

Advances

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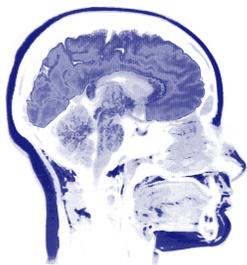
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Carefully Considering the Implications of Surgery

SURGERY CAN BE A TRAUMATIC experience for people with Alzheimer's disease if their families do not thoroughly consider several factors before making a decision. The somewhat cold, unfamiliar world of a hospital or clinic can be unsettling for most people, but for the individual with Alzheimer's, the shift from familiar surroundings to a clinical environment can magnify memory loss and difficult behavior. Add to that the possible negative effect of anesthesia and drug interactions.

"Think of what it is like for any of us during a hospital stay. Our sleeping pattern is disturbed and anesthesia and narcotics make us all less aware of our surroundings," says Eric Tangalos, MD, chair of the community internal medicine division at the Mayo Clinic in Rochester, Minnesota, and a board member of the Alzheimer's Association. "During hospital stays, the Alzheimer patient loses track of space and time and can show his or her worst side."

Restoring individuals with Alzheimer's to their normal state or pre-operative mental and functional state can be quite challenging or never occur.

"Surgeons often want to do surgery with the best possible intent, but the family needs to use extreme care in making the decision," says Geri Hall, PhD, gerontology clinical nurse specialist and



Restoring individuals with Alzheimer's to their normal state or pre-operative mental and functional state can be quite challenging or never occur.

director for policy and outreach for the University of Iowa Center on Aging. "All too often I've seen families make decisions based on the idea that surgery would solve a problem, only to have very poor outcomes."

In general the aged fare badly during emergency surgeries, but families can carefully evaluate elective surgeries in terms of anticipated benefits and risks,

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Piecing Together the Mystery of Dementia with Lewy Bodies

THE TERM DEMENTIA REFERS TO a whole group of symptoms that include a decline in memory, reasoning, and other cognitive abilities. Alzheimer's disease is only one of several illnesses that lead to such symptoms. Some individuals with these symptoms are diagnosed with a condition known as "dementia with Lewy bodies." For most people, the name itself is puzzling. But there are several reasons that dementia with Lewy bodies is also puzzling for neuroscientists and physicians. The condition's relationship with other neurodegenerative diseases is not clear, it is difficult to diagnose, and treatments for related diseases do not often work well for dementia with Lewy bodies.

A Lewy body is an abnormal structure that develops inside a brain cell. The

structures were named after Friederich Lewy, the researcher who first described them to the scientific community in 1913. Dr. Lewy observed these structures in autopsies of brains of people who had Parkinson's disease, a neurodegenerative disease that causes such symptoms as tremors, speech impediments, movement difficulties, and often dementia. For many years, Lewy bodies were recognized as a common sign of neurodegeneration in Parkinson's disease, but there was very little research on what role these structures play.

In the 1980s, several investigations showed that more than 20 percent of autopsied brains that had the characteristic abnormalities of Alzheimer's disease also had numerous Lewy bodies. Much research since then has focused on trying to determine if Lewy bodies are

evidence of a distinct dementing illness or a variant form of Alzheimer's or Parkinson's disease. Because theories on this subject have varied, scientists have used several different names to describe similar cases of dementia, including Lewy body variant of Alzheimer's disease, diffuse Lewy body disease, and Alzheimer's disease with Parkinson's disease changes.

Although some of these names are still used, most researchers and physicians now use the designation "dementia with Lewy bodies." Participants at an international conference on Lewy bodies in 1995 recommended this more generic phrase because it recognizes the presence of the abnormal structures in the brain but does not attempt to define its role in other neurodegenerative diseases.

Symptoms that indicate dementia with Lewy bodies

Another outcome of the Lewy body conference was a consensus on criteria for diagnosing dementia with Lewy bodies. Conference participants determined that, like a diagnosis for

Accurately diagnosing dementia with Lewy bodies is often challenging for physicians, because symptoms may resemble those of Alzheimer's and Parkinson's disease. Current research may lead to better diagnostic guidelines for this perplexing disorder.



