

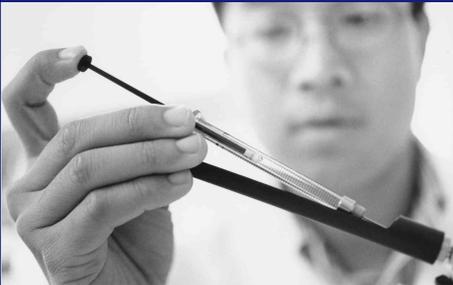
Advances

THE ALZHEIMER'S ASSOCIATION NEWSLETTER

Progress in Alzheimer Research and Care

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Prepping for the Holidays

FOR MOST FAMILIES, HOLIDAYS are filled with opportunities for togetherness, sharing, laughter, and memories. But for families coping with Alzheimer's disease, holidays also can be filled with stress, disappointment, and sadness.

One of the first things you should do is realize that the holidays may no longer be the same as in the past and adjust your expectations accordingly. No one, including yourself, should expect you to maintain every family tradition or event. Give yourself permission to do only what you can reasonably manage. If you've always invited fifteen people to your home for a seven-course dinner, consider inviting five for a more simple meal. Ask others to bring "potluck" dishes or to host the meal at their home. Those close to you and your loved one may welcome this opportunity to help.

To avoid unpleasant surprises or hurt feelings, you may want to discuss holiday celebrations with relatives and close friends ahead of time. Make sure that all family members understand the situation and have realistic expectations for their visit. After months or years apart, family members may be alarmed to see the changes in their loved one. They may be shocked by the person's appearance or behavior and disturbed by the deterioration of memory. They may even suggest that you are not properly providing care for their loved one. You may wish to familiarize them

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with the situation in advance by calling or sending a letter that makes these points:

"While we're looking forward to your visit, we thought it might be helpful if you understood our current situation before you arrive. Because Mom sometimes has problems remembering and thinking clearly, her behavior is a little unpredictable. Please understand that she may repeat conversations and may not remember who you are or confuse you with someone else. Please don't feel offended by this. She appreciates your company and so do I."

Enjoy the moments when meaningful communication and interaction occur, however short and infrequent they may be. If your loved one can engage in conversation with a grandchild for only two minutes, treasure those two minutes, rather than measuring it against the

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Behavior Changes Challenging for Caregivers



Loss of memory, reasoning, words, and a sense of time and place can cause a person with Alzheimer's to be unintentionally difficult, irrational, stubborn, or angry.

ALZHEIMER'S DISEASE IS WELL known for causing memory loss and problems with thinking and reasoning. Most people don't anticipate the numerous behavior changes triggered by the disease.

Loss of memory, reasoning, words, and a sense of time and place can cause a person with Alzheimer's to be unintentionally difficult, irrational, stubborn, or angry. When needs cannot be explained the person may become frustrated, angry, or feel out of control.

Combative, agitated behavior

Changes in behavior may be caused by

- physical discomfort
- over-stimulation
- unfamiliar or confusing surroundings
- complicated tasks
- frustrating interactions or communication problems.

"It is virtually impossible to predict the timing as well as all the possible dangerous or unsafe behaviors of someone with dementia," says Lisa Gwyther, MSW, associate clinical professor in the department of psychiatry at Duke Medical Center in Durham, North Carolina. "Even in the most secure environments, unprovoked combative or unsafe behavior may occur without warning. If triggers for the behavior are not identified, the problem could worsen."

Gwyther notes the most common triggers for combative behavior are fear, misunderstanding or misperceiving a threat that isn't there, an inability to communicate needs or problems, depression, worry, and frustration.

Managing aggressive or unsafe behaviors

People with Alzheimer's may exhibit

aggressive behaviors in their search to find security in a world that no longer makes sense. There are practical ways for caregivers to help minimize challenging behaviors in a person with Alzheimer's:

- Have familiar objects, such as items in a memory box, immediately available to reassure and distract the person.
- Ask for the person's help but do not rush, criticize, or make demands.
- Offer a snack or treat to divert the person's attention.
- Remove potentially dangerous or confusing items, such as sharp objects.
- Learn the person's nonverbal signs of increasing agitation (e.g., red face, clenched fists, rapid searching with the eyes, or waving hands in the air).
- Learn verbal signs of escalating anger such as cursing, using a loud voice, and muttering.

