ALZHEIMER’S DISEASE
A GUIDE FOR PATIENTS AND FAMILIES

Featuring Lea Thompson
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In 1906, a German doctor peered into a microscope. He was looking at samples of brain tissue from a woman who had recently died. The patient was only in her 50s. For years she had suffered severe memory problems and other difficulties. What the doctor saw were unusual changes in the woman’s brain. The doctor’s name was Alois Alzheimer, and the disease he described now bears his name.

Alzheimer’s disease (AD) is the most common cause of memory loss and other problems with thinking. AD is not currently reversible and frequently leads to death within three to nine years of diagnosis. About one in ten people over age 71 in the United States has AD. Millions of Americans now live with AD, and it has been estimated that a new case is diagnosed every 70 seconds.

DID YOU KNOW?

Neurologists are medical doctors who specialize in disorders of the brain and nerves. They are the specialists who most often treat people with Alzheimer’s disease.
Treatments exist today that may help maintain thinking, memory, and speaking skills, though no medicines can currently change or reverse AD. There are also many ways that both a person with AD and his or her caregivers can preserve quality of life.

This booklet will help you or a loved one learn about:

- AD and its causes
- Medicines that might help
- Ways to live life to the fullest

This booklet and program are intended to be tools for people who have mild to moderate AD and those who care for them. The care of people with advanced Alzheimer’s disease is beyond the scope of this booklet.
WHAT CAUSES ALZHEIMER’S DISEASE?

Scientists do not yet know what causes Alzheimer’s disease. Some people may have genes that put them at higher risk for AD. This is the likely cause when AD strikes a person in their 40s or 50s. But most people who get AD—about 9 out of 10—are 60 or older. In these people, genes may play a role, but so might other factors, such as having type 2 diabetes, heart disease, or high blood pressure.

No matter what the root cause, however, AD occurs because brain cells are slowly dying. As the cells die, parts of the brain shrink and stop working. There are three telltale signs of AD in the brain:

- Clumps of material in the spaces between brain cells called amyloid plaques (AM-uh-loid PLAKs)
- Tangles of protein molecules inside brain cells
- Loss of connections between brain cells
HOW DO I KNOW IF I OR A LOVED ONE HAS ALZHEIMER’S?

AD symptoms most commonly appear after age 60, and the way the disease progresses varies from person to person. Most experts believe that AD can be reliably diagnosed using current procedures. New techniques are being developed that may make early diagnosis of AD even easier in the near future.

To diagnose AD, your neurologist or health care provider will conduct a complete exam that may include:

- Asking questions about your health and medical history
- Asking about changes in memory, behavior, or personality
- Conducting tests of memory, problem solving, attention, and language
- Performing tests to rule out other possible causes of your symptoms
- Talking with family members or caregivers
Memory problems are one of the first signs of Alzheimer’s disease, but it is hard, at first, to tell the difference between normal forgetfulness and mild AD. As AD progresses, memory loss continues and other problems occur, such as getting lost, having trouble with money, repeating questions, and experiencing mood or personality changes.

Contact a neurologist or other health care provider if you think you or a loved one has signs of Alzheimer’s disease.

“We all feel like we’re losing our memory—but it’s one thing if you don’t remember where your purse is, and another if you don’t remember what a purse is.”

—Lea Thompson
10 WARNING SIGNS OF ALZHEIMER’S DISEASE

1. Memory changes that disrupt daily life. Examples: forgetting important dates or events, asking for information over and over, or relying on reminder notes or electronic devices.

2. Challenges in planning or solving problems, such as keeping track of bills or a checking-account balance.

3. Difficulty completing familiar tasks, such as driving to a known location, remembering the rules of a favorite game, or needing help using devices that once were mastered.

4. Confusion with time or place. Examples: losing track of dates, seasons, or the passage of time, or forgetting where you are or how you got there.

5. Vision difficulties, such as problems reading, judging distance, or determining color or contrast.
6. New problems understanding or expressing words when speaking or writing.
   Examples: calling things by the wrong name or stopping in the middle of a conversation and not knowing how to finish.

7. Misplacing things and losing the ability to retrace steps.

8. Poor judgment, such as giving large amounts of money to strangers or not paying attention to personal grooming.

9. Withdrawal from work or social activities.

10. Mood or personality changes.
    Examples: feeling confused, suspicious, depressed, fearful, or anxious.
“It’s a hard thing to face, but it’s always important to get help early.”