Alzheimer's disease, a diagnosis of dementia with Lewy bodies depends primarily on a progressive decline in cognitive skills to such a degree that the symptoms interfere with normal functioning in daily life. One possible distinction between the two diagnoses may be the onset of memory loss, an early symptom of Alzheimer's that may not appear in the beginning stages of dementia with Lewy bodies.

The recommended diagnostic criteria also included the observation of at least one of the following features.

1. Fluctuations in cognitive skills.

These fluctuations, particularly a significant variation in attention and alertness, are common features. An individual may have a period of confusion or "going blank," followed by a period of clear thinking and normal alertness. The frequency and duration of these shifts in cognition vary considerably from one person to the next.

2. Recurring, detailed visual hallucinations.

This symptom may be one of the first to be observed. Although the themes of hallucinations vary widely, individuals often see people or animals invading their homes. Some people are frightened by the hallucinations, while others react with indifference or are even aware of the unreality of the hallucination.

3. Symptoms of Parkinson's disease.

Muscle rigidity and loss of spontaneous movement are the most common Parkinson symptoms in dementia with Lewy bodies. In some cases, the Parkinson symptoms appear first, and in other cases, the cognitive symptoms appear first.

Other symptoms that may occur are frequent falls, temporary loss of consciousness, and delusional anxieties usually based on past hallucinations.

Although a key factor in dementia with Lewy bodies is a fluctuation in cognitive symptoms, the disease results in a constant decline in cognitive abilities and leads to severe, irreversible dementia. Most individuals succumb to the disease within seven years of diagnosis. One question under investigation is whether a more rapid decline, which occurs in a few cases, is associated with a greater severity in one of the symptoms.

Much research has focused on trying to determine if Lewy bodies are evidence of a distinct dementing illness or a variant form of Alzheimer's or Parkinson's disease.

Treatment options

Some people diagnosed with dementia with Lewy bodies respond positively to drugs approved for treating Alzheimer's. These drugs, called cholinesterase inhibitors, are designed to boost the level of a chemical messenger that appears to be important in memory and other cognitive functions. Unfortunately, there are often complications with other pharmaceutical treatments for dementia with Lewy bodies. Drugs used to treat Parkinson symptoms may worsen hallucinations

and delusions. Likewise, medications for treating hallucinations may worsen the Parkinson symptoms. Therefore, current treatment options are often limited.

Current research

Research on Lewy bodies increased significantly during the 1990s. A number of scientists have shown that a primary component of Lewy bodies is a protein called alpha- (α -) synuclein and that the abnormal processing of the protein may lead to the development of the structures. Researchers have also identified the gene that provides the blueprint for α -synuclein and have determined that a mutation, or variant form, of the gene is associated with some cases of Parkinson's disease. Any investigations that reveal what Lewy bodies contain or how they are formed may eventually provide researchers with clues on how to develop new pharmaceutical treatments.

In other studies, including one funded by a three-year grant from the Alzheimer's Association, researchers are working to improve the methods for diagnosing dementia with Lewy bodies. This is an important pursuit because more reliable diagnostic methods generally lead to early intervention.

Researchers also continue to grapple with the fundamental mysteries of these brain abnormalities: Is dementia with Lewy bodies a distinct disease process, and to what extent does it contribute to cognitive deficits? Answers to these questions may lead to a better understanding not only of dementia with Lewy bodies but also of Parkinson's disease, Alzheimer's, and other neurodegenerative disorders. ♦



Investigating Gene Therapy for Alzheimer's Disease

GENE THERAPY HAS BEEN heralded as the treatment of the future for many diseases, including Alzheimer's. The basic premise of gene therapy is fairly straightforward—introduce into a patient's body a gene that initiates the production of a therapeutic protein. However, the process that might make this happen is by no means simple. A whole array of research has arisen to investigate methods for delivering genes safely and effectively. Although scientists studying gene therapy have encountered formidable challenges, they continue to gain a better understanding of the possibilities of this advance in medicine.

Alzheimer researchers are a part of this scientific vanguard. One research team at the University of California at San Diego (UCSD), led by Mark H. Tuszynski, MD, PhD, is investigating a novel gene therapy for Alzheimer patients. This work is funded in part by a three-year grant of \$180,000 from the Alzheimer's Association. After reporting favorable results with animal models, the UCSD scientists received approval from the U.S. Food and Drug Administration (FDA) to begin a small-scale clinical trial. In March 2001, the first of eight individuals is expected to undergo surgery for this investigational treatment.

