Advances

The Alzheimer's Association Newsletter

Progress in Alzheimer Research and Care

Vol. 22 No. 4 Winter 2003

Early-Onset Alzheimer's Brings Special Challenges

Among the myths surrounding Alzheimer's disease is the notion that it only affects people over age 65. While most commonly occurring after that age, early-onset Alzheimer's, simply defined as a diagnosis of the disease under age 65, can strike people in their 50s, 40s, and even 30s.

Just ask Chip Gerber. Diagnosed in 1997 at age 51, Gerber, a minister and social worker living in Satsuma, Florida, had to retire from a life devoted to serving others in order to better manage his condition. To his chagrin, his social work license will soon expire because he is not able to take the classes required to renew it.

"Things have definitely changed for me," Gerber admits. "My memory fails me terribly, and my attention span is very short. I do a lot of sitting and staring. I wake up in a fog and, after a few hours, I go into sundowning. But I use the hours in between to my advantage."

Or consider Mary Lockhart of Oklahoma City, Oklahoma, diagnosed seven years ago when she was 55. Lockhart spends a lot of time trying to convince skeptics that she isn't too young to have Alzheimer's, sometimes feeling as though she should carry a copy of her neurologist's report in her purse.

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inside

Chronic Wasting Disease May Threaten Safety of Deer and Elk Meat in U.S. and Canada

A fatal disorder of deer and elk that is related to mad cow disease is causing growing uneasiness among hunters and public health authorities as it spreads through U.S. areas in the West and Midwest and Canada's prairie provinces.

Known as chronic wasting disease, the disorder causes deterioration of the nervous system as well as increasingly severe weight loss. It was first noticed in 1967 in deer near Fort Collins, Colorado. Experts believe that the disease now affects deer and elk in 10 states and two Canadian provinces, but its extent is extremely difficult to gauge accurately and is probably expanding.

Known locations where the disorder currently occurs include Illinois, Kansas, Minnesota, Montana, Nebraska, New Mexico, Oklahoma, South Dakota, Wisconsin, and Wyoming as well as Alberta and Saskatchewan.

Chronic wasting disease is the latest prion disease to raise concern that it may, like mad cow disease, have the potential to move from animals to people. This concern has led some experts to urge caution in butchering and eating deer and elk meat. Colorado, for example, warns hunters not to shoot for personal consumption any animal that appears sick or abnormal in any way, to wear gloves while butchering, and not to consume any part of the central nervous system (brain and spinal cord) or any meat from an animal that may have the disorder. Other states suggest similar precautions.

The World Health Organization, the health agency of the United Nations, recommends against using any part of an animal that may have chronic wasting disease in human or animal food.

Prion (pronounced PREE-awhn) diseases are an unusual group of disorders that develop when a protein normally present in nerve cells acquires an abnormal three-dimensional structure. The abnormal shape gradually induces the same abnormality in the protein throughout the brain, causing increasing damage and, ultimately, death.

In addition to mad cow disease in cattle, other prion disorders include Creutzfeldt-Jakob disease in humans and scrapie in sheep and goats.

The abnormally folded proteins that initiate the destruction can arise spontaneously for unknown reasons, as occurs with most Creutzfeldt-Jakob cases. In chronic wasting disease and some other prion diseases, the prions act as infectious agents, transmitting the disorder from one individual to another. This property is the source of the term "prion," shorthand for "proteinaceous infectious particle."

Species to Species

Some prion diseases appear to travel from one species to another, a process called "jumping the species barrier." Many experts believe that mad cow disease developed in the United Kingdom primarily from use of cattle feed that contained by-products from scrapie-infected sheep. Other experts believe that the disorder, although spread by animal by-products, originated in cattle.

Consumption of beef containing residue from brains or spinal cords or use of other products derived from "mad cows" in turn caused a human disorder called variant Creutzfeldt-Jakob disease that has affected more than 100 people in Europe, primarily in the United Kingdom.

