

**Progress in Alzheimer Research and Care** 

Vol. 21 No. 4 Winter 2002

## Web of Compasssion

## Internet Site Provides Information and Support

Topic: Family Caregivers and Friends

Author: Judy

Time: 10/02/2001 19:55:31

Subject: My husband, lost.

Only married 13 years and living with this disease for almost 12. Not fair. Didn't get to have a life with the man I fell in love with and married. He is becoming more childlike each day. I also have an 89-year-old mother with dementia—vascular, probably. She is in a nursing home. My 90-year-old dad is trying to live alone in a fleabag hotel; both of them are 350 miles away from me.

I make the trip monthly, taking my husband with me to check on them. As I am an only child, they have no one else. It is overwhelming, and I am getting very tired trying to manage all of them and working full time, too.

Judy's message—one of many posted each day on the Community Circle boards on the Alzheimer's Association Web site (www.alz.org)—is an example of the sort of poignant plight experienced by members of the Association's on-line fellowship. Those directly affected by the disease seek solace in sharing personal stories—even if they don't know what to say or how to say it—and search for information, hope, and understanding. This quest encapsulates the Web site's purpose: to provide people with Alzheimer's and their caregivers with a way to find empathy and answers to their many questions.

"Our goal is to furnish people with as much information as we can—when and how they want it," said Catherine Henry, vice president of communications. "People with the disease and their caregivers find out where to go for support, how to plan for the future, and what to expect as the disease progresses."

Jose Escobedo, specialist, Web communications, added: "The amount of useful material, including local chapter contact information, breaking news items, support groups, and advocacy opportunities—as well as the community boards and an early-stage chat room—contribute to a positive and practical experience for everyone who comes to us."

# inside research Vascular dementia dialogue What do you do when a loved one begins wandering? caregiving Early-onset Alzheimer's disease question + answer Dental amalgam—Is it true that silver dental fillings may cause Alzheimer's disease? in the news September 11 and its aftermath in brief 10 Holidays memory walk 12

# Vascular Dementia: Complex Pathology, Confusing Symptoms

Although the average brain weighs only three pounds—accounting for just 2 percent of the weight of a 150-pound person—it consumes 20 percent of the body's oxygen and receives 20 percent of the body's blood supply. Events that interfere with the brain's blood supply pose a serious threat—its cells can survive without oxygen for only three to five minutes. When brain cells die, their death disrupts the mental or physical function controlled by the area where the damage occurs.

Vascular dementia is a general term for thinking impairment resulting from disruptions in the brain's blood supply to cells involved in memory, reasoning, and emotion. The most frequently diagnosed type of vascular dementia is multi-infarct dementia, in which a series of small strokes block small arteries. Individually, these strokes are too slight to cause the catastrophic symptoms associated with a major stroke—such as numbness or paralysis on one side of the body, inability to speak, or loss of consciousness—but their combined effects gradually become noticeable. One rare type of vascular dementia is Binswanger's disease, in which multiple small strokes tend to occur deep below the brain's surface in an area called the white matter.

Many symptoms considered characteristic of vascular dementia mimic symptoms of other dementias, including Alzheimer's disease. Common symptoms include problems with recent memory, confusion, wandering or getting lost in familiar places, having trouble following instructions, problems with bladder or bowel control, and laughing or crying inappropriately. In some cases—although not all mental impairment associated with vascular dementia may occur in discrete "steps" rather than in the slow, steady decline of Alzheimer's. Another difference is that people with vascular dementia may retain a greater awareness of their mental impairment. Individuals with vascular dementia may also have other diseases of the heart or circulatory system, or risk factors for those disorders such as high blood pressure, elevated cholesterol levels, or diabetes.

### Evolving Ideas about a Complex Disorder

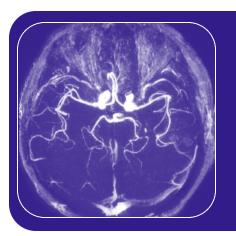
Medical thinking about vascular dementia has changed considerably over the past few decades. At one time, doctors attributed almost all mental impairment associated with old age to "hardening of the arteries" in the brain. As scientists gained deeper understanding of other dementing illnesses, Alzheimer's

gradually earned recognition as the most common dementia, and vascular dementia was considered the second most frequent.