A strategy for repairing brain cells

The focus of Tuszynski's research is a protein called nerve growth factor (NGF). It is one of a group of naturally occurring proteins that promote nerve cell growth and may protect cells from damage. In the Alzheimer-afflicted brain, cells that are important in memory, reasoning, and other cognitive functions are damaged or destroyed. The intent of the new therapy is to supply the brain with NGF to reinvigorate damaged cells and protect against complete cell death.

We might wish that there were simply an "NGF pill" that could accomplish this task. However, the walls of blood vessels in the brain and special cells in them create what is known as the blood-brain barrier. This molecular screen is designed to keep out unwanted substances. It also keeps out most drugs. Tuszynski's team hopes to use gene therapy as an alternative route to the brain.

The approach has three basic steps. First, the human gene that provides the blueprint for making NGF is inserted into the altered genetic material of a harmless virus. This virus serves as the vector, or the vehicle that gets the gene inside a human cell. When a virus enters a cell, it transfers the gene into the nucleus of the human cell. Then the human cell starts to produce a pro-

tein (such as NGF) that is coded by the newly introduced gene. In this case, a human cell can then become a sort of workshop for NGF production.

The intent of the new therapy is to supply the brain with nerve growth factor to reinvigorate damaged cells and protect against complete cell death.

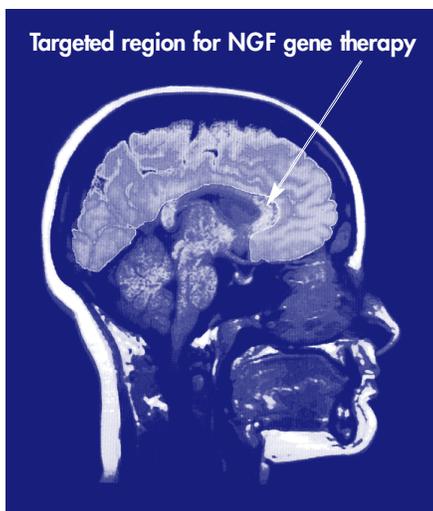
The second step then is to collect human cells to serve as the workshops. Tuszynski's group has retrieved cells called fibroblasts from the skin of the person who will be getting the treatment. Because the scientists are using the patient's own cells, the body's immune system is not likely to reject them as foreign substances. In the third stage, the surgical procedure, they will inject the NGF-producing fibroblasts into the brain.

Encouraging developments in animal studies

Tuszynski's investigational treatment is based on studies with several animal models, particular research with mon-

keys. Because animals do not get a disease like Alzheimer's, it is difficult to predict the exact effect of a new therapy. However, as monkeys age, they do exhibit a decline in memory and other cognitive abilities that somewhat parallels the modest declines that are a normal part of aging in humans.

In comparisons of the brains of young and old monkeys, the UCSD scientists analyzed the number and size of cells in the basal forebrain, a region deep inside the front section of the brain. These cells act as the control center for cells elsewhere in the brain that are important for memory, learning, and other cognitive functions. All of the cells in this particular system, called cholinergic cells, communicate with other cells using a chemical messenger called acetylcholine. The researchers detected about 40 percent fewer cholinergic cells in the basal forebrains of the older monkeys, and the remaining cells were about 10 percent smaller than the cholinergic cells in the basal



The investigative therapy will use a surgical procedure to deliver genetically altered cells to regions in the basal forebrain (arrow). These cells produce nerve growth factor (NGF), a protein that may reinvigorate damaged brain cells.

forebrains of the young monkeys. The researchers then implanted NGF-producing fibroblasts in the basal forebrain of older monkeys. After three months, Tuszynski's team observed that many of the "missing" cells had been reinvigorated. The restored cells in the basal forebrain totaled about 92 percent of the number identified in young monkeys, and the restored cells were only 3 percent smaller than young cells.

In other studies performed both in monkeys and in rats, the implantation of NGF-producing fibroblasts was also able to prevent the death of cells in the basal forebrain.

