

advANCES

PROGRESS IN ALZHEIMER RESEARCH AND CARE

Innovative Studies Target Prevention

The recent launch of two new large-scale clinical drug studies has brought to light a promising new area of research focused on preventing or delaying the onset of Alzheimer's disease. Treatments that have shown benefits in individuals with Alzheimer's will be tested in people who suffer from mild cognitive impairment (MCI).

MCI is a condition that causes mild memory loss in otherwise healthy individuals. Unlike individuals with Alzheimer's, people with MCI do not require assistance with daily activities, such as driving, shopping, or paying bills, and usually do not exhibit problems with thinking, reasoning, and decision-making.

Individuals with MCI are the focus of prevention studies now because recent research shows that those diagnosed with MCI may be at higher risk for Alzheimer's disease. Some researchers believe that MCI actually may precede the onset of Alzheimer's.

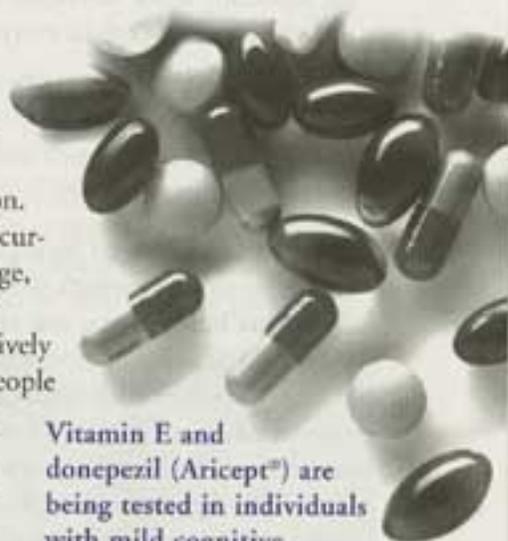
The two new drug studies aim to determine whether available medications can slow down or stop memory loss in individuals with MCI before they go on to develop Alzheimer's disease. A second objective is to determine whether existing Alzheimer treatments can alleviate memory problems in people with MCI.

"These studies are as much a trial of the research methodology as of the particular drugs being tested,"

says William Thies, PhD, vice president of medical and scientific affairs at the Alzheimer's Association. "Even with all of our current medical knowledge, we are not yet certain whether we can effectively identify and recruit people who are experiencing mild memory loss and are at higher risk for Alzheimer's but do not yet have the disease."

The Memory Impairment Study will test donepezil (Aricept®) and vitamin E (-tocopherol) in 720 individuals with MCI. Donepezil is a cholinesterase inhibitor approved by the Food and Drug Administration (FDA) in 1996 for the treatment of mild to moderate Alzheimer's disease. Vitamin E is thought to have antioxidant properties and in a previous study was shown to slow the progression of functional decline in individuals with moderate Alzheimer's disease.

The Memory Impairment Study is funded through the National Institute on Aging's Alzheimer's Disease Prevention Initiative. Congress appropriated an additional \$50 million for this initiative as a direct result of the Alzheimer's Association's advocacy efforts.



Vitamin E and donepezil (Aricept®) are being tested in individuals with mild cognitive impairment.

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Physician Should Disclose Diagnosis

From the perspective of someone with early-stage Alzheimer's, I believe very strongly that the diagnosis should be disclosed as early as possible. I feel a physician is better equipped to disclose the diagnosis, especially if the physician is willing to take extra time to carefully explain everything.

*Carol LeBarge
San Diego, California*

No Explanation of Symptoms Frightening

It's better to know what's wrong with you and what the future holds so you can plan accordingly. I would think it would be frightening to experience the symptoms of Alzheimer's and have no explanation. Perhaps reluctance to reveal the diagnosis comes from not wanting to watch the patient's reaction. This disease is a long and difficult road for all involved. Not admitting that it exists will not make it go away.