Experts now acknowledge that neither the frequency nor the characteristics of vasculardementiaare well understood. Several professional bodies have developed different sets of criteria for diagnosing the disorder, making it difficult to estimate its frequency with any precision. Estimates found in recent scientific literature indicate that vascular dementia accounts for anywhere from one-tenth to one-third of dementia cases.

Thinking about the pathological changes that occur with vascular dementia and Alzheimer's also continues to evolve. Autopsy studies suggest that dementia caused exclusively by vascular abnormalities is actually quite rare. Many individuals with dementia have both vascular lesions and pathology associated with Alzheimer's—a condition sometimes called "mixed dementia." In his book Aging with Grace, which describes investigations into healthy aging and Alzheimer's with the School Sisters of Notre Dame (the Nun Study), David Snowdon reports that sisters with vascular brain lesions tended to have symptoms of dementia only

Research



This brain angiogram shows the rich network of blood vessels that carry oxygen and food to brain cells. Small strokes or other obstructions that interrupt blood flow kill brain cells by depriving them of needednourishment.

Image courtesy of Michigan State University Department of Radiology

if they also had plaques and tangles—characteristic Alzheimer abnormalities.

### Clarifying the Relationship between Alzheimer's and Vascular Dementia

To help clarify the relationship between the symptoms and pathology of Alzheimer's and vascular dementia, the Association designated vascular factors in dementia as one of the core areas of investigation in its 2001 research grants programs. Exploring the connection between these two disorders has the potential to significantly broaden our knowledge of dementia mechanisms and suggest new therapeutic strategies. Understanding the relationship also raises the exciting possibility that established strategies for reducing the risk of cardiovascular disease—such as exercising, limiting dietary fat and calories, avoiding smoking, and controlling blood pressure and cholesterol levels-may also have value in lowering Alzheimer risk. The following two examples illustrate the range of investigations in this promising area.

### Exploring a Cholesterol-Alzheimer Connection

Elevated cholesterol is a known risk factor for cardiovascular disease. The degree of risk depends not only on a person's total cholesterol level, but also on the relative

amounts of cholesterol-transporting molecules—called lipoproteins—that are present in the blood. A high proportion of high-density lipoprotein (HDL) is considered protective against heart disease, while a large amount of low-density lipoprotein (LDL) is undesirable.

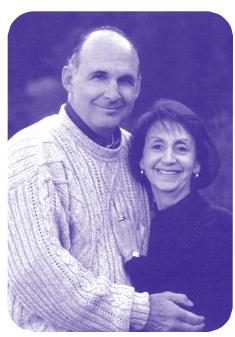
Anne M. Fagan Niven, PhD, of Washington University in St. Louis, received Association funding to investigate whether HDL plays a role in treating or protecting against Alzheimer's disease. Previous laboratory research has offered evidence that one type of HDL—apolipoprotein AI (ApoAI)—may help clear protein fragment beta-amyloid (A ) from the brain. Efficient removal of A may short-circuit the fragment's consolidation into plaques, a process that many scientists regard as a key event in Alzheimer nerve cell degeneration.

Niven's team will conduct laboratory investigations to gain additional insight into how ApoAI and A interact and then further explore the effects of these interactions in genetically modified mice. Insights gained in this project may provide evidence that strategies for managing cholesterol levels may help prevent or treat Alzheimer's.

### Investigating the Role of Blood Vessel Damage in Alzheimer's

In previous research, Paula Grammas, PhD, found that individuals with Alzheimer's have biochemical and functional abnormalities in their brain blood vessels, and that these damaged vessels produce toxins that kill nerve cells. In her current Association-funded project, Grammas and her team at the University of Oklahoma aim to find evidence supporting their hypothesis that cardiovascular risk factors may damage the blood vessels, and that after the vessels are damaged, they produce certain proteins that kill nerve cells. Demonstrating this connection may suggest Alzheimer prevention or treatment strategies based on modifying an individual's cardiovascular risk factors.

## When a Loved One Wanders, Safe Return Can Help



Craig and Judy six months prior to his death in 1999.



Craig running in a marathon.

The Alzheimer's Association Safe Return Program allowed Craig Seegmiller to continue doing something he loved—running. Diagnosed with early-onset Alzheimer's disease at age 52, Craig wanted to maintain as normal a life as possible. Judy, his wife of more than 30 years, immediately registered him in Safe Return. She says she will always be grateful to the program.