Questions for continued investigations

The primary goal of the current clinical trials is to determine if the treatment is well tolerated in humans. There are four main hypothetical risks: 1) bleeding in the brain from the surgical procedure, 2) the formation of tumors from fibroblast cells, 3) chronic pain, and 4) weight loss. Animal studies indicate that these risks are probably very low.

The researchers will also use neuropsychological tests and brain-imaging techniques to assess the effect of the treatment over an 18-month period. Some of the questions that the researchers need to answer include the following:

- Can NGF treatment reinvigorate brain cells damaged by Alzheimer's in the same way it reinvigorated normally aging cells in monkeys?
- Do reinvigorated cells function as they did before they were damaged by Alzheimer's?
- What impact does NGF treatment of cholinergic cells in the basal forebrain

have on the function of the entire network of cholinergic cells in the brain?

The findings from the clinical trials and further investigations with animal models will help the UCSD scientists determine if NGF gene therapy is a viable option for Alzheimer patients. While this investigational treatment is not considered a possible cure for Alzheimer's, it may provide an additional strategy for counteracting the effects of the disease and alleviating its devastating symptoms.

For details about this research project, visit the Tuszynski Lab on the Internet at <http://obsidian.ucsd.edu/~tuszynski/index.htm>. ♦

Advances

Are you a working caregiver?

WE WANT TO HEAR FROM YOU!

- What problems have you faced balancing work and caregiving responsibilities?
- How have you creatively solved these problems?
- What do you advise other caregivers in the same situation?
- What do you think should be done to help working caregivers?

Send your feedback, no later than April 16, by e-mail to michele.pellissier@alz.org or by mail to Michele Pellissier, 919 North Michigan Avenue, Suite 1100, Chicago, Illinois, 60611.



Making the Move

WHEN A LOVED ONE REQUIRES MORE CARE

“I know that I tried keeping Mom at home but it was not something I could do,” says Sherri Preston, a 36-year-old mother of three children and primary caregiver to her 62-year-old mother.

LIKE PRESTON, MANY CAREGIVERS do all they can to keep their loved one at home. As the disease worsens and the person with Alzheimer’s requires more care, caregivers often reach the crossroad they’ve dreaded—making the decision to move their loved one into a care facility.

Even when caregivers know that the decision to move the person in to a care facility is in everyone’s best interest, it doesn’t take away the feelings of guilt. Many caregivers feel as if they’ve betrayed their loved one who may have asked never to be placed in a nursing home. Others wonder what they could have done to prevent the move.

“I moved Mom home with my family. After three months I could no longer handle the constant ‘watching’ it took. The toll it took on my family was

beyond description. I moved her to a care facility where I know she is now safe and well cared for. Nothing will ease the guilt,” says Preston. “I worry that I’ve devoted so much of myself to my mom that I’m losing precious time with my kids that I can’t get back. I think that we all have to come to the point that we realize we can’t ‘fix’ this disease by being there every second of the day. We can try to protect our own sanity. If we don’t take care of ourselves, we won’t be any good for anyone else.”

Carol Malok’s 81-year-old mom was living at an independent living senior housing community when she realized that it was no longer safe for her mom to live on her own.

“No one person can oversee another for 24 hours-a-day. It’s literally impossible,” says Malok. “Mom and I lived in the same family house all our lives. She raised her family there and so did I. Separating myself from her was terrible but we did it and now she is doing well and so am I.”

Malok says that after all they have been through, her Mom is finally in a place that she trusts.

“I was not completely pleased with the first nursing home my mom was in because most staff are not trained to care for Alzheimer’s patients. Her day charge nurse actually trained herself (took courses on her own) to better care for my mom. After a two-year wait, we now have Mom, who is in the late stages of the disease, in an Alzheimer’s unit at a nearby facility and I have been extremely pleased with her care.”

Malok visits her for two to three hours a day, often helping her at mealtimes. “All the guilt and pain I went through with caring for her and the terrible decisions that have to be made, for me, are done, and I get to see Mom every day and she seems happy and they all love her. There is very little aggressive behavior with her and that is great,” says Malok.

Caregivers should try to research the care settings available in the communi-

ty soon after receiving a diagnosis. Many long-term care facilities have waiting lists, so it is important to get on the waiting list before a crisis occurs.