- Change the environment or move to a quiet, smaller space.
- Reduce expectations by allowing more time to accomplish fewer activities/tasks.
- Slow down your actions as the person speeds up. Your nonverbal and verbal slowing can have a calming effect.
- Never surround or gang up on someone who is about to lose control. If the person feels cornered or overwhelmed, it can prompt a “fight or flee” response. Physical restraints are not effective in reducing aggressive behavior.
- Do not make any assumptions about what is safe.

Each time a challenging behavior occurs, consider the “when, where, who, what, and why” of the incident. Does the challenging behavior only occur at certain times of day, or in certain places or with certain people? Recognize that people with dementia are very sensitive to the emotional state of those caring for them. They pick up on a caregiver’s clenched teeth and irritability. The challenging behavior could be related to underlying physical causes or needs.

Identifying underlying physical causes

A sudden behavior change may be caused by physical discomfort, pain, constipation, infection, or an adverse reaction. If the behavior occurs frequently, consult a physician to identify potential underlying causes.

Modifying the environment

A soothing environment is essential. Potentially dangerous or confusing items, such as sharp or odd-shaped objects, should be removed from the person’s view. Personalize the room with keepsakes or photos of special

moments. A memory box of work items or the person’s favorite hobby may prompt reminiscing.

Assisting with personal care

Behavior problems most often occur when caregivers assist people with Alzheimer’s with personal care. The person may feel vulnerable or feel as if personal space has been invaded.



- Delay personal care when the person is upset.
- Move to the side or out of the person’s direct vision

when helping with bathing or personal care. The person is less likely to feel attacked if the caregiver stays at his or her eye level and is nonconfrontational.

- The person may need real physical reassurance through hugs or hearing that you are there to protect his or her safety.
- If the person grabs your arm or wrist, stroke the lower arm of the grabbing hand or place your hand over the grabbing hand and squeeze firmly.
- If threatened with an object like a cane or chair, grab a safe object like a pillow that can stop the threatening object without causing harm.

Communicating after an aggressive incident

Gwyther notes that talking in soothing, calm tones of voice, and keeping comments simple will aid in communicating with a person with Alzheimer’s. “Comfort the person after the incident is diffused,” she said. “More reassurance will be needed once everything is under control. Suggest taking a deep breath together.”

- Use short, simple phrases or sentences as well as familiar words.

- Do not argue with the individual.
- Approach the person calmly from the front, move to the side, and speak slowly in a low-pitched voice.
- Give the person time to respond.
- Pay attention to the person’s nonverbal messages as well as what they say verbally. Facial expressions and body language can sometimes provide additional information on how the person is feeling.
- Respond to the feelings behind the words or body language.
- Keep noise and distractions to a minimum.
- Always remind the person who you are and what you are attempting to do.
- Offer guided choices such as, “Would you prefer to wear the blue shirt or the red shirt?”



It is important to realize that not all behavior changes are problematic. If a certain behavior doesn’t cause difficulties for the

person with Alzheimer’s, caregivers, or others, the best strategy may be to do nothing. If all nonpharmacological approaches have not reduced or successfully addressed the escalating aggressive behavior, refer to a physician for appropriate medications. ♦

Alzheimer's Association Funding Fuels Advances in Research

TWO DECADES AGO LITTLE information existed about the symptoms and underlying causes of Alzheimer's and only a handful of scientists were investigating the disease. Since then, scientists have made great progress in understanding this deadly disease, due in part, to the Alzheimer's Association's \$100-million contribution to research over the past twenty years.

As the nation's largest private funder of research—second only to the federal government—the Alzheimer's Association invested a record \$18.4 million in research in fiscal year 2000.

“Our research program is designed to enhance government funding and to encourage scientists to enter the field of Alzheimer research,” says Bill Thies, PhD, Alzheimer's Association vice president of medical and scientific affairs. “The Association's funding has attracted leading scientists in the quest to find effective interventions and a possible prevention for Alzheimer's disease.”

In 1984, four years after the Association's founding, researcher Joseph Rogers, PhD, president and senior scientist at the Sun Health Research Institute, received an award of \$33,000 from the Alzheimer's Association. This was a significant amount to Rogers, then assistant professor of neurology at the University of Massachusetts. In fact, the grant was his only source of funding.