The mad cow epidemic is the source of concern that chronic wasting disease could spread from deer and elk to farm animals or to human beings. Although there is no evidence

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that either type of transmission has taken place, at least five states and one Canadian province have initiated programs to eliminate affected animals.

It is not yet known how chronic wasting disease spreads from animal to animal—current theories of transmission focus on nose-to-nose contact, saliva, and waste products.

Searching for Answers

Chronic wasting disease experts from around the world convened in Denver in August 2002 to share information about the best strategies for understanding and dealing with the disorder.

One closely watched study is testing whether the disorder can infect baboons, which are, like other primates, close biological relatives of humans. Results of this study, due out in about two years, are expected to provide the best indication to date on whether the disorder can infect people.

Mad cow disease has proved highly transmissible to a variety of species in animal studies. However, molecular studies so far suggest that it would be difficult for chronic wasting disease to jump to humans.

Prions and Dementia

When Stanley B. Prusiner, MD, first proposed in 1982 that proteins could function as infectious agents and coined the term “prion” to describe them, the theory drew profound skepticism. Unlike all other known infectious particles, including bacteria, viruses, and fungi, proteins completely lack genetic material. However, a growing body of research gradually documented the validity of the concept, and prion theory earned Prusiner the 1997 Nobel Prize in Physiology or Medicine.

In addition to providing a novel explanation of the mechanism behind this unusual group of disorders, prion theory is now gaining prominence for its potential to shed light on protein disruptions in common forms of neurodegenerative disease.

For example, although Alzheimer’s disease, Parkinson’s, and dementia with Lewy bodies are not infectious in any way, they all involve increasing deposits of abnormally folded proteins. The culprits are beta-amyloid and tau in Alzheimer’s and alpha-synuclein in Parkinson’s and dementia with Lewy bodies. Many experts share a growing conviction that there may be elements of self-perpetuation in the protein misfolding involved in these disorders just as there are in prion diseases.

Understanding the fundamental biochemical and biophysical mechanisms involved in protein misfolding may provide important clues in solving the mystery of neurodegeneration. Prusiner explored some of these issues in his plenary address, “Mad cows, demented people, and the biology of neurodegeneration,” at the 8th International Conference on Alzheimer’s Disease and Related Disorders. This premier event in global neuroscience, hosted by the Alzheimer’s Association in July 2002 in Stockholm, Sweden, brought nearly 3,700 attendees up to date on the latest findings in prions and virtually every other topic important in dementia research.

What Do You Do When Family Members Second-Guess Your Decisions?

Shirley James, RN, knew something was wrong with her mother, Lettie, several years before her sister or father would acknowledge anything more than stress or the "normal aging process."

The family eased Lettie's load by doing household chores, paying bills, and grocery shopping. Yet James felt she was neglecting her then 82-year-old mother because she didn't push her family to have Lettie evaluated for Alzheimer's disease.

She writes: "A family is made up of more than one member and creating further turmoil by insisting on my own way would have led to conflict between my sister and me and even my folks. If Mom would have agreed to something Dad wasn't ready to pursue, he would have been mad at both of us and his verbalized anger would have caused more confusion and tension in Mother."

The family eventually made the joint decision to have Lettie evaluated, and James' gut feeling was correct: Lettie had Alzheimer's. "Mom has been on Aricept® three years and has experienced a slowdown in the disease's progression. While we really don't want to be on this horrible road, being a family in harmony is a restful place."

To avoid confrontation, James advises families to start making decisions together as soon as possible. When there is a stalemate, anger, and when decisions can't be postponed, she believes the care partner should have the greatest say in decision making.

Ted Distler, of Jefferson City, Missouri, agrees. After caring for wife Norma, now 63, at home for over 10 years, Distler made the painful decision to place her in a nursing home last February. "It was the hardest decision I've ever had to make. My doctor told me I had two choices—find full-time help or arrange my funeral," he says.

The nursing home idea, however, was not embraced by other family members. "They volunteered to provide full-time care supplemented by day care, but they worked full time. They weren't being realistic about Norma's condition or the care required." Now the family finally agrees with Distler's decision.