“My father had a seizure/stroke a few months ago and was unable to return home. My family is still having a difficult time finding a location that can deal with his needs,” says Kellie Sherrill, whose 60-year-old father has Alzheimer’s disease. “If you have a location that has an open bed you may want to consider placement earlier rather than deal with the struggle to find a place when it’s too late.”

Becoming familiar, in advance, with the facility and staff may help caregivers feel more comfortable about making the choice to move a loved one.

“Before placing your loved one in a care facility, make a surprise visit, in addition to scheduled meeting with the administration and staff,” says Malok. “Find out if the staff is trained to provide care for Alzheimer residents and ask to review the state report on the facility.”

Right before making the transition from home to the care facility, determine how much information the person with Alzheimer’s can handle about the move. Often, telling the individual days or weeks ahead of time will result in increased trauma and anxiety. Many experts suggest not telling the individual until it’s time to begin making the move.

Transition is generally easier if a family member or some other familiar person spends some time with the individual at the time of admission. Many care facilities will make arrangements to

have the first meal together which can make the person more comfortable.

There are things caregivers can do before and during the transition to help the person adjust more easily.

“Place familiar objects or a favorite chair in the room to make it feel as much like home as possible,” says Malok. “I also make sure I have a constant presence at the nursing facility. I truly believe that Mom will get the best care if the staff is aware of me being there.”

Picking the person’s best time of day for admission may also help ease the transition. Try to avoid staff shift changes or meal times when facilities tend to be loud or hectic. Mid-morning hours are usually best because generally more staff members are present and there are activities the new resident can attend right away, which may help ease the transition for everyone involved.

As difficult as it may be, caregivers should do their best not to show fear or sadness. Individuals with Alzheimer’s

disease can be very perceptive about the emotions of those around them.

Relinquishing caregiving responsibilities often makes a caregiver feel worried and guilty. But family caregivers can remain active in the loved one’s care by discussing with the provider the ways they would like to be involved.

Share concerns and suggestions with staff so they can provide a safe and comfortable environment for the individual. Caregivers know their loved one better than anyone so offering information will not only help the staff, but will improve the quality of life for the person with Alzheimer’s.

At first, caregivers may need some time away to process the change, define their new role, and accept the placement. Visit as often and for as long as it is comfortable. Bring a friend or family member along if it is too difficult to visit alone. Develop a visitation schedule with family members if the visits are difficult. This is a good way to involve the family in the person’s care.

A caregiver’s role changes (but doesn’t end) when a loved one moves into a care facility. Consider sharing meals or performing an activity together, like attending a church service. A change in the caregiving environment can be a difficult challenge for caregivers as well as their loved ones, so it is good to stay active and pursue some personal interests, as well. Caregivers should give themselves permission to have fun—it will not mean that they are abandoning or forgetting their loved one. ♦

Help care providers get to know your loved one better by

- providing photographs
- sharing stories or memories
- preparing a written personal history
- explaining favorite hobbies, activities, and interests
- relaying caregiving tips that worked for you



Helping Teens Cope with Alzheimer's Disease

ALZHEIMER'S DISEASE HAS A great impact on family life. Often overlooked as "victims" of this disease are the younger members of the family, especially teens. The degree to which teens are affected by Alzheimer's depends on who has the disease—a parent or grandparent, relative, or friend. Other factors include how close the teen is to the person and where the individual lives (in the same home, a nursing facility, etc.).

Because teens are at an age when they can be left at home alone and can be more responsible for handling household chores, many teens are left to handle some caregiver responsibilities because their parents need to work or be away from the home. Placing this responsibility on a teen's shoulders can be overwhelming and potentially dangerous.

"I wish my parents would have known the symptoms of Alzheimer's," says 13-year-old Ashley, whose grandmother has the disease. "I remember staying home alone with my grandma and she had walked up the stairs and then she just peed in her pants. It freaked me out. I had no clue what to do, no one was home, and she had this blank look on her face as if she was a zombie or something. Her disease has really affected me."