–Lea Thompson
No medicines yet exist to reverse or prevent the progression of AD itself. But some medicines can slow the progression of symptoms of AD. These medicines do not change the underlying disease, but they may help slow memory loss, improve thinking ability, and maintain functioning.

Talk to your health care provider to find out whether any of these medicines might be right for you or a loved one with AD.

Medicines for AD symptoms work best when they are started early, before losses become severe.
CLINICAL TRIALS

A clinical trial is a way for scientists to learn about new treatments for diseases. Many types of clinical trials for Alzheimer’s disease are being conducted now. These trials may offer patients a way to try new experimental medicines or therapies for AD, but there is no guarantee that any of these treatments will work. Because a clinical trial often involves comparing a treatment to an inactive medication (called a placebo), there is also no guarantee that a patient in a trial will receive the experimental medicine. But the care and attention that you or a loved one can receive by being part of a trial may be helpful.

If you or a family member is interested in learning more about clinical trials for AD, talk to your health care provider; consult the U.S. government’s Web site for all clinical trials, Clinicaltrials.gov; or go to the Alzheimer’s Association Web site, www.alz.org, and click on “TrialMatch.”
In addition to taking medications, there are many other ways to maintain your quality of life.

**Heart health.** Research suggests that keeping your heart and blood vessels healthy may help slow the progression of AD. This means it’s important to:

- Control high blood pressure
- Reduce high cholesterol levels
- Avoid smoking
- Keep type 2 diabetes well managed

**Exercise.** Some studies find that the more physically active you are, the better you’re able to cope with AD.
Mental exercises. Some studies show that people who challenge their brains are better able to hold off symptoms of Alzheimer’s disease. Activities that may help include:

- Social engagements of any kind, such as book clubs or outings with friends or family
- Playing cards
- Reading
- Playing board games
- Playing a musical instrument

Support groups. People with mild to moderate AD may find it very helpful to join a support group of others with AD. It can be stimulating to be with peers. Support groups can also build self-esteem and help people cope better with everyday challenges.
DID YOU KNOW?

It was once thought that vitamin E might help protect against Alzheimer’s disease. Recent studies, however, have found no benefit from vitamin E.
CARING FOR A PERSON WITH ALZHEIMER’S DISEASE

In 2009, nearly 11 million family members and friends provided unpaid care for a person with Alzheimer’s disease or another type of dementia. Many of these caregivers understandably want to keep loved ones at home as long as possible. Caring for a person with Alzheimer’s disease, however, can be very demanding. Caregivers have a higher risk for depression and illness than the general population. Preparation, education, and ongoing support are essential for any person caring for someone with AD.

It is important for caregivers to know that just because a person’s memory is failing, his or her emotions are likely to be intact. In fact, recent research strongly suggests that people with severe memory loss continue to feel the emotions of an event even after they have forgotten the event itself. They may continue to feel sad from an upsetting event. They may still feel happy after a positive event. For example, a simple visit or telephone call from a family member might have a lingering positive influence on a patient’s mood, even though the patient might quickly forget the visit or call.
The following tips may help if you are caring for somebody with AD. Of course, each person with Alzheimer’s disease is unique. Some tips may work, some may not, and some may need to be adjusted for your situation.

**AT DIAGNOSIS**

- Talk to the patient’s health care provider about all treatment options that might be right for him or her
- Find a support group for caregivers (see the Resources section on page 25 of this booklet)
- Consider adult day care or respite services to ease the day-to-day demands of care giving
- Begin to plan for the future. This may include getting financial matters, advance care plans, and legal documents in order, or looking into long-term care options

“Make those calls. Don’t isolate yourself. Reach out—there are lots of resources, there are lots of people to help you.”

– Lea Thompson
COMMUNICATION

- Speak slowly enough for the person to understand
- Avoid talking about the person as if he or she weren’t there
- When talking, minimize distractions from televisions or radios
- Allow enough time for a response
- Don’t interrupt

“It’s really important to give support and to be there emotionally for them, the caregivers…for a family to get together and to understand how hard it is for the closest people.”