Established in 1993, Safe Return is a nationwide registration and identification program that assists in the timely return of individuals with Alzheimer's disease or a related dementia who wander and become lost. The statistics are alarming:

Nearly 60 percent of people with Alzheimer's will wander during the course of the disease. If the person is not located within 24 hours, 46 percent of wandering individuals may die from dehydration or hypothermia

"I recommend Safe Return to everyone. It made me and Craig feel safe, which is what theprogram is all about," about," says Judy. "It allowed us a degree of normalcy. My husband cosponsored races and ran 10 to 20 miles a day. I helped him dress and made sure he had his Safe Return identification on every day.

"I felt safe and secure knowing that if Craig got lost, someone would be able to get him home again. He did get lost, and someone called and located me. It was awesome to see this work," says Judy, who published her caregiver's diary, *Life with Big Al* (*Early Alzheimer's*). Although Craig died at age 55, Judy still advocates and raises funds for Alzheimer's disease. The Salt Lake City, Utah, resident was recently selected as a torch bearer for the 2002 Olympics, where she will light the way" to raise awareness for those with Alzheimer's.

### A Safety Net for Families

Now it its eighth year, Safe Return provides a safety net for families living with Alzheimer's. It has registered nearly 80,000 memory-impaired individuals nationwide and has located and returned more than 6,400 individuals to their families and caregivers, says Brian Hance, associate director, Safe Return Program.

"That's the best feeling in the world—to reunite people safely with their loved ones," says Hance, pointing to a large poster containing pictures of registrants of different ages and cultures. Safe Return brochures, fact sheets, and registration forms are available in English and Spanish.

Dialogue

Two educational training videos, Safe Return Saving Lives and Safe Return and Law Enforcement: Saving Lives Together, released in 2000 and 2001, respectively, have helped professional and family caregivers, peopleinthe Association's chapternetwork, and lawenforcement officers to better understand wandering and how to respondeffectively.

Safe Return can be invaluable when a person with Alzheimer's is away from familiar surroundings, a situation that may increase the likelihood of wandering. During a trip to Niagara Falls, Jeannie Krathwohl got up in the early morning hours, managed to unlock the door to the hotel room, and was found wandering in a parking lot. "I was so grateful that the clerk noticed the Safe Return bracelet, called the number, found out who she was, and matched the name with the registry," says husband David. "We stayed another night, but this time we barricaded the door with chairs."

#### **How Does Safe Return Work?**

A person with dementia or his/her caregiver registers by filling out a simple form, supplying a photograph, and choosing the type of identification product that the registrant will wear or carry. This information is then entered into a confidential national database available 24 hours a day, 7 days a week. There is a one-time enrollment fee of \$40 and a \$5

charge for caregiver jewelry that can help should the caregiver become incapacitated.

There's no way to predict who will wander, or when or how it might happen. The best safety measure is to register loved ones with Alzheimer's in the program *before* they get lost.

# For more information and a free Safe Return brochure:

Call the Association's Contact Center (800) 272-3900

Register on-line at www.alz.org

Register by phone
(888) 572-8566
Monday through Friday
8 a.m. to 8 p.m. CST

# solutions to curtail wandering

Enroll in the Safe Return Program.

Install an alarm on doors or hang bells or other noisemakers on front and back doors.

Purchase a "safe first" gate at a baby department. This gate requires simultaneous release action that a person with dementia usually can't master.

Place a hook-and-eye lock high on exit doors, out of a wandering person's reach.

Write a large note and place on the door as a reminder of what room an individual with Alzheimer's is in—for example, kitchen, bathroom, bedroom.

Explain the dangers of wandering to your loved one with Alzheimer's disease and discuss your concerns about keeping the individual safe to family, neighbors, and law enforcement.

## Planning Ahead for a Future with Alzheimer's

Four million Americans have Alzheimer's disease. After recovering from the initial shock, affected individuals in the early stage of the disease and their families question if they will be able to continue working, how they will tell others, and how fast the disease will progress. Many questions center on the future and how they will prepare themselves for the many health care, legal, and daily living issues that will arise as the disease progresses.

Alzheimer experts say this kind of forethought is critical, *before* the person with Alzheimer's experiences further cognitive decline.

"It's incredibly important to think about the future as soon as possible, so that you aren't making decisions later in crisis mode," says Melanie Chavin, MS, program director for the Alzheimer's Association's Greater Illinois Chapter, Skokie, which offers seminars for caregivers and individuals in the early stage of dementia.