“Receiving the award had a huge impact on my career. It caused me to shift my entire focus of research to

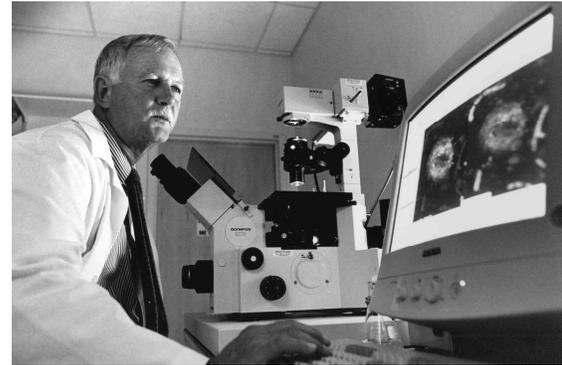
Alzheimer's disease, and since then, I've never turned back,” says Rogers.

When Rogers hypothesized that inflammation played a role in the Alzheimer brain, “The idea was considered not only out in left field but way out of the ballpark.” The more he was able to find evidence of inflammation in the brain, the more the research community took him seriously. Eventually he discovered that beta amyloid protein, commonly found in the Alzheimer brain, stimulated inflammation.

To further Rogers' work, the Alzheimer's Association awarded him an Investigator-Initiated Research grant of \$50,000 in 1994. “The grant gave me the freedom to conduct innovative research that I had no hope of having funded by more conservative sources,” says Rogers. Three years later, the Association awarded Rogers another grant—the Zenith Award for \$250,000. Soon Rogers' laboratory was able to confirm that neuroinflammation might be one of the mechanisms that causes damage to the Alzheimer brain.

Like Rogers, scientist Dennis Selkoe of the Harvard Medical School and Brigham and Women's Hospital, received funding from the Alzheimer's Association at a pivotal time in his career.

“The Association's award was a shot in the arm for my fledgling lab. It was at that time that I made a purposeful scientific transition from studying the tangles of Alzheimer's disease to studying



Above: Joseph Rogers, PhD, searches for a cure for Alzheimer's disease

“Receiving the award had a huge impact on my career. It caused me to shift my entire focus of research to Alzheimer's disease, and since then, I've never turned back”

—Joseph Rogers, PhD

beta amyloid,” says Selkoe. “When I received the grant in 1983, the amyloid theory was essentially not spoken of and very few had noticed or agreed that it was an interesting approach to Alzheimer's.”

The amyloid theory is one of several concepts being investigated to understand the underlying mechanisms of

Alzheimer's. Selkoe is exploring the amyloid theory and it is on that theory that a promising vaccine for Alzheimer's is based. To continue his research, the Alzheimer's Association gave Selkoe the Pioneer Award in 1999, a grant of \$1 million.

The Alzheimer's Association promotes discovery not only in the basic science of the disease, but also in social and behavioral research to help families cope with Alzheimer's and care for their loved ones in the best possible way.

At the Polisher Research Institute in Philadelphia, M. Powell Lawton, PhD, is leading a research project that will create a model describing the best practices for planning, designing, building, administering, staffing, and operating nursing home facilities for people with dementia. Lawton's research will combine insights gained from intensive interviews and observational studies at six nursing homes. According to Lawton, the finished work will serve as

a dynamic database that can be updated to reflect new data or solutions as they become available. This year, Lawton was awarded \$240,000 from the Alzheimer's Association to continue this research.

The Alzheimer's Association has provided funding early in the careers of many young research superstars who go on to make an impact on the field. Today, Marcelle Morrison-Bogorad, PhD, is associate director of the neuroscience and neuropsychology of aging program at the National Institute on Aging (NIA), which oversees the distribution of nearly \$327 million in public funding for Alzheimer research. In 1994, Morrison-Bogorad, then of the University of Texas Southwestern Medical Center, received the Association's Investigator-Initiated Research Grant.

"I've witnessed the powerful impact on scientific progress that comes from the federal government joining forces with the Alzheimer's Association. When

public and private funding come together to support research, it speeds the timetable for finding treatments and a prevention for Alzheimer's disease," says Morrison-Bogorad.

Since 1980, the Alzheimer's Association has continued to expand its portfolio of research grants designed to meet the funding needs of scientists worldwide. Six types of awards comprise the grants program: Pioneer Award, T. L. L. Temple Foundation Discovery Awards, Senator Mark Hatfield Award, Zenith Fellows Award, Investigator-Initiated Research Grants, and the New Investigator Research Grants.