*E. P. H.
Westport, Connecticut*

Much to Gain by Telling Diagnosis

I hope that if I ever develop this disease, I am told about it without delay. I cannot even imagine why anyone would consider keeping this knowledge from a person with Alzheimer's. Obviously if the person is so far gone that he or she does not understand on any level, it won't matter much, but they have nothing to lose by telling the patient and much to gain.

*S. H.
Billings, Montana*

Honesty About Diagnosis Is Important

I strongly believe that the physician should NOT lie about a diagnosis. That being said, the physician should evaluate the individual patient and family situation. Guided by respect for the patient's dignity and the importance of trust in the physician-patient relationship, the physician should be honest but not crude. I work with the families on disclosure of the diagnosis. I don't believe there is an absolute answer. Sometimes the family wishes to disclose the diagnosis themselves. Sometimes they want me to do so. Since this disease has such a tremendous impact on the whole family, they should be incorporated into the decision-making process.

*Edward Zamrini, MD
Augusta, Georgia*

WE WANT TO HEAR FROM YOU!

Please share with us your experiences related to issues covered in *Advances*, or suggest topics you'd like to read more about.

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Facing the Realities of Late-Stage Care

Comfort, dignity, and respect—these are important words for caregivers to remember in ensuring quality of life during the late stage of Alzheimer's disease.

At this point in the disease process, people typically lose the ability to talk and walk and experience difficulties with eating. Families and care providers play a critical role in making tough decisions that ultimately respect the person's end-of-life wishes and at the same time maintain the person's dignity and comfort.

Advance directives

Ideally, discussions about end-of-life issues should take place while the person with the disease still has the capacity to make decisions.

"Families should talk about these issues before they are faced with a crisis situation," says Ladislav Volicer, MD, PhD, clinical director of the Geriatric Research Education Clinical Center in Bedford, Massachusetts.

People with Alzheimer's have the legal right to limit or forgo medical or life-sustaining treatment, including the use of mechanical ventilators, cardiopulmonary resuscitation, antibiotics, and artificial nutrition and hydration. These wishes can be expressed through advance directives.

Two common forms of advance directives are a living will and a durable power of attorney for health care. A living will states the individual's choices for future medical care decisions. The durable power of attorney allows the person with Alzheimer's to designate a surrogate, usually a trusted family member, to make specific decisions about treatment on his or her behalf.

Family members should not equate the refusal or withdrawal of treatment, including treatment for life-threatening illnesses (infections, hemorrhaging, heart attacks, etc.), as euthanasia or assisted suicide.

In fact, aggressive medical treatment may feel like torture to an individual who is in unfamiliar surroundings and does not understand the intentions of care providers.

If there are no advance directives in place, families and care providers should try to make decisions consistent with what they think the individual's wishes would have been. Typically, nursing homes and hospitals have ethics committees that can facilitate the decision-making process if there is a conflict between family members or with the care provider.



Family members play a critical role in maintaining their loved one's dignity and quality of life in the late stage of Alzheimer's.

Artificial nutrition and hydration

People with Alzheimer's may also refuse to eat and drink. Such cases should be evaluated to make sure that they are not due to conditions, such as constipation, kidney failure, nausea, and fluid and electrolyte imbalance that could be reversed with medications.

One of the more difficult decisions for families to make is whether or not to withhold nutrition and hydration in response to a patient's refusal to eat or drink. Many families and care providers believe that

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Dispelling the Myths of Alzheimer's Disease

Due to the accelerated pace of Alzheimer research, consumers hear reports of research "breakthroughs" in the news every day—on television, in newspapers, and on the radio. Unfortunately, news of "breakthroughs" is often poorly reported or contradictory, making it difficult to distinguish myth from reality.

Will vitamin E protect you from Alzheimer's? Is it time to get rid of all of your aluminum pots and pans because you're afraid of putting yourself at risk for Alzheimer's disease? These are the kinds of questions that arise as a result of conflicting news reports of breakthrough research.

Following are answers to these and other common questions that will help *you* dispel the myths of Alzheimer's disease.