### How Alzheimer's Disease Progresses

Alzheimer's disease is an age-related and irreversible brain disorder that occurs gradually and results in memory loss, behavior and personality changes, and a decline in thinking abilities.

Researchers at New York University Medical Center's Aging and Dementia Research Center report that people in the early stage of Alzheimer's exhibit some or all of these symptoms: Getting lost.

Decreased performance at work.

Difficulty findingtherightwords and names.

Diminished reading comprehension.

Losing or misplacing valued objects.

Lack of concentration.

Mild to moderate anxiety.

### **Knowing What to Expect**

Patricia Hunter, MSW, family services director for the Alzheimer's Association's Western and Central Washington State Chapter, Seattle, says most people who are diagnosed with Alzheimer's don't prepare for the future. "The impaired judgment and communication difficulties experienced early in the disease affect the individual's ability to plan in isolation without some trustworthy guidance."

Caregivers feel a heavy responsibility in being the sole decision makers, says Hunter, who coordinates the chapter's program for caregivers and family members in the early stage of the disease. She notes that better communication and planning early on can help eliminate crisis decision making and ensure that the person with Alzheimer's has input on care preferences, finances, and legal concerns that will affect his or her future.

Experts say those with early-stage Alzheimer's and their caregivers should start planning now for the challenges ahead. Here are their recommendations:

### Social and Family Relationships.

Family and friends may not see the person with the disease every day and, therefore, may not understand or believe the changes that are happening.

Experts recommend that those with the disease be up-front and honest with family and friends, telling them about their memory loss. If the person with the disease feels comfortable discussing it, others may feel more comfortable with that person, they say.

Self-Esteem. Those diagnosed with Alzheimer's may experience low self-esteem. Experts advise that people with Alzheimer's may benefit from focusing on things that have helped them build their self-esteem in the past. They also recommend that those with the disease and their caregivers—create new goals, congratulate themselves on their daily successes, take care of their physical health to enhance emotional and psychological well-being, and spend time with people who enjoy their company and who make them feel good.

Stress. Memory loss can be stressful for caregivers as well as for people with Alzheimer's. About 80 percent of Alzheimer caregivers suffer from high levels of stress, and nearly half suffer from depression.

Signs of stress include loss of appetite, insomnia, oversleeping, chest pain, chronic fatigue, increased moodiness, a hopeless outlook, withdrawal



Caregiving





from family and friends, and frequent crying. To alleviate stress, experts say caregivers should learn about the disease and available resources, ask for help from family and friends, take care of their own health, give themselves credit for what they're doing, and give themselves time to grieve for their losses.

Legal Documents. People with the disease may want to meet with an elder law attorney who can help them get important legal documents in order, experts say. Experts also advise that people with the disease bring a family member to such meetings. Important legal documents include a power of attorney, living will, will, and living trust.

"It's critical to take care of power-ofattorney documents while the person with dementia is still able to state his or her wishes and assign an agent," Chavin says.

**Financial Planning.** Individuals with Alzheimer's and their caregivers need to consider the cost of future care.

Experts recommend identifying potential care expenses, such as physician visits, prescription medications, care services, and housing. They also advise that people investigate what current income sources are available, such as insurance, personal savings, investments, and employee or retirement benefits.

Financial resources may be available through government assistance or community-based organizations.

**Health Care Providers.** As Alzheimer's advances, those with the disease may require full-time professional health care. Experts recommend that affected individuals talk to family members about their care preferences and needs.

Health care services fall into three categories: respite care (in-home care, adult day care), residential care (retirement housing, assisted living, skilled nursing facilities, continuing care retirement communities), and hospice care.

The Alzheimer's Association has chapters across the country that offer programs and services for caregivers and individuals with Alzheimer's. Some programs are specifically designed for people in the early stage.

#### For more information:

*Contact Center* (800) 272-3900

Internet www.alz.org



# communication tips for caregivers

Researchers from the University of California, San Diego, Alzheimer's Disease Research Center offer the following advice to caregivers when communicating with an Alzheimer's individual:

Speak slowly and distinctly.

Use simple words and phrases.

Use nonverbal gestures to help convey your message.

Ask one question at a time, and give the person time to respond.

Use a warm, positive tone of voice; it's as important as the words you use.