The opposite is true for E. Roman, PhD, who was shocked to find her mother had been placed in a New York City nursing home, with no forewarning or discussion even though her mother seemed in good health. Although her older sister was the health proxy, Roman doubted that her mother had Alzheimer's disease or needed nursing home care. Roman offered to quit work and care for her mother or provide a health aide, and a legal struggle ensued when Roman, armed with a pass authorized by her mother's doctor, brought her mother home.

"My mother said I saved her life. I showed her a new addition to my home where she could live if she wanted, but my sister and aunt disagreed and had the nursing home send the police to my home."

After five weeks in the nursing home, Roman's mother fell and broke her hip and died nine months later at age 83. Roman wishes nursing home administrators would have been less obstructive and instead facilitated better family communication, enabling family members to see beyond their differences and to work as a team for their mother's welfare.

Connecting with the Alzheimer's Association can help eliminate second-guessing and communication breakdowns, says Alycia Altman, case manager, Greater Richmond Chapter, who assesses the at-home needs and concerns of persons with dementia and their families.

"I ask 'Who helps care for your mother?' and discover that one person, usually a daughter, is doing all the caregiving but angrily resents being second-guessed by a long-distance sibling or a relative who spends only a short amount of time with the person," says Altman.

She adds: "We facilitate family meetings and encourage support group participation. Caregiving seems to be shared more effectively and there's better communication among family members when they've reached out to the Alzheimer's Association. They know they're not alone in their struggles."

Cynthia Cole's husband Bob was diagnosed with ataxia disorder, a form of dementia, in 2000. Now 53, the former fireman can no longer drive a car or work. He attends adult day care but due to the high risk of falls, incontinence, swallowing problems, and other risks of dementia, Cole is now looking for a nursing home for her young husband.

Cole notes ironically that even her grandparents don't require nursing home care. "I feel like a failure because I can't keep him at home. There are so few options available to young families who don't have the financial resources for private care," she says.

While there are no siblings or parents second-guessing Cole's decision, the couple has a blended family of seven children ranging in age from 8 to 27. "The older children still have not accepted their father's illness is terminal," she says. "The college students plead with me to keep him at home a little longer. They dread that they will have to visit him in an 'old' person's home. The younger children simply want their daddy back."

Cole credits the Association's Western Carolina Chapter for providing her with needed resources and support as she searches for the right place for her young husband. "I have nightmares sometimes," admits Cole, "but I've had to set aside what everyone else thinks and consider what is best for Bob and our family."

For More Information
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www.alz.org
info@alz.org

What Helps You Alleviate Caregiver Stress?

The Alzheimer journey can be long, painful, exhausting, and stressful, as the needs of people affected by the disease and their care partners change with the disease's progression.

As an Alzheimer care partner, you devote a significant amount of time and energy to the person with Alzheimer's while working, caring for other family members, doing household chores, and running errands. As a result, you are likely to experience varying degrees of stress. All too often, care partners don't recognize their own needs, fail to do anything about them, or simply don't know where to turn for help.

We Want to Hear from You!

How do you balance your life and get relief from the demands of caregiving? Do you attend a support group, enjoy a hobby, exercise, or share caregiving responsibilities? Please tell us what you're doing to alleviate caregiver stress. Has your quality of life improved as a result?

Your experiences could be incorporated into a "Dialogue" article in the spring 2003 *Advances*. Please send your stories to us no later than January 6.

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Alzheimer's Disease—Then and Now

A 20-Year Progression from Helplessness to Hope

On October 22, 1982, then President Ronald Reagan launched a national campaign against Alzheimer's disease when he called members of the newly formed Alzheimer's Association to the White House and signed a proclamation declaring National Alzheimer's Disease Week. This was a significant step toward drawing national attention to Alzheimer's disease as a major health menace.

That historic event, which came over 70 years after German neuropsychiatrist Alois Alzheimer described the first case of the disease, marked the beginning of a revolution in awareness of, advocacy for, and insight into Alzheimer's disease.