Is Alzheimer's disease hereditary?

Alzheimer's occurs in two forms—early-onset and late-onset. The early-onset form of the disease is *very rare* and affects people in their 30s, 40s, and 50s. It has been linked to three different genes and has been observed in only 120 families worldwide; individuals who carry one of the early-onset genes will most likely develop Alzheimer's disease.

Much more common is the late-onset form of the disease, which occurs after age 65 and accounts for more than 90 percent of all cases of Alzheimer's. It is unclear whether a genetic abnormality, environmental factors, or a combination of both causes this form of the disease.

What *is* known for certain is that a person's risk of developing Alzheimer's at any given age appears to be slightly increased if he or she has a first-degree relative with the disease, such as a brother, sister, or parent.

Can vitamin E protect me from Alzheimer's?

At this time, vitamin E is not recommended specifically for the treatment of Alzheimer's because there is no direct evidence that vitamin E prevents the disease. However, because previous research has demonstrated that vitamin E has other health benefits, there appears to be no reason *not* to take it in moderation.

Vitamin E is a lipid-soluble vitamin obtained naturally through the diet or through vitamin supplements. Because vitamin E is an antioxidant, researchers believe that it may aid in the breakdown of free radicals that may be damaging brain cells in individuals with Alzheimer's disease.

Because vitamin E may be associated with increased bleeding in individuals with risk factors for these problems, all decisions regarding medications or vitamin supplements should be discussed with a physician.

Can ginkgo biloba prevent Alzheimer's?

Ginkgo biloba is a plant extract that may have positive effects on cells within the brain and the body. Ginkgo is thought to have both antioxidant and anti-inflammatory properties and has been used for centuries in traditional Chinese medicine.

Research into the use of ginkgo for the treatment of Alzheimer's disease is still *preliminary*. Further study of ginkgo is necessary to fully understand its potential therapeutic value in treating individuals with Alzheimer's and to uncover possible side effects associated with extensive or prolonged use.

Can head injury lead to Alzheimer's?

Several studies have found that Alzheimer's disease is more common among individuals who have sustained a severe head injury (accompanied by loss

of consciousness) during the course of their lives. What remains unclear is whether head trauma is a result of falls during the early stages of Alzheimer's or whether Alzheimer's results from an earlier head trauma. Additional research is necessary to fully understand the association between Alzheimer's disease and head injury.

Does aspartame cause memory loss?

Aspartame's role in memory loss is just one of the many health scares associated with artificial sweeteners over the years. Several studies have been conducted on aspartame's effect on cognitive function in both animals and humans. These studies found no scientific evidence of a link between aspartame and memory loss.



Aspartame was approved by the FDA in 1996 for use in all foods and beverages. The sweetener, marketed as Nutrasweet® and Equal®, is made by joining two protein components, aspartic acid and phenylalanine, with 10 percent methanol. Methanol is widely found in fruits, vegetables, and other plant foods.

Can I get Alzheimer's from drinking out of aluminum cans or cooking in aluminum pots and pans?

Based on current research, getting rid of aluminum cans, pots, and pans will not protect you from Alzheimer's disease.

Aluminum is one of 90 naturally occurring chemical elements. It is the third most common element found in the earth's crust, after oxygen and silicon. The focus of ongoing research is to clarify how aluminum affects the body and whether it is a factor in Alzheimer's disease.

Currently, most researchers believe that there is *not enough evidence* to consider aluminum a risk factor. **h**

STATISTICS ON ALZHEIMER'S DISEASE

- Alzheimer's disease is the most common cause of dementia.
- Currently, 4 million Americans suffer from Alzheimer's. It has been estimated that this number will grow to 14 million by the year 2050.
- One in 10 individuals over 65 and nearly half over 85 have Alzheimer's disease.
- A person with Alzheimer's can live an average of 8 years (and as many as 20) from the time symptoms of the disease first appear.
- More than 7 out of 10 people with Alzheimer's live at home, with 75 percent of home care provided by family and friends.
- The average lifetime cost of care for an individual with Alzheimer's is \$174,000.
- At least half of all nursing home residents have Alzheimer's disease or another dementia.
- Alzheimer's disease costs American businesses \$33 billion annually—\$7 million toward the total cost of care plus \$26 million in lost productivity of caregivers.
- In fiscal year 1999 the federal government will spend an estimated \$400 million on Alzheimer research. This represents \$1 for every \$250 the disease now costs our society.