How your family's teen may feel

- Sad about changes in a loved one's personality and behavior

- Confused about how people get the disease and why the person behaves differently
- Afraid of the behaviors that the person exhibits
- Worried that they or their parents might develop the disease
- Angry and frustrated by the need to repeat activities or questions
- Guilty for getting angry or being short-tempered with the person
- Jealous and resentful because of the increased amount of attention that is given to the person with Alzheimer's
- Embarrassed to have friends or other visitors to the house

Adult caregivers will likely be faced with some difficult moments throughout the course of the disease, making it challenging to control emotions. Be careful not to take out anger and frustration on or in front of the teen in your family because teens may take the behavior personally.

A teen's common reactions to Alzheimer's disease

Teens may exhibit their emotions in ways you may not easily recognize. They may:

- Verbalize vague physical complaints, such as a stomachache or headache,
- Perform poorly in school,
- Spend time away from home, or
- Stop inviting friends to the house.

One of the most important things you can do for the teen in your family is learning as much as you can about the disease.

Ways to help teens cope

- Maintain open lines of communication.
- Offer comfort and support.
- Provide opportunities for them to express their feelings.
- Let them know their feelings are normal.
- Educate them about the disease and encourage them to ask questions.
- Respond honestly to questions.

Activities that teens can do with the person who has Alzheimer's

- Go for a walk.
- Do household chores together, such as folding laundry, raking leaves, or washing dishes.
- Listen to music, dance, or sing.
- Look at old photographs.
- Read a favorite book or newspaper.
- Develop a memory book about the person.
- Make a family tree.
- Watch a movie.
- Keep a journal together.

Ashley visits her grandmother regularly at the nursing home. "She is very happy there. Animals are allowed there, so sometimes we bring our dog, Diamond. My grandmother seems to remember her but not anyone else. It's O.K. though."

Ashley advises other teens to do all they can to comfort the person with Alzheimer's disease. "They don't know what's going on, so try to help them all you can. You may not get your reward now, but you will when you go to heaven." ♦

[IMPLICATIONS OF SURGERY...
CONT'D FROM PAGE 1]

Hall says. When deciding upon surgery, families should first consider the individual's wishes. The Association urges individuals with the disease to have advance directives in place as guideposts for family members regarding treatment and care.

Decisions also should be based upon several factors including the individual's stage in the disease, capacity to handle a change in routine and environment, and the benefits of the procedure. "I wouldn't opt for surgery for my mother unless I thought it would improve her quality of life," says Elizabeth Figueroa, caregiver to her mother with Alzheimer's and program director for the Cobble Hill Health Center in Brooklyn, New York. "If it's surgery for an acute condition and I'm given an option, I would consider pain management."

Figueroa notes that the choice to pursue surgery or not is very individual and personal to each family, and Tangalos stresses that each situation should be judged on its merits.

Is the surgery worth it?

In 1997, Wally Reed, MD, a retired anesthesiologist from Arizona and caregiver to his wife with Alzheimer's, was faced with the dilemma of deciding whether or not to allow his spouse to undergo surgery for a hip fracture. After considering the risk, he asked the physician to let his wife's fractured hip heal on its own, and it did. "I was convinced that the post-operative cure could not be carried out," he says.

The patient's ability to rehabilitate is critical in determining whether to choose surgery. Caregivers must keep in mind that the individual with Alzheimer's has trouble learning and

problem solving. Major surgeries, such as hip surgery, increase the risks of lowering the quality of life. An elective operation will reduce pain, but the individual could become less mobile because of the inability to learn to use a new hip.

Some surgeries do enhance the life of a person with the disease. An example is cataract surgery. The procedure can be done on an outpatient basis and not disrupt the person's daily routine. The elimination of cataracts also may lead to fewer hallucinations.

Still, surgery can lead to increased confusion and decreased mental status in the individual with Alzheimer's, so families must weigh the consequences. "Is the risk of abrupt decline and functional loss worth the potential benefit from surgery?" asks Hall.

General anesthesia may make the patient extremely confused post-operatively. For someone in the early stages of the disease who is able to perform daily activities, the general level of the person's mental status will decline temporarily, but this may not be the case for a person in an advanced stage. "As the disease progresses, the risks of surgery to mental status and function increase exponentially, as does recovery time," Hall says.

For the normal elderly person over the age of 70, it will take three to five days to restore their mental and physical status for each day of a hospital stay, Tangalos notes. But for the person with Alzheimer's, it could take longer. If the individual is in the end stage of the disease, palliative care might be a better alternative than hospitalization.