At the time, at least 2 million Americans were living with this devastating illness, but until President Reagan spoke out, most Americans had never heard of it. "The emotional, financial, and social consequences of Alzheimer's disease are so devastating that it deserves special attention," Reagan said. Taking lead of the issue, he went on to advocate research as "the only hope for victims and families." (Reagan, now 91, courageously announced his Alzheimer's diagnosis to the public in November 1994.)

In addition to the White House proclamation, the Alzheimer's Association recently marked other key milestones, including:

The 20th anniversary of the research grants program. In 1982, the first 11 investigators received $78,000 in funding. In 1992, $4.4 million was awarded. In fiscal year 2002, the Association awarded 90 projects $17.5 million, bringing our cumulative funding total to $136 million—making the Association the world's largest private funder of Alzheimer research.

On October 23, 1980, a "Dear Abby" letter from "Desperate in New York" mentioned Alzheimer's and an Association in its infancy was inundated with more than 25,000 letters asking for information about this "rare" disease. Ironically, Pauline Phillips, 84, who created "Dear Abby," recently announced her own diagnosis of Alzheimer's disease. Twenty-two years later to the week, another "Dear Abby" column, now written by her daughter Jeanne Phillips, charted 20 years of progress in Alzheimer care and research.

The Alzheimer's Association also reflects on two decades of extraordinary growth and celebrates the enormous progress made in understanding, managing, and treating the disease.

For example, in 1982, the National Institutes of Health (NIH) spent $20 million on Alzheimer research. In 2002, federal funding for research is $598 million. Twenty years ago, there were no treatments for Alzheimer's. Today, three approved drugs—Aricept®, Exelon®, and Reminyl®—appear to be effective at reducing symptoms of Alzheimer's disease. (See sidebar for other highlights.)

The Association rose from humble beginnings. On October 29, 1979, seven independent groups met with representatives of the National Institute on Aging in Washington, D.C., with an idea to form a national Alzheimer's organization.

The vision became reality under the leadership of founding president and honorary chair Jerry Stone, whose passion and commitment created the Alzheimer's Association in 1980. He and other dedicated visionaries were the catalysts for building the Association from a small cadre of volunteers and staff to a large integrated network of 83 chapters with more than 250 service delivery areas that offer a full spectrum of services, including information and referral, care consultation,

Twenty years ago...

Only a handful of scientists were investigating Alzheimer's disease.

The few scientists researching Alzheimer's were working in isolation.

Fewer than 250 scientific articles on Alzheimer's disease and dementia had been published worldwide.

There were no sound theories on risk factors that could be useful in developing methods of prevention.

Medicare practice and local policy widely denied services to beneficiaries with Alzheimer's on the theory that there was nothing to help them.

Today...

This past July, the Association hosted the largest-ever dementia research conference in Sweden which drew nearly 3,700 researchers from 78 countries.

The National Institute on Aging funds a nationwide infrastructure of Alzheimer research based in 30 centers at major academic institutions.

More than 3,000 peer-reviewed articles have been published in leading scientific journals worldwide.

A growing body of evidence points to known risk factors for heart disease, including high blood pressure and high cholesterol, as risk factors for Alzheimer's.

The Centers for Medicare and Medicaid Services have banned discrimination in coverage.

educational programs, and support groups.

Today the Alzheimer's Association is the premier source of information and support for 4 million Americans with Alzheimer's. The Association's mission is to eliminate Alzheimer's disease through the advancement of research and to enhance care and support services for individuals, their families, and caregivers.

Two unique national programs—the Contact Center and Safe Return—have helped those affected by Alzheimer's realize they are not alone in their fight against Alzheimer's.