Each of the 631 grant applications received this year underwent a rigorous peer review process to ensure compliance with the highest scientific and ethical standards.



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Meeting the needs of the research community

The Association's diverse portfolio of research grants is designed to meet the funding needs of scientists worldwide. Six types of awards comprise the grants program:

- The **Pioneer Award for Alzheimer's Disease Research** is the Association's largest award, providing \$1 million, over five years, to an elite group of scientists who have made important, groundbreaking contributions to Alzheimer research.
- The **T. L. L. Temple Foundation Discovery Awards** for Alzheimer's Disease Research provide \$250,000 a year,

over two to three years, to study the causes of Alzheimer's and develop effective treatments for the disease.

- The **Senator Mark Hatfield Award for Clinical Research in Alzheimer's Disease** grants \$240,000, over two years, to a young scientist whose goal is to build a career focused on clinical issues in Alzheimer's.
- The **Zenith Fellows Award Program** funds \$250,000, over two years, for cutting-edge biomedical research that has the potential to challenge current conventional scientific wisdom.

- The **Investigator-Initiated Research Grants**, established in 1986, are the backbone of the Association's grants program. In fiscal year 2000, the Association awarded 54 Investigator-Initiated Research Grants, each worth up to \$240,000, for up to three years.

- The **New Investigator Research Grants** fund young scientists with less than ten years of research experience following their doctorate, up to \$100,000 for up to two years.

The Struggle to Seek a Diagnosis



IN THE FALL ISSUE OF ADVANCES, we asked readers to share experiences and advice on how to get a person with symptoms of Alzheimer's disease to see a doctor. Readers responded with touching stories of their struggles, first, to face the loved one's illness, then to seek a medical diagnosis and treatment.

Many respondents mentioned relatives' difficulty accepting the seriousness of the person's illness. We repeatedly heard that spouses, siblings, and children refused to believe their relative had Alzheimer's disease or insisted that he or she might be "in the early stages."

How a diagnosis can help

Debra Salonek says that she and her siblings had all come to the realization and acceptance of their father's Alzheimer's disease long before the diagnosis came through. They were angry with their mother for attempting to cover it up.

"Finally, we were able to make Mom realize that she wasn't being fair to others by not telling them of Dad's Alzheimer's. We told her that others had things they wanted to share with Dad while he was still able to comprehend them."

Tricia Melton of Smithville, Missouri, wrote that her grandmother's three children dismissed any notion of

Alzheimer's, "She's just getting older," they'd say.

After much discussion the three finally said, "Okay, so it's probably Alzheimer's. What good would it do to have a doctor officially diagnosis it? You know there's no cure."

Giving her mother solid reasons for obtaining a diagnosis, Melton suggested that medication could lessen the symptoms of the disease and a neurologist who specialized in Alzheimer's could tell them how to care better for her.

Eric G. Tangalos, MD, professor of medicine and chair, division of community medicine, Mayo Clinic, Rochester, Minnesota, and a member of the Alzheimer's Association national board, offered advice to those dealing with relatives' denial of the illness.

Tangalos noted, "If the family doesn't want to know, there is a tendency for their physician not to open Pandora's box." He said that it might be necessary to perform a mental status test in the family's presence. Stressing the importance of communication among family members, Tangalos said they must be unified in their approach to the person's condition.

Families in denial of the disease often don't realize how important it is to

obtain a diagnosis to identify the actual cause of dementia and ensure the person receives the proper care. Dementia can be caused by depression, drug interactions, thyroid problems, and vitamin deficiencies, and may be reversible if detected early.

Easing fears of a doctor's examination

Before looking at ways to convince the person who may have Alzheimer's to see a physician, it is important to understand and appreciate his or her feelings. In many cases a patient knows that something is wrong; he or she may even suspect the problem is Alzheimer's disease. Often they are aware of being forgetful, confused, and disoriented at times. They may struggle for simple words or be unable to recall the names of loved ones or caregivers.

These events are frightening to the person, who may try to hide the problem, or become angry about it. Not knowing what to do and faced with this loss of independence the individual becomes increasingly fearful.

Imagine then, a person's terror at facing the prospect of a mental evaluation. No wonder many are so resistant. Expecting to do poorly, they must wonder if once their disability is discovered, they will be "put away" or in some manner abandoned by loved ones and/or caregivers.

