, exercise and use of tobacco and alcohol and the person's overall medical condition.

Will my children or grandchildren get Alzheimer's disease?

Researchers are trying to determine what role heredity plays in developing the disease. A majority of people with this disease have a common form called Sporadic Alzheimer's disease. Only a small percentage of people have an inherited form of the disease called Familial Autosomal Dominant Alzheimer's disease. With some families it does pass on to one generation to the next. It is important to know though just because one person in the family has Alzheimer's disease this does not mean that your family has inherited the form.

Genetic Testing

Mutations in APP, PS1, or PS2 all virtually guarantee that a person will develop Alzheimer's disease. However, there is a fourth gene – called APOE – that is also involved in determining Alzheimer's risk. The APOE gene comes in three forms, called e2, e3, and e4. Having the e4 version puts people at higher risk of Alzheimer's disease, but does not ensure that they will develop the disease. Because testing for e4 cannot predict who will get the disease, many medical ethicists and geneticists have recommended against testing for APOE in healthy people.

The rationale for not testing for APOE is that over half the people who carry e4 will not develop Alzheimer's and many people who don't carry e4 will still go on to develop the disease; therefore, genetic testing is not very useful. In fact, genetic testing for this gene is only currently available to help confirm doctor's diagnoses of Alzheimer's, and a doctor is required to sign a form that says the patient has dementia before the test can be performed.

Considering genetic testing for Alzheimer's is complicated by the fact that even if you test positive for a mutation, there is no way to prevent the disease or treat it once it develops. Despite this drawback, some people decide to pursue genetic testing because it helps them plan for the future and relieve anxiety. However, other people find that they simply don't want to know whether they are going to get a disease that they cannot prevent.

Meeting with a genetic counselor can help you understand both whether you are eligible for genetic testing and what risks and benefits there are to testing. In addition to meeting with a genetic counselor, it can be helpful to discuss the decision with family members, religious advisors, and possibly other people who have faced the same decision, such as through a support group.

Often the first place to start when you are trying to find a genetic counselor is with your doctor. In addition to being aware of the nearest genetics center, your doctor may also be able to provide a direct referral, which is necessary for coverage by some insurance plans.

Resources and Directories of Genetic Counselors

[National Society of Genetic Counselors](#). Search for a genetic counselor by location

How does Alzheimer's disease progress?

Alzheimer's disease progresses differently in each individual, but usually the areas of the brain that control memory and thinking skills are initially affected. The course of Alzheimer's disease may last just a few years or as long as 20 years. On average, an Alzheimer's patient will live eight years after diagnosis.

For some, the illness may progress slowly over many years, whereas for others it may progress rapidly.

The Stages of Alzheimer's disease

A medical model of the progress of Alzheimer's disease is often measured in 7 stages. Understanding the stages of Alzheimer's can provide some insight into what to expect and prepare both the caregiver and the person affected by Alzheimer's. Not everyone's journey with Alzheimer's will be the same and as much as we are individuals now, so there will be individual differences through the stages of Alzheimer's

Alzheimer's disease is a progressive neurological disorder that leads to personality changes, memory loss, intellectual slowing and difficulty with regular activities. Although, each person with Alzheimer's is different, most individuals affected by the disease progress through a series of stages. Each stage is characterized by more serious symptoms.

These seven stages were developed by researchers and physicians to describe how your or your loved one's functioning will change over time. Your doctor might consolidate the seven stages into early/middle/late or mild/moderate/severe, so these classifications are provided as well.

Stage 1 (Absence of Impairment)

There are no problems with memory, orientation, judgment, communication, or daily activities. You or your loved one is a normally functioning adult.

Stage 2 (Minimal Impairment)

You or your loved one might be experiencing some lapses in memory or other cognitive problems, but neither family nor friends are able to detect any changes. A medical exam would not reveal any problems either.

Stage 3 (Noticeable Cognitive Decline)

Family members and friends recognize mild changes in memory, communication patterns, or behavior. A visit to the doctor might result in a diagnosis of early-stage or mild Alzheimer's disease, but not always. Common symptoms in this stage include:

- Problems producing people's names or the right words for objects
- Noticeable difficulty functioning in employment or social settings
- Forgetting material that has just been read
- Misplacing important objects with increasing frequency
- Decrease in planning or organizational skills

Stage 4 (Early-Stage/Mild Alzheimer's)

The cognitive decline is more evident. You or your loved one may become more forgetful of recent events or personal details. Other problems include impaired mathematical ability (for instance, counting backwards from 100 by 9s), a diminishing ability to carry out complex tasks (for example, throwing a party or managing finances), moodiness, and social withdrawal.