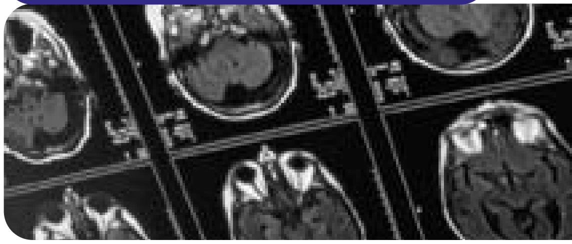
The Contact Center provides information, support, and referrals 24 hours a day, seven days a week through a toll-free number. During its first eight months of operation, inquiries reached 147,023. Safe Return is a nationwide registration and identification program with 93,368 registrants that assists in the timely return of individuals with dementia who wander and become lost.

Through the support of the Association's chapter network, volunteers, and donors—who demonstrated their steadfast commitment to conquering Alzheimer's disease by giving a record $62 million last year—the Association is the largest national voluntary health organization in America dedicated to Alzheimer's.

The Association has become the premier venue for information, care, and research through its biennial research and education conferences. Our annual public policy forum brings hundreds of people to Washington, D.C., for a candlelight vigil to honor those touched by Alzheimer's and to advocate for increasing federal funding for research to $1 billion annually.

There are many milestones ahead and the Association is moving closer to our ultimate goal—a world without Alzheimer's disease.

On October 22, 1982, President Ronald Reagan invited representatives of the newly formed Alzheimer's Association, including, from left, Jerry Stone, Mrs. George F. Berlinger, and Princess Yasmin Aga Khan, to the White House to celebrate the first National Alzheimer's Disease Awareness Week.



Q:

Can Brain Scans Be Used to Diagnose Alzheimer's?

A:

The value of brain scans in diagnosis may be best understood if we think of a scan as a piece of a puzzle. If a person with memory problems gets a brain scan but receives no other assessment, a physician cannot state accurately, "This person has Alzheimer's." When images of the brain are combined with other diagnostic information, or other pieces of the puzzle, the physician may then be able to put together a more comprehensive picture of what's happening in the brain.

Structural imaging, pictures of the shape and volume of the brain, is commonly used in diagnostic testing for someone with dementia symptoms. Structual images are created with magnetic resonance imaging (MRI) or computerized tomography (CT).

CTs and MRIs can reveal tumors, single or multiple infarcts (strokes), damage from severe head trauma, or a build-up of cerebrospinal fluid. The presence of one of these factors, which may all cause dementia, can lead to a diagnosis other than Alzheimer's disease.

Structural imaging may also reveal atrophy, or decline in brain volume. Because different diseases target certain areas of the brain, signs of atrophy in one region may help determine the type of dementia. However, some atrophy may exist in older age even in the absence of disease, and an individual may have Alzheimer's or a related disease even if there is no noticeable sign of atrophy in a brain scan. The assessment of brain volume remains the subject of debate. Although several studies have demonstrated differences between structural images of brains in people with and without Alzheimer's, more research is needed to establish a standard for measuring and interpreting brain volume.

Another type of imaging procedure is functional imaging, which takes pictures of brain activity at a particular moment. These images are created with functional magnetic resonance imaging (fMRI), single photon emission computed tomography (SPECT), and positron emission tomography (PET).

Functional imaging methods are usually not part of a standard diagnostic workup, and there continues to be disagreement on their value. However, some specialists may order these tests, and researchers continue to build a case for their diagnostic use.

Functional imaging may help distinguish between two types of dementia, such as Alzheimer's disease and frontotemporal dementia, that cause damage in different regions of the brain. These images may also help confirm a diagnosis when symptoms are mild.

Researchers also continue to investigate the use of functional imaging to identify the abnormal structures associated with Alzheimer's disease, amyloid plaques, and neurofibrillary tangles. Research findings are still very preliminary, and it's still too early to determine whether these strategies might improve on current diagnostic methods.

It is unlikely that any imaging method would entirely replace a thorough diagnostic assessment, which includes various question-and-answer tests to assess memory and thinking skills, a general medical exam, and other tools for determining the cause of symptoms. Nonetheless, imaging technology holds much promise for helping us "see" and understand the effects of Alzheimer's disease.

Our consultant for this column was William Jagust, MD, professor of neurology at the University of California, Davis. Jagust specializes in the investigation of PET, SPECT, and MRI to study Alzheimer's, Parkinson's disease, and normal aging.