Tangalos says that when someone has a good doctor–patient relationship, it’s fairly easy for the family to convince him or her to see the physician. The doctor can make the mental evaluation part of a regular examination.

He suggested the physician might say: “This year I need some information to help in planning your future needs,” or “I want to get some testing that will tell me whether it’s a good idea for you to live by yourself. Let’s have a neutral party help us with this decision.”

He advised that the patient’s visit to the doctor should be a patterned or routine activity that plays off old habits. Noting that Alzheimer’s patients need a very stable environment that’s easy for them to understand, Tangalos suggested that the atmosphere surrounding the doctor’s visit be as familiar as possible. This may include a car they often ride in and a driver with whom they usually ride. “Patterns of activities, including voice recognition, are important. If someone visits the patient on Wednesdays and usually takes him or her for a drive, the visitor can drive to the doctor’s office,” he said.

Tangalos suggested that families look for opportunities to get the person to the doctor’s office. If a person develops a cough or other illness, the family may take advantage of the situation. They may point out that it is flu season and a flu shot is needed. Or perhaps it’s time for a chest x-ray or pneumonia vaccine. An opportunity might arise if a person is burned by the stove or clothes dryer.

Patient denial of symptoms and diagnosis

Tangalos recommends being honest with the person who has Alzheimer’s.

“We’re always truthful with them. And that sends a message to the family so information is not distorted. We’ve really started to talk to patients, not around them. They’re involved more in their treatment plan. Patients should be empowered to make plans about their future even as they progress through the early stages of their disease,” he counseled.

Another reader reported that her mother, who has had Alzheimer’s for four or five years, remains in complete denial. “I took her to a geriatric assessment team at a large hospital for a diagnosis, but I could not, did not, tell her it was for diagnosis. I just told her I’d heard this doctor was particular good at checking out memory problems, that there are new drugs on the market, and perhaps we should look into it. The word Alzheimer’s was avoided as much as possible. That is what worked for her.”

psychiatrist is part of the team. In the consultation report or family conference setting, cognitive problems and management plans can be put in perspective, with proper attention to the caregiver and other social issues.

Geriatric assessment programs can be found at virtually all academic medical centers and some community hospitals. The assessment team should collaborate with the person’s primary physician. Additionally, there are twenty-three Alzheimer’s Disease Centers nationwide that conduct diagnostic tests as well as help provide ongoing care.

Sadly, many diagnoses are made only after a crisis occurs. The person may have wandered or experienced a severe episode of confusion that results in hospitalization. This can be an extremely frightening experience for the person with Alzheimer’s disease and the family.

Families in denial of the disease often don’t realize how important it is to obtain a diagnosis to identify the actual cause of dementia and ensure the person receives the proper care.

Geriatric assessment programs

Patricia Gifford, MD, a geriatrician in Southern California, gave this suggestion: “A common situation presents a perfect role for a geriatric assessment program. Usually there are other problems—physical complaints, depression, multiple medicines—which can serve as acceptable reasons to schedule an appointment with the geriatrician and the team. The loved one does not need to know that a neuropsychologist or

As Tangalos suggested, sometimes the family must wait for an opportunity to get the relative to a doctor. Often it requires a great deal of patience with the loved one, as well as with one another. ♦

Caregivers Express Preferences for the Treatment of People with Alzheimer's

ON TUESDAY, OCTOBER 10, 2000, the journal *Neurology* published a study of caregivers' preferences for the treatment of people with Alzheimer's disease. Researchers from the Alzheimer's Disease Center at the University of Pennsylvania health system asked forty caregivers to compare two possible benefits from a hypothetical drug for Alzheimer's disease. According to the researchers, nearly 70 percent said delaying nursing home care was a more important benefit than an additional year of life. More than half added there were treatment benefits they would rank even higher than either of those options, including quality-of-life benefits such as maintaining memory, the ability to communicate with and recognize family, and the ability to perform daily tasks.

The study also showed most caregivers would take some risks to see benefits from the hypothetical drug, although the risk they would accept ranged widely from mild gastrointestinal bleeding to the need for a transfusion to possible death. More than 65 percent of caregivers were willing to allow some risk of death in order to obtain treatment benefits.