What to do if surgery is the choice

If a family decides to proceed with

surgery, they should share as much medical information about the person as they can with the surgeon and arrange a discussion between the individual's physician and the surgeon.

Families also may want to pursue aggressively the least invasive procedure and ask if it can be performed on an outpatient basis. Less invasive operations could lead to briefer hospital stays and better options for those with the disease. The family needs to meet with the anesthesiologist in advance and discuss the type of anesthesia and be clear that the person has Alzheimer's. To reduce post-operative confusion, choose a local or regional (spinal) anesthesia that may not heighten confusion as much as general anesthesia and ask that any post-operative pain medications be scheduled, rather than "on demand," so the patient does not have to ask for it.

Moreover, many families think the pain medication will heighten confusion so they refuse it for their loved one. This may cause increased pain and decreased post-operative mobility, thus precipitating agitation, confusion, pneumonia, and prolonged recovery.

When the person enters the hospital, family members may want to take turns staying overnight and spending time during the day with the patient. It's a good idea to involve a social worker in discharge planning to assist a family in mobilizing resources to meet additional needs. Also, consider family members' needs for respite and anticipate additional demands on the caregiver at discharge.

With foresight and planning, families can shield the person with Alzheimer's disease from some of the unpleasant consequences of surgery and hospitalization. ♦

Q My mother, who has been diagnosed with Alzheimer's disease, has a vision impairment. What kind of challenges will she be facing, and what can I do to help?

A Visual impairment can present a significant barrier to good communication.

Many people with Alzheimer's begin to lose their powers of concentration early in their illness. Diminished visual acuity or keenness due to cataracts, macular degeneration, diabetic retinopathy, and unused eyeglasses can exacerbate concentration problems and orientation to time and place. Visual perceptual problems also cause difficulty in judging distances, depth, and subtle distinctions in light and shadow. The ability of the person with Alzheimer's to use visual cues declines and uncertainty about a speaker's identity is heightened.

To determine the treatment required, degree of vision loss, and type size the person can still read, an ophthalmologist or optometrist should give a thorough low-vision exam. Results of an exam will enable family and friends to determine the steps needed to help overcome communication challenges. The examiner may be able to provide a more accurate assessment if the person is still able to read a little, tolerate short periods of darkness, and can follow simple directions.

Many individuals with Alzheimer's can still read written words long after losing the capability to understand spoken language. If someone is born blind and learned to read Braille, they should be encouraged to continue to do so. But as the disease progresses,

you may want to substitute Braille publications that are at a lower reading level suitable for the person's comprehension at the time.

For the person with low vision, you may want to make adaptations in the living environment, such as rearranging furniture to make it safer to move around, improving lighting, and using contrasting colors for greater visibility. Make sure there is adequate lighting near furniture and use brightly colored accessories so objects are easier to locate. Eliminate hazards, such as worn carpeting.

Caregivers should help orient the individual to the living environment so that they know the layout of their living space. Do not move an item, including furniture, without telling the person about the new location. You may want to keep personal items in one place, so the individual does not have to search for them.

Consistency in visual clues is important. One good visual clue is a white index-card. Black markers can be used to write in large letters. Black letters on white cards create a strong contrast and makes it easier for the person with low vision to read the words. Cards can be used to label items around the household or to leave simple messages and reminders. For example, to remind the individual to take medication, a card labeled "medication" could be left near the bottles or a place where the medications

can be found. Other visual clues include a memory board that contains images of family members or friends.

Encourage the person to use their other senses. For example, keep the house filled with familiar scents and sounds. Touch is especially important to the visually impaired person and remains a source of comfort to individuals with Alzheimer's. A memory box filled with small familiar objects, such as jewelry or souvenirs, may keep the person's memories alive.

When initially approaching a visually-impaired person, announce that you are in the room and identify yourself. Stand where you can be seen or let the individual know where you are. Say when you are leaving and where you are going. If the individual can still understand spoken language, use descriptive language. For example, don't say that something is "here" or "there." Instead, say something like "it's on the table," or "it's in the second drawer of the cabinet."