THINKING OUTSIDE THE BOX

AN ALTERNATIVE APPROACH TO CARE

It's a world infused with animals, music, plants, and children. No—it's not a zoo or special school program. It's the Eden Alternative, and it's defying all stereotypes of institutional care.

The goal of the Eden Alternative is to make nursing homes habitats for human beings rather than institutions for the frail and elderly. Since gardens are known to provide social, spiritual, and dietary benefits, founder Bill Thomas, MD, has created a Garden of Eden for his residents.

Thomas, a bushy-bearded man who resembles more a relic of the 70s rather than the typical Harvard medical school graduate, developed the Eden Alternative after taking a break from life in a hospital emergency room to work in long-term care.



That so-called "break" has turned into a crusade to turn nursing homes into places that offer a sense of purpose and community to all who reside in them. Thomas's Eden Alternative, perched on a hillside in rural upstate New York, takes a holistic approach to medicine and care.

"A holistic approach is absolutely essential in a world of dementia and aging," says Thomas. "We need to get away from the overmedicalization of the elderly."

The philosophy of the Eden Alternative is to eliminate the three plagues of the long-term care institution—loneliness, helplessness, and boredom.

The Eden Alternative cures loneliness by providing residents with companions such as children and pets. People with Alzheimer's disease benefit from such companions because they offer meaningful relationships without making demands on residents' memories or communications skills.

"I can't cure loneliness with medication," explains Thomas. "I can cure it by providing residents with companions."

The Eden Alternative's mission to show how the opportunity to care for other living things and a spontaneous environment can succeed where pills and therapies fail.

"Bringing animals, plants, and children into the environment yields quality of life for elders," says Thomas. "It's a direct pipeline to their spirits."

Creating this nurturing environment is not just a matter of bringing in a dog for an hour or having a busload of schoolchildren visit once a month. The animals actually live at the facility, and children visit every day from a nearby day care center. Infusing the environment with living things allows the residents to love and be loved unconditionally.

"People with Alzheimer's benefit most from this environment because they don't need their memories or communication skills to have relationships with others," says Thomas.

Thomas points out that a major blindspot for Westerners in providing care is our view of Alzheimer's disease as a terrible blow.

"Other cultures view caregiving as an opportunity to honor their elders for who they are now rather than viewing them as a corrupted version of what they used to be," elaborates Thomas.

"We need to transform the way we think about and care for our elders," says Thomas.

According to Thomas, caregivers can adapt the Eden philosophy in their homes by simply using their imaginations and always keeping the person's spiritual dimension in mind.

"The environment should be shaped by the people who live and work there so that when people walk out of one place and into another, it's different," explains Thomas.

The Eden approach appears to be working. Compared with other similar facilities, the Eden Alternative shows a 50 percent reduction in the use of medications, a 26 percent decline in nurse assistant turnover, a 50 percent reduction in infections, and a 15 percent decline in mortality.

"I look forward to the day when nursing homes will be replaced by elder gardens," says Thomas. "Elder gardens will be distinguished by vitality and life, a commitment to growth, and the ability to adapt to change." 

It Can Be Different!

In July Thomas and his family will board a 45-foot long bus and begin a 10,000-mile journey that will take them to 25 cities nationwide in 31 days. They will convene a series of public meetings to spread their message that "It Can Be Different" in long-term care. In addition, Thomas will perform a one-man show that tells the story of an undiscovered country where elders form the vital center of society. Proceeds from the performances will be donated to local charities dedicated to helping the elderly, including the Alzheimer's Association.