This study reinforces the importance of families discussing complex, difficult issues and making decisions as soon as possible when a diagnosis of Alzheimer's disease is made. The family must consider and understand what the person with the disease wants, and if possible, discuss the issue of treatment options. The family's first responsibility is to protect the rights and represent the



interests of the person with the disease. But, it is ethically appropriate in such personal and complex health care situations to consider other issues as well, such as the burden on the family and implications for the larger community.

Families who have loved ones with Alzheimer's should seek information from the Alzheimer's Association, as well as talk to other families and people who face similar situations, to understand the difficult issues involved. ♦

Taxes and Alzheimer's Disease

Did you know . . .

- how to benefit from current federal tax provisions that may allow you to deduct maintenance and personal care services for someone with Alzheimer's disease?
- long-term care costs, including nursing homes, assisted living facilities, group homes, day care centers, respite care, in-home and companion care, home equipment, and incontinence products may be deductible medical expenses?
- your parents' medical expenses, including qualified long-term care services, might be deductible on your return?
- deductible medical expenses for the taxpayer and his or her dependents must total more than 7.5 percent of adjusted gross income?
- obtaining and retaining documentation is important because in order to take the deduction you must show that you meet certain requirements, including annual certification and a plan of care?
- medical expenses, including qualified long-term care services, are only deductible if the taxpayer itemizes deductions?

You may have read about proposals that are still under consideration in Congress that could add further tax benefits for family caregivers in certain situations. If those proposals are enacted, however, they will not affect your 2000 taxes.

The Alzheimer's Association has a set of fact sheets titled *Taxes and Alzheimer's Disease* that offer general information and guidelines to help you and your tax preparer file your 2000 tax return. Call your local chapter or (800) 272-3900 to request a copy.

[CONTINUED FROM PAGE 1]

entire four-hour holiday gathering. Thelma Walburn of Forest Park, Georgia agrees. "Our family still cherishes the time we visited my husband, Eugene, and our great-grandson gave him a simple bag of cookies. Eugene's face lit up with such absolute joy and he and the other residents, breaking their virtual silence, oohed and ahed over the child and the cookies," says Walburn. "When times are difficult, we all try to remember and take solace in that magical moment when everyone was so happy."

Involve the person with Alzheimer's disease throughout all stages of holiday preparation. Pick manageable activities: wrapping gifts, setting the table, or preparing simple foods such as appetizers. Avoid asking the person to do more complicated and potentially frightening activities such as lighting a menorah or hanging blinking lights.

"A holiday is still a holiday, whether it is celebrated with your loved one at home or in a residential care facility," says Anna Ortigara, vice president of program development for Life Services Network, which operates residential care facilities. "The most important thing is to spend time together, enjoying the moment for what it is."

According to Ortigara, families should carefully evaluate whether persons with Alzheimer's disease should spend the holiday in their usual environment or elsewhere. Some people do not deal with change very well, and spending the holiday away from home or their facility may not be pleasurable for them. Taking your loved one on short outings prior to the holiday can help ease the transition and allow more enjoyment when the time comes to visit your home. If the person with Alzheimer's

disease must stay at a residential care facility, think of ways to celebrate the holiday together.

"If planned carefully, visiting a loved one in a residential care facility can be a wonderful experience for everyone," says Anna Ortigara. "Bringing a favorite holiday food or singing holiday songs along with other residents may make the day special and more comfortable."

"A holiday is still a holiday, whether it is celebrated with your loved one at home or in a residential care facility"



Other ways you can make the holidays enjoyable:

- Maintain your loved one's normal routine as much as possible in order to limit disruption and confusion. For example, if the person goes on a daily walk, try to continue that practice, even on a holiday.
- Build on past traditions and memories. Your family member may find comfort in singing old holiday songs, for example. But also experiment with new holiday traditions, such as renting seasonal videos that the less active person may enjoy.
- Sign your loved one's name to some of the presents you give to other family members. This will help the person contribute to the holiday celebration.
- During the holiday gathering, be alert

for signs of agitation and frustration in your loved one. Do not seat him or her in the middle of a noisy room as it may result in over-stimulation and agitation. The person with Alzheimer's may be able to focus better on questions and comments in a corner area of the room where there are fewer distractions.

Give yourself a gift

Caregiving is a labor of love. "Those who provide care to others often overlook their own needs, believing that they must take a backseat to their loved ones," says Steven Zarit, PhD, professor of human development and assistant director of the Gerontology Center at Pennsylvania State University. They can grow depressed, lonely, and frustrated, particularly around holidays. Caregivers often do not exercise, watch their own nutrition, or get enough sleep. "Caregivers in this situation often burn out quickly and are unable to care properly for their loved one in the long term," adds Zarit.

