National Alzheimer's Disease Awareness Month

November 2007

The number of people affected by Alzheimer's disease (AD) -- those who have the disorder as well as their caregivers, family and friends -- continues to rise at an alarming rate. Today, more than 4.5 million Americans are thought to have AD, and this number could triple by 2050. The emotional, physical and financial drain on families is staggering – indirect and direct costs of care are estimated at $100 billion annually. The health care system in the U.S. is also overwhelmed by the AD tidal wave. Researchers continue to learn more about this complex disease, but only further investment in their work will move us closer to effective treatments that significantly slow its progression or one day, even prevent its development.

Through its Alzheimer's Disease Research program, the non-profit American Health Assistance Foundation, is committed to funding the most innovative research worldwide. We also believe that an informed public is of paramount importance. To carry out this part of our mission, we disseminate print publications, as well as TV and radio Public Service Advertisements (PSAs), and our website (www.ahaf.org) contains a wealth of up-to-date, accurate information on all aspects of AD. We urge you to assist us in our endeavors by publishing the following information for your readers. The material may be reprinted without prior approval, but please credit the Alzheimer's Disease Research program of the American Health Assistance Foundation as the source. The back of this publication contains information for your readers on our website and on ordering our brochures and booklets.

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Information for the public: Alzheimer's Disease Research, a program of the American Health Assistance Foundation, 1-800-437-2423, www.ahaf.org, 22512 Gateway Center Dr., Clarksburg, MD 20871

The information in this publication should not in any way substitute for the advice of a qualified health care professional and is not intended to constitute medical advice. ■

• INSIDE •

Diane Marcello is well aware of the impact that Alzheimer's disease (AD) has on those diagnosed as well as their loved ones. She is the Director of Sunnyside Health Services, an assisted living community and nursing home (part of Sunnyside Village Retirement Community) in Sarasota, Florida. She is also one of the newest members of the American Health Assistance Foundation's Board of Directors. As the director of Sunnyside for the past 8 years, Ms. Marcello, a speech and language pathologist and former educator, has helped resolve some of the many issues her residents, their caregivers and families face when confronted with AD. In an interview on p. 2, she answers some commonly asked questions from a very personal and informed perspective.

See **Q&A**, page 2

An Interview with Diane Marcello, Director of Sunnyside Health Services

Q: *How does a family member decide if and when to place the person with Alzheimer's disease (AD) in a nursing home?*
A: This is never an easy decision. Most people prefer to live on their own or in a family home as long as possible. However, when a loved one has Alzheimer's, a long term care facility may be necessary. In my experience, some caregivers wait too long to make a decision. Often a traumatic event occurs—the person has a serious fall or wanders and gets lost, and this necessitates quick action. For others, the stress of caregiving and the strain on family relations drives them to make the choice to move the loved one into a home for the aged. In many cases, family members, particularly adult children of those with AD, feel tremendous guilt about placing their parent in a nursing home. They know that people with AD often fear change in their environment and prefer to remain in familiar surroundings. That said, it is wise to plan for long term care as early as possible in order to choose the best facility for the individual.

Q: *What are the most important things to look for in the nursing home?*
A: I encourage people assessing nursing homes to use their keenest senses of observation during both planned appointments and unannounced visits. First and foremost, look closely at the residents. Do they appear engaged and content? Positive interaction between the staff and residents is critical. The staff should be happy and genuinely focused on and interested in the residents, not simply performing tasks. Check to see what types of activities are available. Is the staff competent and trained to deal specifically with AD? Note the color schemes of beds, chairs, walls and floors. This goes beyond aesthetics, because many AD patients are unable to discern colors very well. There should be a clear contrast between the floors and bedcovers, for example, to prevent confusion and falls. Also, the nursing home should be free of unpleasant odors. If the individual is prone to wandering, it is essential to find a secured facility. For more insight, talk to families of residents. Locate and read the posted state survey of the facility and use the internet to find more information.