Stage 5 (Middle-Stage/Moderate Alzheimer's)

Some assistance with daily tasks is required. Problems with memory and thinking are quite noticeable, including symptoms such as:

- An inability to recall one's own contact information or key details about one's history
- Disorientation to time and/or place
- Decreased judgment and skills in regard to personal care

Even though symptoms are worsening, people in this stage usually still know their own name and the names of key family members and can eat and use the bathroom without assistance.

Stage 6 (Middle-Stage/Moderate to Late-Stage/Severe Alzheimer's)

This is often the most difficult stage for caregivers because it's characterized by personality and behavior changes. In addition, memory continues to decline, and assistance is required for most daily activities. The most common symptoms associated with this stage include:

- Reduced awareness of one's surroundings and of recent events
- Problems recognizing one's spouse and other close family members, although faces are still distinguished between familiar and unfamiliar
- Sundowning, which is increased restlessness and agitation in the late afternoon and evening
- Difficulty using the bathroom independently
- Bowel and bladder incontinence
- Suspiciousness
- Repetitive behavior (verbal and/or nonverbal)
- Wandering

Stage 7 (Late-Stage/Severe Alzheimer's)

In the final stage, it is no longer possible to respond to the surrounding environment. You or your loved one may be able to speak words or short phrases, but communication is extremely limited. Basic functions begin to shut down, such as motor coordination and the ability to swallow. Total care is required around the clock.

Although the stages provide a blueprint for the progression of Alzheimer's disease, not everyone advances through the stages similarly. Caregivers report that their loved ones sometimes seem to be in two or more stages at once, and the rate at which people advance through the stages is highly individual. Still, the stages help us understand the disease and prepare for potential symptoms and their accompanying challenges.

Sources:

Progression of Alzheimer's disease: The Global Deterioration Scale. Alzheimer's Society of Canada. October 2005. <http://www.alzheimer.ca/english/disease/progression-gdscale.htm>

Understanding stages and symptoms of Alzheimer's disease. National Institute on Aging. October 26, 2007. <http://www.nia.nih.gov/Alzheimers/Publications/stages.htm>

Coping with Alzheimer's disease

The key to coping with Alzheimer's is to understand the relationship between your brain and your behavior. Once you understand this relationship, you can approach your diagnosis with compassion and courage. Consider these ten tips to help you live with Alzheimer's disease.

1. Appreciate the Power of the Brain

The brain is the source of your thoughts, emotions, personality, and behavior. Everything you experience in life, and every decision or action you make, can be traced back to your brain.

2. Remember that Alzheimer's is a Disease of the Brain

Although more and more people are recognizing Alzheimer's as a medical condition, many still believe that Alzheimer's is a mental illness, a psychological weakness, or simply what happens when we get old. This stigma is dangerous because it suggests that Alzheimer's is something we bring on ourselves or let happen to us.

3. Consider That Alzheimer's Affects Everything the Brain Controls

If your brain affects your thoughts, feelings, personality, and behavior, and Alzheimer's is a disease of the brain, then Alzheimer's is going to affect how you think, what you feel, who you are, and what you do. Don't underestimate the range of symptoms that can be traced back to what's happening in the brain.

4. You Don't Have to Look Sick to Be Suffering from a Physical Illness

Although Alzheimer's disease is a physical illness, it probably won't affect your appearance until the later stages of the disease. This can be confusing to those around you, because you may seem as healthy as ever -- you're just acting differently. Remember that you don't have to look sick to be experiencing Alzheimer's disease.

5. Prepare Yourself for the Unpredictable

Alzheimer's disease affects different parts of the brain at different times and at different rates. Have you ever had a loose light bulb in the house? Sometimes it works; other times, it doesn't, even though

you haven't touched the light bulb since the last time it worked. That's kind of how Alzheimer's affects the brain. Although you will go through some predictable stages, the stages are not clear-cut and often overlap.