You will be a better, stronger caregiver if you don't neglect your own needs. If friends or family members ask you what you want for a gift, suggest a gift certificate for a take-out restaurant, dry cleaner, laundromat, or cleaning service. If you don't receive those gifts, celebrate the holiday by giving such a gift to yourself.

Ask for help and support. Develop a list of tasks that need to be done, from buying groceries to washing clothes to preparing meals. Ask family and friends to volunteer for some of the tasks on a regular basis. If someone asks, "What can I do to help?" you can respond with a specific idea. Close friends and family will appreciate the opportunity to help you in this difficult situation. ♦

Q My father, who has worn a hearing aid for several years, has been diagnosed with Alzheimer's disease. What kind of challenges will we be facing, and what can I do to help him?

A Hearing loss is fairly common among older people. More than half of all Americans over sixty-five years of age have significant hearing impairment. The incidence of hearing loss among people with Alzheimer's may be as much as 20 percent higher than the incidence among other older Americans.

Hearing loss creates some obvious communication challenges. An otherwise healthy individual with hearing loss must work hard to concentrate during conversations and listen to spoken language. If the condition is not treated, the individual may withdraw from social contact, be suspicious of people, and become depressed. These communication problems are similar to those associated with Alzheimer's disease. Therefore, if a person has Alzheimer's and experiences hearing loss, the two conditions may have a compounding effect. The caregiver may not always be able to tell which condition is the actual cause of miscommunication or poor comprehension.

In your father's case, since he already wears a hearing aid, you should encourage him to continue wearing it. Making the placement of the hearing aid a part of his daily routine will help him to wear it longer. You should consult a licensed audiologist to learn how to fit the earpiece appropriately, clean the tubing, change batteries, adjust for adequate volume, and correct any problems with the hearing aid itself. As the Alzheimer symptoms increase, you will need to assume full responsibility for maintaining the hearing aid and watch carefully that he does not misplace it.

In other cases, a hearing impairment is identified after the diagnosis of Alzheimer's. As the disease progresses, it is difficult for the patient to learn new skills. Therefore, the patient may not like the feeling of an unfamiliar device in his ear or someone assisting with the placement and adjustment of the hearing aid. A trial period can be attempted, however. A caregiver should also be aware that problems of the outer and middle ear—wax buildup, fluids, and inflammation—can cause hearing loss. A physician can advise the caregiver on how to monitor and treat such problems.

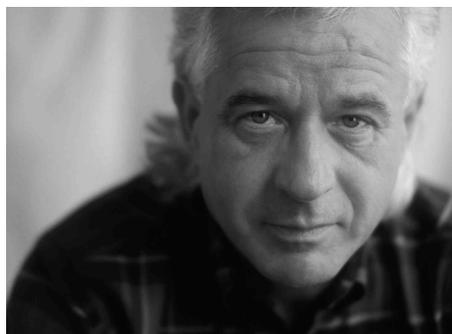
Your family, friends, and other caregivers should consider several practical steps to help your father. Always approach him from the front and make eye contact before you begin speaking. Touching him from behind or speaking

before you have his attention can be confusing and upsetting. You should also be sure that your face is well lit when you are speaking to help him see your expressions. You should speak clearly and slowly in a low pitch, but not a louder tone of voice.

Background noise can be distracting and make it particularly difficult for your father to listen to speech. Always turn off the radio or television before speaking, and move to a quiet place when necessary. Sound absorbing materials, such as carpets and upholstered furniture, help to eliminate the "echoes" that make it difficult to distinguish sounds.

Making use of visual cues will be especially important. Create one-word labels for important places and objects in the house, such as the bedroom, bathroom, closet, kitchen, hearing aid, and glasses. You can also make name cards for people who visit often. Use photos of the people and memories you talk about. The more ways you can engage his attention and communicate through visual cues, written words, and touch, the more you will be able to work beyond the challenges of the hearing impairment. ♦

Elizabeth Ostuni is a speech-language pathologist and director of Accent on Communication, a private consulting agency in Sparta, New Jersey. She is a coauthor of Successful Communication with Alzheimer's Disease Patients: An In-Service Manual published by Butterworth-Heinemann.