The more ways you can make use of the person's vision capability and other senses, the more able you will be to handle the challenges of communicating with someone who has both Alzheimer's and a visual impairment. ♦

Tina Tucker is national program associate for the National Foundation for the Blind in its Atlanta office, and Elizabeth Ostuni is director of Accent on Communication, a private consulting agency in Sparta, New Jersey. She also is the coauthor of Successful Communication with Alzheimer's Disease Patients: An In-Service Manual published by Butterworth-Heinemann.



Alzheimer Programs Fare Well in Final Federal Budget

ALZHEIMER PROGRAMS AND research received important increases in the federal budget passed by Congress on December 15.

“We believe the budget is a bipartisan recognition of the significant impact that Alzheimer’s has on families,” said Judy Riggs, deputy vice president of public policy for the Alzheimer’s Association. “This legislation will provide the new administration with important building blocks needed to tackle the disease’s growing threat to our nation’s health care system.”

“Homebound” definition allows for day care

A provision to clarify the Medicare “homebound” definition to allow beneficiaries to attend adult day care was included in the final budget bill.

In the past, Medicare rules dictated that in order for beneficiaries to be eligible for home health benefits, they must require skilled nursing care and be declared “homebound” (i.e., the beneficiary can only leave the home infrequently and with great assistance from another individual). Under the old rules, a beneficiary with Alzheimer’s disease who left home to attend adult day care failed to meet the “homebound” test and was denied the home health benefits to which they are otherwise entitled.

Alzheimer demonstration grants increased

The Labor and Health and Human Services Appropriations bill included a 14 percent increase in funding for Alzheimer research. This will bring federal spending on Alzheimer research

to more than \$530 million in fiscal year 2001.

In addition, the bill contained \$9 million for the Alzheimer demonstration grants at the Administration on Aging—a 50 percent increase over the previous years’ funding. The demonstration grants are provided to states to develop innovative services targeting people with Alzheimer’s.

Family caregiver support programs

The Caregiver Support Program, newly established by the re-authorization of the Older Americans Act, received full funding at \$125 million. This new program will provide money for community-based programs, including respite care, counseling services, and caregiver training.

Safe Return funded

The budget contained \$900,000 in funding for the Alzheimer’s Association Safe Return Program. Safe Return is a nationwide identification program that assists in the safe return of individuals with Alzheimer’s or related dementias who wander and become lost.

For more information about federal legislative activities, visit the advocacy section of the Alzheimer’s Association’s Web site at <http://www.alz.org/involved/advocacy>. ♦

R_x CORNER

Several Web sites provide information on clinical trials for Alzheimer treatments but identifying the most reliable, up-to-date information may not be easy. Recently, the Association has revised its own clinical trials Web pages in an effort to direct people to the most helpful on-line resources and to focus our efforts on providing understandable background information on investigational treatments.

We have created two categories on our public site:

- **Clinical Trials Currently Recruiting Individuals**
<http://www.alz.org/research/clintrials/index.htm>
- **Clinical Trials Closed to New Participants and Other Investigations**
<http://www.alz.org/research/clintrials/Closed/index.htm>

We have also begun to supply local chapters and call specialists at our toll-free number with updated print versions of drug fact sheets and clinical trials information. To locate the chapter nearest you or speak to a call specialist, call (800) 272-3900.



Alzheimer Advocacy: *The Future is Now*

ALZHEIMER ADVOCATES ARE serving as change agents in local, state, and federal government. They are ensuring funding for Alzheimer research and securing resources to help families pay for the enormous costs of health and long-term care.

In early April at the Alzheimer's Association National Public Policy Forum, more than 500 advocates will go directly to Capitol Hill to pitch recommendations for funding of research

and care. They will meet one-on-one with congressional leaders to make sure their message is heard. They will also bring national attention to the disease at a candlelight vigil on the steps of the Lincoln Memorial.

Caregivers and those with the disease make great advocates because of their passion and experience. Although it is natural to have reservations about one's ability to undertake and execute advocacy activities, there is deep satisfaction in educating. Legislators and

lawmakers must be educated about what is urgently needed for people with Alzheimer's.

If you are interested in participating in the Public Policy Forum on March 31–April 3 or becoming an Alzheimer advocate, call the Public Policy office in Washington, D.C. at (202) 393-7737, or visit the advocacy section of the Alzheimer's Association's Web site at <http://www.alz.org/involved/advocacy/how>. ♦

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