Q: *Do you have suggestions for assessing the family's financial situation and ability to pay?*
A: Unfortunately, assisted living and nursing home care are very expensive propositions. Medicare does not cover the cost of long term health care, and Medicaid is reserved for those who do not have the financial means to pay. I suggest that people plan well in advance and carefully consider long term care insurance as early as possible, even in their 40s and 50s. Otherwise, it becomes extremely costly. To make the best decisions, seek good advice and examine the whole financial picture.

Q: *Once in the nursing home, what are the best ways to maintain the connection between the resident and loved ones?*
A: I always encourage caregivers of those with AD to have their loved ones bring familiar mementos from home, such as framed photos and other personal items. Another wonderful idea is to put together a "memory book" that contains photos and anything else having to do with the person's life, such as greeting cards and postcards. Even when the resident no longer remembers the past, looking at these mementos can be calming and is appreciated. We also believe in "validation theory" when interacting with our residents. For example, if the individual begins talking about someone who is long gone as if he were still alive, we join in this "reality." Reorienting the person to the truth is not useful and may be upsetting. Visit as often as you can – even without memory it can give your loved one a sense of peace.

Q: *Of course each person is different, but are there some common things that are most appreciated and enjoyed? What are some activities you have for residents in your home?*
A: Our residents really enjoy the company of pets, and we have several dogs, a cat and birds with which they can interact. If they are able to, they can play organized Bingo and other games, and participate in arts and crafts. For those who are more impaired, we have other activities such as aromatherapy, listening to generational music and sensory stimulation. In

this last activity, we may use cinnamon, for example, to smell, taste and reminisce. Our residents also appreciate hand massages – the sense of touch is very important, especially to someone who may have been living alone. We have intergenerational programs in which children come in to visit or entertain. We also bring our residents outdoors for fresh air and to view the gardens.

Q: ***What is the most important advice you give to family and friends of those who have Alzheimer's disease?***

A: It is difficult to deal with Alzheimer's disease, especially when the person affected is a loved one with whom you are so closely connected. However, people should try to accept the individual where he or she is in the disease process and attempt to make life as pleasant as possible. This may not be the person you remember, but you will always cherish those memories. Even though your loved one may not remember who you are, keep in mind that this is a person you love, and one who deserves the best you can give him. Simply being with your loved one provides comfort, and is a wonderful gift for both of you. ■

The Family Meeting: An Essential Strategy for Dealing with Alzheimer's Disease

A diagnosis of Alzheimer's disease (AD) is devastating both for the individual who receives it and family members. The health issues and financial and legal aspects can be overwhelming, but cooperative information and resource gathering, early planning, division of responsibilities and regular communication will ease the burden. There are a number of ways that families can work together to cope with AD and its ramifications.

A suggested plan of action:

Call a family meeting as soon as possible to discuss short and long term planning, and division of caregiving responsibilities. Be sure to include the person with AD in the meeting. If some family members cannot attend in person, arrange a teleconference. Prior to the meeting, gather information and resources – area Agencies on Aging are good places to start.

- The person with AD may be resistant to suggestions and still overwhelmed emotionally. Other family members need to allow the individual to express needs and desires, remain flexible and make positive suggestions.
- If an AD diagnosis sparks sibling rivalries, exacerbates ongoing family problems or brings out negative feelings, a counselor or other objective mediator, such as a geriatric care manager, may be called upon to moderate the meeting. Disagreements will almost inevitably occur, but everyone should be encouraged to voice their opinions and make suggestions.
- Each member should honestly assess personal preferences, financial abilities and time availability to determine his or her appropriate role. There will normally be a primary caregiver, but that person will need the support of everyone in the family. The primary caregiver needs to explicitly convey needs, and ask for and receive help.
- Draft a written plan that includes decisions on division of responsibilities (hands on and long distance), costs and time commitments. These responsibilities can be divided as follows: medical and physical needs, financial, legal, daily living (for example, cleaning and meal preparation), and other care needs such as transportation and shopping. Although a written plan is recommended, it should also be flexible to adapt to the person's changing needs.
- Put a system in place to ensure essential, regular communication. For example, family members may decide that weekly phone calls will be made on certain days and times.