6. Ask Loved Ones to Break Tasks Into Smaller Steps

Tasks that used to seem simple actually are made up of many steps that may be overwhelming to you now. For example, brushing your teeth has always seemed like one task -- but if you think about it, tooth brushing is actually made up of many steps (picking up the toothbrush, taking the cap off the toothpaste, and so on). If Alzheimer's has affected your brain in such a way that you don't remember all the steps or don't remember how the steps are sequenced, then you might have difficulty brushing your teeth unless your loved ones break it down into smaller actions for you.

7. Don't Blame Yourself

This is probably the most important thing to remember, and it builds upon the first six tips: ***Behavior changes you experience are caused by damage to the brain and are not something you can control or prevent.*** If you become upset with your loved ones, they might find it hard not to take it personally. But don't blame yourself -- your behavior was simply caused by damage to the brain.

8. Ask Your Loved Ones for Patience

Alzheimer's makes it more difficult to learn, understand, reason, or remember. Because arguments can only occur between people who can do all of these things, quarreling is futile. Instead, ask your loved ones to show patience and provide comfort. They can also redirect the situation to a pleasant activity that you can enjoy together, such as taking a walk, watching a favorite movie, or reminiscing about old photographs or antiques.

9. Ask Your Loved Ones To Look for Signs of Distress

As you live with Alzheimer's, you might experience a *progressively lowered stress threshold*, meaning that the amount of stress you can handle before experiencing discomfort or emotional upset decreases over time. Therefore, you may become distressed more easily and are less able to explain why you're distressed. Your loved ones should watch for subtle signs of discomfort, such as pacing or fidgeting, and learn what may trigger your stress reactions.

10. Accept the Brain-Behavior Relationship

The key to living with Alzheimer's is not only to understand the brain-behavior relationship, but also to *accept* it. Once you do, you can take good care of yourself, teach others about your needs, and look upon your disease with a compassionate, nonjudgmental attitude.

Sources: Charter of Principles for the Care of People With Dementia and Their Carers. Alzheimer's Disease International. May 25, 2005. <http://www.alz.co.uk/adi/charter.html>

Strategies to Head Off or Deal With Behavior Problems. Alzheimer's Foundation of America. 2007. <http://www.alzfdn.org/education-care/strategies.shtml>

You May Experience a Variety of Emotions

You may feel like you are in shock right now because you were actually given a diagnosis to the symptoms that you have been experiencing. You now have a name to the disease that has turned your world upside down; Alzheimer's disease. Some of you may feel a sense of relief, because now you know what you have. Whatever your immediate reaction to the diagnosis, in time you will find yourself experiencing a variety of emotions.

Reactions and Feelings

Denial: You may think that the doctor made a mistake, you may feel that you can't have Alzheimer's disease, because you are still very independent.

Anger: You may feel angry because you have this disease.

Anxiety: You may feel anxious about the unknown.

Guilt: You may feel guilty because of how this is going to affect my family

Frustration: You may have days when you are frustrated with yourself because you can't remember something or might have a hard time finishing a sentence.

Acceptance: Learn as much as you can about this disease so that you can come to accept this diagnosis and you will continue to enjoy life instead of fighting against it.

Depression: Almost everyone with A.D. feels depressed at some point in the disease. Talk to your family about your feelings and frustrations and also let your doctor know how you are feeling.

Hope: Have hope because some day a cure will be found, so you need to fight and hang on.

It can be very helpful to meet with other individuals who also have the disease. Together you can share your feelings and experiences.

Contact the Alzheimer's Support Center, your local resource for an early-stage support group in your area (608) 314-8500

Helpful Hints to Help You Cope

1. Acknowledge that you have Alzheimer's disease.
2. Take one day at a time.
3. Surround yourself with people who care.
4. Be with people who have a sense of humor and can laugh.
5. Ask for help when you need it.

6. Continue to be involved in community functions, don't isolate yourself.
7. Get exercise.
8. Join a support group.
9. Focus on what you can still do.
10. Do not give up on life. You have a lot of living to do.

Focus on What You Can Do

One way to help you cope with the changes that are experiencing is to focus on what you are still able to do. Continue to do the things that you enjoy and are meaningful to you.

When the time comes you may need more help, ask your family members and friends. Let them know what you may need help with so this can still allow you a degree of independence.

Some Changes You May Experience

You may find that you will start having problems remembering a person's name or when you are talking with someone and in mid-sentence you forget what you were talking about.

You intend to say one word and a different word comes out.