Observe feelings expressed in the individual's voice, face, and gestures; they are just as important as their words.

Eliminate as much noise as possible.

# Q: Is it True That Silver Dental Fillings May Cause Alzheimer's Disease?

According to the best available scientific evidence, there is no relationship between silver dental fillings and Alzheimer's. The concern that there could be a link arose because "silver" fillings are actually made of an "amalgam," a mixture that typically contains about 50 percent mercury, 35 percent silver, and 15 percent tin. Mercury is a heavy metal that, in certain forms, is a potent nerve toxin both in laboratory cultures and in the environment.

Studies have confirmed that amalgam fillings emit small amounts of mercury vapor during installation or removal and as they wear in the mouth. In theory, these vapors could be absorbed by the body and travel to the brain, where they might damage nerve cells.

In March 1991, the Dental Devices
Panel of the U.S. Food and Drug
Administration (FDA), which regulates
amalgam, met to discuss possible
hazards of the material. After carefully
reviewing scientific literature, animal
studies, and patient case reports,
the panel concluded that there was no
scientific evidence that amalgam
poses any danger. However, the panel
also recommended more research
to further clarify any potential risks.

In 1991, the U.S. National Institutes of Health (NIH) funded a study at the University of Kentucky to investigate the relationship between amalgam fillings and Alzheimer's disease. The study— a collaboration involving

the university's Sanders-Brown Center on Aging and the College of Dentistry—enrolled hundreds of participants from central Kentucky and some people from Wisconsin. Kentucky enrollees came from research programs at the university's Alzheimer's Disease Center. Wisconsin enrollees were participants in the Nun Study, a long-term projectinvestigating the relationship between Alzheimer's disease and a variety of environmental and genetic factors in 678 School Sisters of Notre Dame.

The amalgam study research team obtained an extremely detailed dental history documenting how many fillings each participant had, where the fillings were located, how long the fillings had been present, and how much surface area they covered. Participants also agreed to have their brains autopsied to confirm their Alzheimer diagnosis or lack of brain pathology and to measure mercury levels in their brain tissue. Over the length of the study, the researchers collected data from 68 individuals with Alzheimer's and 33 without the disease who met all study criteria.

Data analysis by University of Kentucky statisticians revealed no significant association between Alzheimer's disease and any aspect of silver fillings—their number, location, duration, or surface area. Furthermore, brain tissue samples revealed no correlation between Alzheimer's disease and levels of mercury in the brain. Many scientists consider this study compelling evidence that dental amalgam is not a major risk factor for Alzheimer's disease. Public health agencies, including the FDA, the U.S. Public Health Service, and the World Health Organization, endorse the continued use of amalgam as a safe, strong, inexpensive material for dental restorations.

Our expert consultant for this Q+A was Stanley R. Saxe, DMD, the primary investigator in the NIH-sponsored study evaluating the relationship between dental amalgam and Alzheimer's disease. At the time of the study, he was professor of periodontics and geriatric dentistry and director of the Geriatric Oral Health Program at the College of Dentistry, University of Kentucky. The results of the study were published in: Saxe, Stanley R., et al. "Alzheimer's Disease, Dental Amalgam, and Mercury." Journal of the American Dental Association 1999; February: 130 (2): 191–199. The article is also posted on the American Dental Association's Web site at

http://www.ada.org/prof/pubs/jada/index.asp

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In the News

### September 11 and Its Aftermath

September II changed America. That Tuesday's terrorist attacks and the subsequent anthrax threat and bombing of Afghanistan have dominated local, national, and world news coverage. The events have profoundly affected the psyche of the American people. Children fear they will lose their parents. Husbands and wives worry they may not see each other at the end of the day. Americans long for normalcy—never has the ordinary seemed so attractive. As President Bush has said several times, the terrorists win if America—its government, organizations, and people—becomes a nation paralyzed by fear.

While the Alzheimer's Association mourns the loss of the many Americans who have perished at the hands of these terrorists, it promises its donors, volunteers, staff, and the four million people with Alzheimer's and their caregivers that its work will move forward. The Association is continuing to fund groundbreaking research, to advocate for people with the disease and their family caregivers, to increase public awareness of the disease, and to provide Alzheimer programs and services throughout the country. Too many people are relying on the Association for it to lose sight of its mission: to create a world free of Alzheimer's.