For more information, visit Thomas's Web site at www.kallimos.com or call (607) 674-5232.

Residents' Rights in a Nursing Home

All nursing home residents have rights protected by the Nursing Home Reform Law and Americans with Disabilities Act. Family members should be aware of these rights to ensure that their loved ones are receiving the best care possible.

Access to information. Residents have the right to:

- information on all services available and the charges for those services;
- information on the facility's policies, procedures, rules, and regulations;
- information on how to contact their state ombudsman and licensure office and advocacy groups;
- review the state survey reports on the facility;
- daily communication in their own language; and
- assistance if there is sensory impairment.

Participation in care. Residents have the right to:

- receive adequate or appropriate care;
- be informed of their medical condition and participate in treatment planning;
- refuse medication and treatment and be offered treatment alternatives;
- participate in discharge planning; and
- review their medical records.

Make independent choices. Residents have the right to:

- choose their physician;
- participate in activities in the facility and community; and
- participate in a residents' council.

Privacy and confidentiality. Residents have the right to:

- private and unrestricted communication, including privacy for phone calls, mail, and meetings with family, friends, and residents;
- access to any entity or individual that provides health, social, legal, and other services; and
- confidentiality regarding medical, personal, and financial affairs.

Dignity, respect, and freedom. Residents have the right to:

- be free from mental and physical abuse;
- be free from physical and chemical restraints;
- self-determination; and
- be treated with consideration, dignity, and respect.

Security for possessions. Residents have the right to:

- manage personal financial affairs; and
- file a complaint with the state survey and agency for abuse, neglect, or misappropriation of property.

Transfers and discharges. Residents have the right to:

- be transferred or discharged only for medical reasons, if health or safety is endangered, for nonpayment of services, or if the facility closes;
- be notified of transfer 30 days in advance (in most instances);
- know the reason for transfer, the date it's effective, the location to which they will be discharged, and a statement of the right to appeal;
- receive preparation from the facility to ensure a safe and orderly transfer; and
- have policies and practices upheld by the facility that are the same for all individuals regardless of payment source.

Concerns and complaints. Residents have the right to:

- present grievances to the staff or others without fear of reprisal; and
- have grievances promptly resolved by the facility.

Adapted from *Nursing Homes—Getting Good Care There* by the National Citizens' Coalition for Nursing Home Reform, Washington, D.C., (202) 332-2275. 

LATE-STAGE CARE...CONTINUED FROM PAGE 3

it is appropriate to do everything in their power to get the person to eat or drink. The use of feeding tubes and intravenous (IV) hydration is often assumed to prolong life when in fact it could lengthen the dying process. In addition, if these artificial means are used, families will eventually be faced with the tough decision about whether or not to withdraw such treatment.

Treating infections

Pneumonia and urinary tract infections are common in the last stage of Alzheimer's. The person's advance directive should indicate whether preventive measures such as pneumonia vaccines and antibiotics may be used. If the Alzheimer patient does not wish to receive these, medications can be used to reduce pain and make the person more comfortable.

If the patient cannot talk, look for behavioral clues such as depressive or psychotic symptoms, anxiety, and sleep and activity disturbances that may indicate he or she is experiencing pain.

Restraints

Restraints are often used in long-term care settings and hospitals as a means to control Alzheimer-related behavior problems such as wandering, agitation, and combativeness.

Although restraints are intended to protect the safety of the patient, their use can cause harm as well as jeopardize the individual's independence and dignity.

"Achieving a restraint-free environment should be the goal of every facility," says Carole Patterson, deputy director of the Department of Standards for the Joint Commission on Accreditation of Health Care Organizations (JCAHO), an organization that

evaluates and accredits health care organizations. "Studies have demonstrated that effective programming can eliminate the need for restraints."

Physical restraints restrict the person's ability to move and can cause incontinence, loss of muscle tone, pressure sores, depression, and decreased appetite.