As much as possible, family members should be resources for one another, offer assistance and respite to the primary caregiver, and stay up to date on the physical and emotional condition of the person with AD. They should take advantage of the many resources available for caregiver support. Some websites with more information on caregiving include: American Health Assistance Foundation at www.ahaf.org; ElderCare Online at www.ec-online.net; Family Caregiver Alliance at www.caregiver.org; and CarePathways at www.carepathways.com. ■

A Healthy Lifestyle May Lower Risk

While nothing can be done to control age and genetics, the known risk factors for Alzheimer's disease (AD), healthy practices may lower the chances of developing the disorder. These are not treatments, but solid recommendations for overall health and well-being. In general, what is good for the heart and the body is good for the brain, and it is never too early or too late to begin these habits. Family and friends of older adults should encourage their loved ones to live fully, physically, socially and mentally and should join them in these activities.

Diet

Eat a varied diet that includes vegetables, legumes (for example, beans, peas, and seeds), fruits, whole grain and fish, and is low in saturated fat and added sugar. Consume foods that contain omega 3 fatty acids, found mostly in "oily" fish (for example, tuna and salmon), but also in certain oils, nuts and seeds. Include fruits and vegetables high in antioxidants (vitamins A, C and E) such as green leafy vegetables, broccoli, cauliflower, berries, tomatoes, red grapes and carrots.

Non-smoking

Avoid smoking – it may lead to oxidative stress and damage to cells, making them more vulnerable to the disease.

Exercise

Physical activity reduces the risk of many diseases, helps maintain a healthy weight and enhances mental fitness. Experts recommend a combination of three types of activity: thirty minutes of moderately intense aerobic exercise 3-5 days a week (for example, walking or gardening); strength training (lifting weights or carrying groceries) 2-3 times per week; and daily activity that increases flexibility (stretching or yoga). Many health clubs and community recreation centers have programs geared toward older adults.

Physical condition

Research has shown that vascular disease, stroke, high blood pressure, high cholesterol and diabetes may all be associated with an increased risk of developing or worsening AD. Control these conditions if they are already present, and if they have not developed, avoid them through diet and exercise.

Emotional state and sociability

Keep in touch with family and friends and increase social connections through creative and intellectual pursuits, such as crafts and hobbies, playing cards and games, attending plays, musical performances and lectures, and visiting parks and museums. Depression and stress have also been linked to an increased risk of cognitive impairment. Consider seeking professional help if feelings of depression and sadness persist for too long.

Mental activity

Children and young adults build up brain "reserves" through reading and mental challenges, but older adults can also increase these brain connections. Continue to enjoy favorite pastimes, but engage in new and challenging activities too. Examples include playing video, board and card games, solving puzzles and brain teasers, reading books, magazines and newspapers, writing and corresponding through mail and email, using the computer to broaden your knowledge base, and even conversing and singing. Take a class, learn to play a musical instrument, try a new language or begin a hobby. ■

Basic Facts about Alzheimer's Disease

Alzheimer's disease (AD) is a progressive, incurable and terminal disorder in which beta amyloid protein plaques and tau protein tangles in the brain disrupt nerve cell communication and eventually lead to cell death. Those with the disease lose their mental ability to remember, communicate and reason.