### **Pounding the Pavement**

About 250 local newspapers across the country, as well as local TV and radio stations, mentioned the Association's trademark walk-a-thon and national signature fund-raising event, Memory Walk. (*See back cover.*) Held nationwide in over 400 communities from September through October, Memory Walk has raised over \$100 million since its inception in 1989.

#### All Day, All Night

The September 15 issue of the *Non Profit Times* and the October–November issue of *Managed Care Magazine* featured stories on the Alzheimer's Association's Contact Center. The Contact Center employs call specialists and care consultants (who are licensed social workers) who provide callers with information about Alzheimer's, connect them to local resources, and offer help and support around the clock, seven days a week.

### Gala Goes on in Big Apple

Articles in the October 11 New York Daily News and the October 14 New York Post featured the New York Rita Hayworth Gala, which raised more than \$2.4 million, including a generous \$1 million gift from this year's civic honoree, Lillian Goldman. The galas have raised \$32 million to date. Held annually for the past 17 years in New York and Chicago, the Rita Hayworth Galas, were founded by Princess Yasmin Aga Khan, honorary vice chair of the Association's national board of directors and daughter of legendary film star Rita Hayworth, who died with Alzheimer's in 1987 at age 69.

### **Studying Wandering**

On October 26, Reuters Health covered the preliminary release of a groundbreaking report on Alzheimer wandering. The report analyzed data from the Association's Safe Return Program, which helps identify and returnhome safely, people with dementia who have wandered from their caregivers. (See page 4.)

### Researching a Cure

An article on the state of Alzheimer research in AARP's November-December issue of *My Generation* magazine quoted the Association's vice president of public policy, Stephen McConnell, PhD, who underscored the urgency of finding a cure.

### **Looking for Support**

On September 1, "Dear Abby" columnists referred a questioner, whose wife has Alzheimer's disease, to the Association's toll-free phone number, (800) 272-3900, for referrals to family support groups.

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In Brief

## Celebrating the Holidays

The holiday season—regardless of how we celebrate—means significant changes in our routines. Some of us move furniture to put up a tree. Others light candles to celebrate Hanukkah, Kwanzaa, or Advent. We attend social events or entertain guests in our homes. And we rearrange our schedules to cook larger meals, send more mail, and run more errands than we do at any other time of the year.

These changes, unfortunately, often "break the rules" for the kind of predictable environment that is best for an individual with Alzheimer's. The following suggestions may help people with Alzheimer's and their families enjoy the holidays with a minimum of disruptions.

Keep daily routines —such as mealtimes, exercise, and bedtime—consistent.

Focus on a couple of traditions that are both meaningful and manageable.

Host or attend small gatherings.

Always build an "out" into plans in case the person with Alzheimer's wants time alone.

Avoid decorations that could be unsafe or disorienting, such as fragile ornaments or blinking lights.

Carefully plan the use of holiday candles to make the lighting of them safe, appropriate, and meaningful.

Plan manageable activities: decorating cookies, stuffing stockings, or reading holiday stories.

#### rx corner

In recent years, researchers have found indirect evidence suggesting that cholesterol-lowering drugs might help prevent or treat Alzheimer's disease. A Phase II clinical trial that will begin testing this hypothesis directly is now under way at the Sun Health Research Institute in Sun City, Arizona. About 120 participants with Alzheimer's disease will receive either a placebo (inactive ingredient) or atorvastatin (Lipitor®). Atorvastatin belongs to a class of drugs commonly called statins, which lower levels of the type of cholesterol associated with stroke and heart disease.

The investigation is an important first step in understanding whether statins may be an effective Alzheimer treatment. Additional research will be needed to determine if these drugs are an effective preventive strategy.

For additional information about this trial or other clinical trials in Alzheimer research, visit our Web site at www.alz.org/research/clintrials/respite.htm, or call (800) 272-3900.

# dialogue survey question

When Is It Time to Put Your Loved One in a Nursing Home?

You've been agonizing over the decision. Perhaps you've been unable to work because of the full-time demands of caring for a loved one with Alzheimer's disease. You can't sleep at night, your house is a mess, other family members are neglected. Your stress has reached a level where you're forced to consider possibilities for relief, including placement of your loved one in a nursing home.

We Want to Hear from You!

Share a story about how you realized it was time to get help.

How difficult was it to place the person with Alzheimer's in a nursing home?

What resources did you access to investigate facilities, and what advice would you give others grappling with this problem?