–Lea Thompson
SAFETY

• Reduce bathroom risks by using a shower bench, installing grab bars, and using nonskid bath mats

• Make sure the person carries some identification or wears a medical bracelet

• Keep doors locked and consider a keyed deadbolt

• Remove locks from bathroom doors to prevent the person from accidentally locking himself or herself in

• Label medications and keep them locked up

• Remove scatter rugs and anything else that might lead to falls

• Consider an automatic shut-off device on the stove to prevent burns or a fire

• Use night-lights in rooms or hallways likely to be used at night
SLEEP PROBLEMS

• Encourage exercise during the day and limit daytime napping
• Schedule physically demanding activities, such as bathing, earlier in the day
• Limit caffeine
• Try to keep bedtime at a similar time each evening

DRIVING

• Look for clues that driving is becoming unsafe, for example, if the person drives too fast or too slow, misses traffic signs, or gets angry or confused
• Be aware of the person’s feelings about possibly losing the ability to drive—this can be a very sensitive issue!
• Ask for help from a health care provider or your local department of motor vehicles

Caring for somebody with AD can be challenging, but it can also be rewarding. Approaching situations with patience, compassion, or even humor may not always be possible, but it is a worthy goal and is often attainable.
“Just be loving. They get your gentle feeling—the love, it’s really important.”

–Lea Thompson
CONCLUSION

Living with Alzheimer’s disease is a journey that changes gradually over time. In this booklet you’ve learned that there are many steps that both patients and caregivers can take to make this journey easier. Treatments are available today that can help improve the symptoms of AD as well as some of the moods or behaviors that can result from AD. Treatments work best when begun early. The earlier a person can be diagnosed, the better! New treatments for AD, and new ways to diagnose it early, are also in development.

Life with AD still has its ups and downs. But it doesn’t need to be overwhelming. With the help of your neurologist and the support of friends and family, it is possible for both patients with Alzheimer’s and their caregivers to enjoy what life has to offer.
RESOURCES

American Academy of Neurology
American Academy of Neurology Foundation
aan.com/patients

Neurology Now® Magazine
Free magazine for patients and caregivers, courtesy of the American Academy of Neurology.
neurologynow.com

Neurology Now Books™
Essential guides for patients and caregivers on various neurologic disorders.
aan.com/patients

Alzheimer’s Disease Education and Referral Center
www.nia.nih.gov/Alzheimers

Alzheimer’s Association
alz.org

Alzheimer’s Foundation of America
alzfdn.org

Family Caregiver Alliance/National Center on Caregiving
caregiver.org

National Institute of Mental Health
nimh.nih.gov
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American Academy of Neurology
The American Academy of Neurology (AAN), established in 1948, is an international professional association of more than 22,500 neurologists and neuroscience professionals dedicated to promoting the highest quality patient-centered neurologic care. A neurologist is a doctor with specialized training in diagnosing, treating, and managing disorders of the brain and nervous system, such as Alzheimer’s disease, multiple sclerosis, epilepsy, stroke and Parkinson’s disease. For more information, visit www.aan.com.

American Academy of Neurology Foundation
The American Academy of Neurology Foundation (AAN Foundation) raises money to support vital research into the prevention, treatment, and cure of brain disorders such as Alzheimer's disease. The AAN Foundation is committed to improving patient care, quality of life, and public understanding of the brain and other neurologic disorders. For more information or to make a donation to the American Academy of Neurology Foundation, visit www.buyabrain.org.
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Credits

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Collaborator

American Academy of Neurology Foundation

Contributors to the Video

David S. Knopman, MD, FAAN
Professor of Neurology
Mayo Clinic
Deputy Editor, Neurology
Rochester, MN

Ronald C. Petersen, PhD, MD, FAAN
Professor of Neurology
Cora Kanow Professor of Alzheimer’s Disease Research
Cadieux Director, Mayo Alzheimer’s Disease Research Center
Director, Mayo Clinic Study of Aging
Mayo Clinic
Rochester, MN

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Special thanks to: Lea Thompson

Project Manager
Gina Conrad Black
Executive Producer
Conrad Productions

Guidebook Author
Stephen Braun
Medical Writer
Amherst, MA

Guidebook Design
Cinda Debbink
Design Partners
dgdesignpartners.com

Video Production
Tania Wilk
Executive Producer
Alan Weiss Productions
awptv.com
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