- AD is now estimated to affect more than 4.5 million people in the U.S. By 2050, the number could increase to 13.2 million.
- One in eight people age 65 and over, and nearly one in two over age 85 have AD.
- Age is the single biggest risk factor for AD. Approximately 4 million Americans are 85 or older, and this age group is one of the fastest growing segments of the population.
- On average, AD patients live for 8 to 10 years after diagnosis, but the disease can last for as long as 20 years.
- Health care expenses and lost wages for patients and caregivers are thought to be $100 billion annually.
- The average cost of the disease from diagnosis until death is estimated at $174,000. The yearly cost of caring for an AD patient ranges from $18,000 to $36,000.
- Approximately 70% of AD patients live at home where families care for them.
- The average annual cost of a private room in a nursing home is $74,095; an assisted living facility averages $34,860 annually. ■

Early Screening for Alzheimer's Disease

Current treatments for Alzheimer's disease (AD) are focused on slowing cognitive decline after the destructive beta amyloid protein plaques have already begun building up in the brain, and many researchers are investigating ways to remove this harmful protein. However, the processes leading to this toxic aggregation may be underway for years or decades before symptoms appear. Early screening for AD could lead to drug therapies that actually prevent this protein accumulation before it begins.

To diagnose AD today, doctors rule out other causes of memory loss, administer memory tests and gather information from people closest to the person. However, scientists believe that early and accurate screening for AD, as well as ongoing examination of its progress could advance the search for a cure. Magnetic resonance imaging (MRI) and positron emission tomography (PET), can scan the brain in detail. Changes in physical traits (called biomarkers) such as protein levels and inflammation can be measured through blood, urine and spinal fluid tests. With this information, researchers may be able to speed progress toward more effective, timely intervention at a lower cost. By building on the knowledge gained from earlier and more accurate screening we may in the future halt the development of AD.

Although it is incurable, using early screening to identify people at elevated risk of developing AD could have benefits. Generally, treatment with modern drugs in the early stages of AD is more effective and can slow cognitive decline. People who find they are at risk can participate more fully in planning and better preparing for the future. Finally, an individual who understands the level of risk may decide to adopt a healthier lifestyle that could delay onset or even potentially lower the chances of developing AD. ■

The Road to Treatment of Alzheimer's Disease

It can take 15 years for a potential treatment to work its way from the laboratory to rigorous testing and finally, approval by the Food and Drug Administration (FDA) for human use. The process begins in the lab with basic investigations using cells and specially bred animal models. Next, translational research moves the therapy to the human setting. Finally, the drug is tested on humans in clinical trials divided into three phases—I, II and III. These trials are used to determine the safety and effectiveness of the drug on progressively larger numbers of people. Normally, if the results are positive in the first two phases, the therapy will proceed to Phase III. The data gathering, analysis and reporting that are necessary to complete these trials can take several years and millions of dollars. Currently, there are numerous potential treatments for Alzheimer's disease (AD) in various clinical testing phases.

While a "miracle drug" is unlikely, several treatments being tested show promise. Some treatments currently in trials include:

- This spring, Medivation, Inc. concluded a Phase II efficacy trial of a treatment for mild to moderate AD called Dimebon™. Patients taking Dimebon in the trial showed cognitive improvement over those taking a placebo. A Phase III trial is scheduled to begin in 2008.

- In August, Neurochem Inc. concluded its North American Phase III clinical trials testing a proposed new treatment for AD called Alzhemed™ (tramiprosate), but efficacy results were inconclusive. Phase III trials underway in Europe may be modified to obtain better data. These European trials will conclude by the end of 2008, with results expected by mid-2009.

- Two pharmaceutical companies, Elan Corporation and Wyeth, are conducting Phase II trials on an AD antibody called bapineuzumab. This is a passive vaccination for AD, in which antibodies to the beta amyloid protein, rather than the beta amyloid protein itself, are given to the recipients. Phase II data will be released in 2008, but based on data already gathered, Elan and Wyeth were planning to begin Phase III clinical trials of bapineuzumab in 2007.

- Myriad Genetics, Inc. is conducting a Phase III trial testing the use of Flurizan™ (r-fluribiprofen) to treat mild AD. In a Phase II study completed in 2006, patients with mild AD showed a reduced rate of deterioration in cognitive function and daily living activities.