Nobel Prize Awarded to Scientists Studying the Brain

THE NOBEL PRIZE IN MEDICINE or Physiology was awarded in early October to three scientists for their work to understand chemical changes in the brain.

Arvid Carlsson of the University of Gothenburg in Sweden, Paul Greengard of Rockefeller University in New York, and Eric Kandel of Columbia University in New York received the Nobel Prize for their research on a type of signaling system in the brain referred to as slow synaptic transmission. Their discoveries are important for understanding the

normal function of the brain and how disturbances in the signaling between cells can lead to neurological and psychiatric diseases.

“The Nobel Prize is the most prestigious and widely recognized award a scientist can receive,” says Bill Thies, PhD, Alzheimer’s Association vice president of medical and scientific affairs. “We are pleased to see an award of such distinction bestowed on neuroscientists who are advancing an understanding of the brain that may lead to the discovery of new therapeutics for Alzheimer’s disease.” ♦

[ADVANCES IN RESEARCH CONT’D FROM PAGE 5]

Award decisions were made during a second-level review process by the Association’s Medical and Scientific Advisory Council, a distinguished group of nationally recognized experts in the Alzheimer field.

Individuals, families, corporations, and foundations helped fuel the momentum of Alzheimer research through generous contributions to the Alzheimer’s Association’s research program. One hundred percent of all gifts restricted to research go directly toward the Association’s grant program that provides scientists with additional resources to extend their investigations. Support from the Alzheimer’s Association has help make possible some of the most important research discoveries in recent years. Although a cure may not lie directly ahead, researchers funded by the Alzheimer’s Association are bringing us closer to the Association’s ultimate goal—a world without Alzheimer’s disease. ♦

R_x CORNER

Ongoing Clinical Drug Studies

Large-scale drug studies currently recruiting patients with Alzheimer’s include:

- Alzheimer’s Disease Prevention Trial (Estrogen and Progesterone)

A study recruiting individuals with mild cognitive impairment:

- Memory Impairment Study

To obtain information about these studies, contact your local chapter or call (800) 272-3900. Additional information on clinical trials that are recruiting Alzheimer patients can be found at the National Institutes of Health Clinical Trials Web site at www.clinicaltrials.gov.

Correction: In the article *Estrogen and Alzheimer’s: Examining the Evidence* in the Fall 2000 issue of *Advances*, Eisai Inc. should have been listed with Pfizer Inc as the manufacturer of donepezil (Aricept®).

Alzheimer's Association Has

Cause to Celebrate

Twenty years of leadership in supporting families and funding research

IN THE LATE '70S ALZHEIMER'S WAS hardly a household word. Families whose loved ones struggled with the disease fought in isolation for basic information and adequate care—in a world with few answers. Left to their own devices, family caregivers forged connections with others undergoing similar experiences, forming support groups in pockets around the country. Word spread, and in 1979 representatives from five family support groups, other caregivers, and government officials met for the first time to discuss the possibility of forming a national Alzheimer's Association. On April 10, 1980, the Alzheimer's Association—

with seven chapters—was legally incorporated.

"In the short time since its founding, the Alzheimer's Association has made tremendous strides in funding research to understand the underlying causes of Alzheimer's, and providing programs and services to the millions of families facing this devastating disease," says Edward Truschke, president and CEO of the Alzheimer's Association. "While the Association has grown and experienced many changes in the last twenty years, our mission to create a world without Alzheimer's disease remains unchanged."

From a handful of caregivers and seven chapters in 1980, the Association has grown to 35,000 volunteers, a national staff of 220, and hundreds of local points of service nationwide.

"Families no longer have to face Alzheimer's disease alone," says Truschke. "Our goal is to spare another generation from being lost to the wrath of this disease. As we work toward this goal, the Alzheimer's Association will remain an aggressive force advocating for better care, pushing for increased government funding for research, and providing support and services for millions of families nationwide." ♦

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For more information on Alzheimer's disease and the Association or to be placed on the *Advances* mailing list, call (800) 272-3900. Information is also available via the Internet at <http://www.alz.org>.

Letters should be addressed to Michele Pellissier, Editor. Faxes can be sent to (312) 335-1110 and email to michela.pellissier@alz.org. *Advances* does not publish unsolicited poems or short stories or accept advertisements.

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Working Toward an Alzheimer's Cure

ALZHEIMER'S
ASSOCIATION