What has helped the nursing home arrangement work or not work?

Your experiences could be incorporated into the Dialogue article in the spring 2002 *Advances*. Please send your feedbackno later than January 19, 2002.

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### Web of Compasssion

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#### One Site Fits All

Divided into five main, easily identifiable sections—people with Alzheimer's disease; family caregivers and friends; physicians/health care professionals; researchers; and media—the site is designed to create a valuable on-line experience for every stakeholder in the Alzheimer community. A sampling of the wide array of features includes:

On-line polls addressing issues of concern Weekly tips to help affected individuals and caregivers

Expert opinions on timely topics

Creative expressions (artwork, poetry, and short stories by affected individuals)

Information in Spanish

Links are also available to Association activities such as Memory Walk (the Association's largest fund-raiser) and the 8th International Conference on Alzheimer's Disease and Related Disorders, being held in Stockholm, Sweden, in July 2002.

"In addition, researchers and other visitors can learn about Association grant programs, Alzheimer clinical trials, and ongoing Association-funded research that promotes progress in the diagnosis, treatment, and prevention of Alzheimer's," Henry added. "In that regard, the Web site reinforces in the hearts and minds of those we serve the Association's dual mission: advancing research and enhancing care and support for individuals, their families, and caregivers."

### **Increasing Traffic**

If user statistics are any indication, the site is demonstrating its value to an expanding audience.

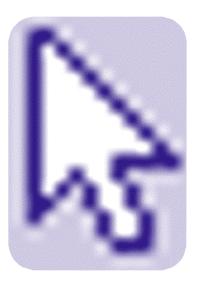
Media coverage of the death of Association board member and Alzheimer advocate Maureen Reagan made August 2001 a record usage month, with over 166,000 visitors. The day Reagan passed away, August 8, the site received 22,382 visitors. With the Memory Walk season quickly approaching, September was also a busy month—the fourth highest overall in Association e-history, with 130,761 visitors. In October, there were 148,852 visitors, the second highest total ever. (To place this activity in perspective, Web traffic never exceeded 100,000 visitors in any month prior to the site's March 2000 redesign.)

### **On-Line Communities**

Message boards are available for people with Alzheimer's, family caregivers and friends, physicians andother health care professionals, and researchers. The Early-Stage Chat Room, located on the People with Alzheimer's Community Circle page, is open 24 hours a day for those in the early stage of the disease who wish to discuss issues of concern or exchange practical information. Links to other on-line Alzheimer chats and discussions are also provided. The message boards offer people like Judy and Lori the opportunity to interact with others to learn about the disease, field care suggestions, or seek encouragement or sympathy

regarding their Alzheimer experience.

"I don't know exactly how well the on-line support is going to work for me, but it helps to know someone out there is willing to read and respond to my situation," said Lori Burrey of McHenry, Illinois, a new visitor to the Community Circle. "Knowing others' situations makes me realize my problems could be worse. Thanks to the Alzheimer's Association for taking an interest in something that is not commonly talked about but that needs attention."



## let us know...

what you think about our new design.

E-mail barbara.harfmann@alz.org

Mail Advances editor
919 North Michigan Avenue,
Suite 1100

Chicago, Illinois 60611-1676

## Thousands "Step Up" for Memory Walk 2001

Since its inception in 1989, Memory Walk—the Alzheimer's Association's signature fund-raisingevent for Alzheimer's disease—has raised over \$100 million nationwide for Alzheimer programs and services such as respite care, support groups, and Helplines for individuals with Alzheimer's, their families, and caregivers. Memory Walk 2001 took place in September and October in over 400 communities coast-to-coast. This year's walk is on target to exceed the \$16.5 million raised last year—thanks, in part, to national corporate sponsor GE Long Term Care Insurance, which pledged \$1 million for the event.

Nine chapters initiated Memory Walk in 1989, raising \$149,440 through the efforts of 1,249 participants. The first national walk, hosted by 167 chapters, in 1993, netted \$4.5 million. In 2000, nearly 200,000 people participated in 400 walks, raising an all-time high of \$16.5 million. All Memory Walk funds are earmarked for local programs and services.



Over 3,500 walkers—including 50 from the notional office—raised \$420,000 for the Greater Winois Chapter during the 2001 Memory Walk.



Alzheimer's Association 919 North Michigan Avenue Suite 1100 Chicago, Illinois 60611

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