- Some research has found that statins, drugs commonly used to lower cholesterol, may decrease the risk of developing AD. A Phase II trial of one such statin, Lipitor®, manufactured by Pfizer Inc., has been completed, as has a Phase III trial testing the efficacy of administering Lipitor together with a currently available AD treatment, Aricept®, also produced by Pfizer.

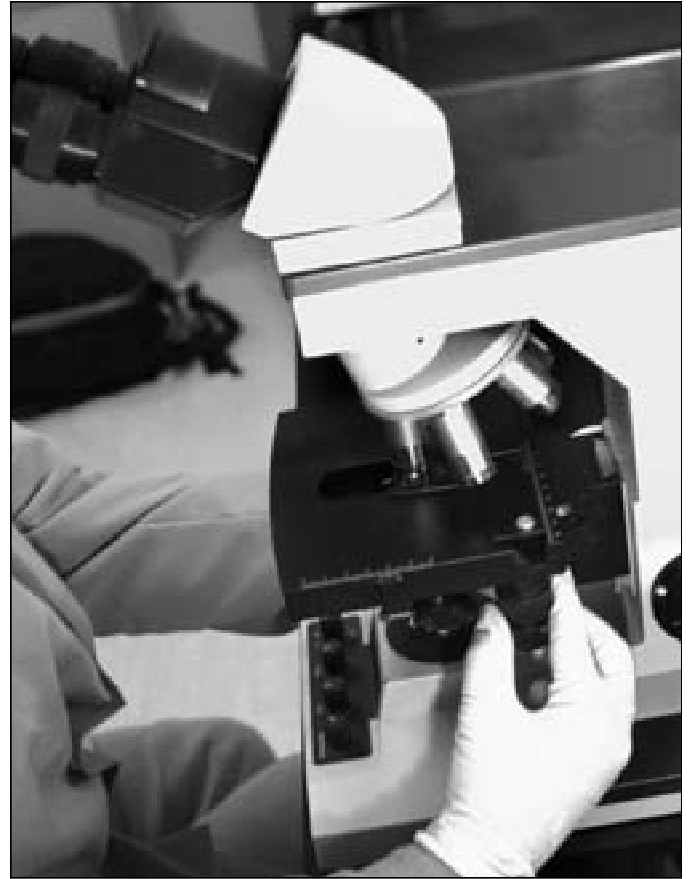
- A Phase III trial that began in February 2007 is testing whether consuming omega 3 fatty acids, found mainly in fish such as tuna and salmon, may lower the risk of developing AD and have a protective effect on the brain.

- There is an ongoing Phase II study of the effect of estrogen on AD risk when administered to post-menopausal women.

- Several trials are looking at the effect of anti-inflammatory drugs on the development of AD.

Those with AD as well as healthy individuals may want to consider participating in clinical trials. Each trial has its own protocol or set of guidelines, and volunteers must meet certain criteria to qualify for inclusion. Before making a decision, get as much information as possible about the trials, and think seriously about the benefits and risks of volunteering. Those who participate will have access to potential new treatments, as well as medical care, and they may help others with AD. However, there may be side effects to the medications being tested or they may not be effective, and participation often requires a time commitment. For more information about ongoing AD clinical trials, go to www.alzforum.org. Individuals who may want to volunteer for trials testing potential therapies or studying other aspects of AD, such as caregiving, should visit www.nia.nih.gov/Alzheimers/ResearchInformation/ClinicalTrials/ or www.clinicaltrials.gov. ■

Some Research Results from 2007



The search for ways to slow the progression of, or prevent Alzheimer's disease (AD), begins with a thorough understanding of its causes and processes or pathology. Over the course of the last two decades, through basic research, our scientific knowledge about AD's complex pathology has broadened enormously. Many current AD investigations focus on clearing the beta amyloid protein plaques and the tau protein fiber tangles from the brain's nerve cells. The road from discovery in the laboratory to approval for human use is long and difficult, but today's research is a critical step in finding new drugs. Results from this year include:

- Dr. Marc Flajolet is working with a team of researchers under Dr. Paul Greengard at the Fisher Center for Alzheimer's Disease Research at Rockefeller University. The team is investigating a protein called casein kinase 1 that appears to block production of the harmful beta amyloid protein in mammalian blood cells.