People with Alzheimer's have the right to receive care without the use of physical or chemical restraints that are not needed to treat a medical condition. Care providers have an obligation to try alternatives to restraints, such as diversions for aggressive behavior or safe places to wander.

Hospice care

People with Alzheimer's disease will likely be in and out of nursing homes and hospitals as the disease advances. One unique care option is hospice.

The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care, and support services for people with terminal illnesses and their families.

"Hospice places an emphasis on maximizing patient comfort and providing counseling and bereavement services to the family before and after their loved one dies," says Volicer.

To qualify for Medicare, a person with Alzheimer's must be diagnosed by a physician as having less than six months to live.

Support for caregivers

It is important for caregivers to seek support, particularly during this difficult stage of the disease. Local chapters of the Alzheimer's Association have support groups and help lines that allow caregivers to deal with the emotions they may be experiencing, including stress, grief, guilt, anger, and depression. To locate the chapter nearest you, call (800) 272-3900.

Ideally, discussions about end-of-life issues should take place while the person with the disease still has the capacity to make decisions.



Q & A presents answers to your research or caregiving questions from leading professionals in the field of Alzheimer's disease. Elisa Marie Ghezzi, DDS, responds to the following question about the stages of Alzheimer's disease.

Q: My mother has Alzheimer's disease and no longer seems to be brushing her teeth. She's never had any major oral hygiene problems before. How do I know if I should step in and help?

A: In the early stages of Alzheimer's, an individual may forget to perform daily oral hygiene or may not remember how to do it. Caregivers can play an important role in maintaining the oral hygiene of an individual with Alzheimer's.

Begin by using short, simple instructions to explain how the individual should hold the toothbrush, apply the toothpaste, and brush the teeth. It may be helpful to hold a brush yourself and show how brushing should be done. If the individual is able to manage brushing without assistance, you should periodically observe her to make sure that she is brushing properly.

As the disease progresses, caregivers often need to assume full responsibility for the individual's oral health. Oral examinations, toothbrushing, and flossing should be incorporated into the individual's daily routine in order to maintain good oral hygiene. Look for signs of oral discomfort such as red or white sores, bleeding gums, broken teeth or fillings, and refusal to eat. These problems should be noted and brought to the attention of a dentist.

Toothbrushing can become difficult since the individual may not understand what's happening and resist the procedure. If the individual seems extremely uncomfortable or anxious, you may want to wait for a better time. Always begin slowly, and calmly explain what you are doing. Try to establish a routine in which the various tasks are performed at the same time of day and in the same order.

Individuals with Alzheimer's should be seen by a dentist every four months. Inform the dentist that the person has Alzheimer's disease so that an appropriate oral care routine can be established. Also ask your dentist for oral hygiene aids and fluoride supplements that will help facilitate oral health.

People who wear dentures should also receive regular oral examinations by a dentist and maintain daily oral hygiene. After each meal, dentures should be removed and brushed. Each night they should be removed, cleaned, and stored in a cup of water. The gums, tongue, and roof of the mouth can be brushed after removal of the dentures.

Early detection and prevention of disease is the key to maintaining oral health for the person with Alzheimer's disease. Through their participation in the daily oral hygiene routine, caregivers play an essential role in helping to maintain a clean mouth by noticing any changes or problems and seeking professional intervention from a dentist. **H**

Elisa Marie Ghezzi, DDS, is a lecturer in geriatric dentistry at the University of Michigan Medical Center and School of Dentistry in Ann Arbor, Michigan.

The Washington State Dental Association has developed a video entitled *Oral Care for the Alzheimer Patient*. To request an informational brochure or order the video, call (206) 448-1914. The price of the video is \$30 (includes tax, shipping, and handling.)

Send us your questions...

If you have a question you'd like to ask about Alzheimer research or care, please mail it to: Alzheimer's Association, 919 North Michigan Avenue, Suite 1100, Chicago, Illinois 60611-1676, Attn: Sara Dusenbery, or send e-mail to: sara.dusenbery@alz.org.