It may become more frustrating for you to do the things that you have always done, like following a recipe, turning on the stove, doing a craft project, changing the oil in the car and balancing the check book.

You may find it more difficult to remember what day of the week it is when you have a scheduled appointment, you arrive too early or late for that appointment.

This disease does affect your visual perception at times. You may be looking at a shoe but you can't identify it by name. When you are looking at coins it might be difficult to tell a dime from a nickel.

You may find that you are having difficulty walking up and down the stairs. Your visual perception is impaired and this makes it difficult to judge the distance and height of the stairs.

When your judgment is affected because of Alzheimer's disease, you may choose clothing to wear that is improper for the season and time of year.

It is normal to feel anxious and irritable and moody, especially with all of the changes that you have going on. Your family may begin to see some personality changes happening also.

Alzheimer's disease can also affect your physical coordination. You might notice that you feel a little clumsier when trying to put your arm in the sleeve of your shirt.

Helpful Hints to Help You Adjust

- Write things down in a notebook.
- Use post it notes.
- Do one thing at a time.
- Take your time and ask others to allow you more time.
- Keep busy, continue doing the things that you enjoy.
- Join a support group for early stage.
- If noise and large crowds bother you, choose a time of day when it might not be as busy with as many people.
- Don't isolate yourself from family and friends.
- Get a good nights rest.
- Ask for help.
- Follow a routine.

Continue Living a meaningful Life

Enjoy everyday by doing the things that bring meaning to your life. As of now there is no cure for the disease, but there are many things that you can continue to do, to enjoy life.

- Take care of yourself by eating properly and exercising.
- Rest when you are tired.
- Continue to socialize with your friends and stay connected with family members.
- Take all of your medication that has been prescribed by your physician.

Driving and Alzheimer's disease

As the disease progresses, it will affect your abilities that are needed to be a safe driver.

Being told that you should no longer drive is something that no one wants to hear. It is so important that you and others are safe when you are behind the wheel. As with anything, it is easier when you make the decision not to drive instead of having someone else tell you that you can no longer do this. It is very important to have this conversation and be open and honest with your family about how this makes you feel. Just making this decision early on allows you to have some control over your life.

Alzheimer's disease gradually affects the skills that are needed for driving:

- Visual perception
- The ability to read road signs and understand what you have read.
- The ability to understand directions
- Physical coordination
- Spatial perception
- Judgment
- Memory

Signs that driving abilities are declining

- Dents and scratches on the car
- Getting lost
- Traffic tickets
- Response time is slow
- Forgetting the rules of the road
- Takes longer time to reach a familiar destination

I Have Alzheimer's disease ,whom should I tell ?

Everyone reacts differently to the idea of sharing this news that you have Alzheimer's disease. Some of your friends will want to know and others may feel uncomfortable with this news.

You may want everyone to know or maybe just tell a few people. By you speaking out about having Alzheimer's disease you can help others to understand what you are experiencing and what it is like to live with the disease.

You may want to tell those who are the closest to you so that they are aware of the changes in your life. Talk with those whom you feel the most comfortable with.. Tell them how you want to be treated and that you will let them know when you may need help. Encourage your family and friends to educate themselves about the disease.

Just as you are adjusting and coping , so will your family members too. Tell them how you are feeling and what you worry about. Remind them that you are still independent and want to do as much as you can for yourself. Let them know that you want to be involved in making decisions for as long as you can. Have a discussion with your family regarding how you can help and support one another.

Talk to your Doctor

Make a list of any questions and concerns that you have so that you can ask your doctor about at your next visit.

Take a family member or friend with you for emotional support. This person can ask questions or clarify any information.

These may be a few questions that you may want to ask;

- What kind of changes can I expect in the next 6 months?
- Is there any medication that I can take , for Alzheimer's disease?
- Where can my family and I go in the community for help and information?

- What can I do for activities to slow down the progression of this disease?

Join in a Support Group

Talking with another person who is experiencing many of the same changes will be helpful. Contact your local resource, The Alzheimer's Support Center at **(608) 314-8500** for listings of a group in your community, or one-on-one support.

How will this group help me?

- It will put you in touch with others who know first hand what you are experiencing.
- It will provide an opportunity to talk with a facilitator who is sympathetic and understanding.
- You will be able to vent your feelings.
- Everything that is said within the group is confidential.