- Dr. Beka Solomon of Tel Aviv University administered a harmless bacterial virus, "filamentous phage" through the nasal passages of mice. These phage particles appeared to dissolve the harmful beta amyloid protein plaques without unwanted side effects.

- Dr. Gunnar K. Gouras and his team at Weill Medical College of Cornell University are investigating antibodies that may reduce the levels of beta amyloid in mouse nerve cells and help restore cell communications. This renewal of communication between cells means that memory could actually be improved.

- Dr. Einar Sigurdsson and researchers at New York University Medical Center immunized mice with a detrimental piece of tau protein and found that the vaccine slowed deterioration of the animals' motor abilities. The scientists believe these antibodies may bind to the harmful tau protein, a hallmark of AD, and clear it from the brain.

- Dr. William L. Klein and his colleagues at Northwestern University are studying the process that leads to insulin resistance in the brain's nerve cells. Dr. Klein's team has shown that a toxic protein found in AD, beta amyloid-derived diffusible ligand (ADDL) attaches itself to brain cell synapses and removes the insulin receptor molecules, preventing their build up on the cell surface where they are needed for memory formation. If this insulin resistance is related to, or is another form of diabetes, then drugs used to treat diabetics could possibly also be used for AD.

- Dr. Dennis Selkoe and Matthew Hemming, along with researchers at Harvard Medical School placed into mice a gene that forms a beta amyloid protein-busting enzyme known as neprilysin. Using the animals' own skin cells, the researchers introduced the gene into the bodies of mice and found that it led to clearing of beta amyloid plaques.

- Dr. Berislav Zlokovic and a team of researchers at the University of Rochester Medical Center found they could use a soluble low density lipoprotein receptor related protein or sLRP to "soak up" beta amyloid. They synthesized a powerful form of sLRP, that bound to the harmful beta amyloid protein and virtually eliminated it from mice blood cells. The scientists theorize that if levels of protein in blood can be lowered, they may also be reduced in the brain. ■

Resources for Living with Alzheimer's Disease

An important part of the mission of **Alzheimer's Disease Research**, a program of the American Health Assistance Foundation is to provide the public with accurate, detailed information about Alzheimer's disease, including risk factors, preventative lifestyles, available treatments and coping strategies.

The AHAF website, **www.ahaf.org** contains a wealth of information on Alzheimer's disease (AD), including a section called "Real Life Questions." In "Real Life Questions" people can post an inquiry, read answers to recently asked questions or search a database of questions and responses going back over the past year. Every other week, a range of scientific, medical and caregiving inquiries related to AD are answered by a qualified research professional. The professional can offer advice, make suggestions to resolve issues and find more assistance, but a physician should be consulted for medical advice.

One free copy of each of the following publications, in English or Spanish, may be ordered from AHAF: "Understanding Alzheimer's Disease: It's Not Just Forgetfulness" and "Safety and The Older Driver." The following publications are available in English, and will soon be translated into Spanish, "Care for the Caregiver: Managing Stress" and "Staying Safe: Wandering and the Alzheimer's Patient."

To order print copies of all publications call toll-free 1-800-437-2423 or order online at www.ahaf.org; free electronic PDF versions may also be downloaded or read online at www.ahaf.org.

AHAF is completing a booklet titled, "Living with Alzheimer's Disease" that will contain health, financial, legal and caregiving information and will be available to the public for a nominal fee of $5.00.

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