Prescription Drug Discount Cards Provide Seniors Some Financial Relief

Doctors say that about half the people affected by Alzheimer's disease demonstrate memory and thinking improvement on medication. Three approved drugs—Aricept®, Exelon®, and Reminyl®—may help reduce symptoms of Alzheimer's disease, but these can be expensive treatments for those on limited, fixed incomes.

While the national debate continues over adding a prescription drug benefit to Medicare, resources are available for individuals with Alzheimer's and their care partners who do not have prescription drug coverage or who are struggling with the high cost of prescription drugs.

For example, several pharmaceutical companies have developed new programs to offer discounted drugs to lower- and middle-income seniors. In addition, the Centers for Medicare and Medicaid Services (CMS), the federal government agency that administers Medicare, has developed an easy-to-use Web site to provide consumers with information about various prescription drug assistance programs.

The Prescription Drug Assistance Program's section provides information about both private and public programs that offer free or discounted medicines to Medicare beneficiaries through Medigap plans, Medicare Managed Care Plans, federal employee benefits, veterans benefits, and state-based programs as well as various other sources.

Consumers can search the database by zip code or by state/region. The database also allows users to search for programs targeted to certain health conditions/diseases or those administered by specific pharmaceutical companies. Users can print out information about the various programs or download the entire database to their personal computers.

Earlier this year, eight large pharmaceutical companies (Abbott Laboratories, AstraZeneca, Aventis, Bristol-Myers Squibb Company, GlaxoSmithKline, Janssen Pharmaceutica Products L.P., Novartis, and Ortho-McNeil Pharmaceutical Inc.) partnered together to launch the Together Rx Card, a program which provides discounts on more than 150 widely prescribed medications.

Medicare beneficiaries with annual incomes of less than $28,000 for an individual ($38,000 for couples) who do not have other private or public prescription drug coverage are eligible to enroll in the free program. (Income limits vary in Alaska and Hawaii.)

A list of the discounted medications available through the program and additional enrollment information is available on the Together Rx Web site.

Pfizer has also launched a discount prescription program through its Pfizer for Living Share Card™. Medicare beneficiaries with a gross income less than $18,000 per year ($24,000 per couple) who have no other prescription drug coverage and are not eligible for Medicaid or any other state-funded drug benefit pay a flat fee of $15 for up to a 30-day supply of certain Pfizer medications.

There is no cost to join the Share Card™ program. Register on-line or call the toll-free hotline to request an enrollment kit. The Web site provides a list of medications covered by the program as well as information on 16 different health topics.

For More Information

Prescription Drug Assistance Programs
www.Medicare.gov

Together Rx Card
www.Together-Rx.com
800.865.7211

Pfizer for Living Share Card™
www.Pfizerforliving.com
800.717.6005

around the association

Association Welcomes New CEO

In December, the Alzheimer's Association welcomed Sheldon Goldberg, 55, as president and CEO of the national organization. Goldberg brings a frontline perspective rooted in more than 30 years experience managing and representing the interests of not-for-profit health care associations and long-term care organizations. He most recently was president and CEO of Jewish Home and Hospital in New York City, one of the nation's oldest and largest long-term-care health systems. Prior to that, he spent 16 years as head of the American Association of Homes and Services for the Aging which, under his leadership, grew from a membership of 1,200 to 6,000 organizations.

Many Voices to Advocate for Research Funding

Join the Alzheimer's Association for its 15th Annual Public Policy Forum March 29–April 1, 2003, in Washington, D.C. This year's theme, "Many Voices, One Message," speaks to the rich diversity of people involved in the Alzheimer advocacy movement. The Forum brings people together from across the country to deliver a common message to Congress—immediate action must be taken to assure affordable quality care and services for those living with the disease. The goal is a commitment of $1 billion to support research funding.

For More Information www.alz.org/publicpolicy2003 or call 202.393.7737

Association Sponsors Regional Education Conferences

Local chapters of the Alzheimer's Association are offering several educational opportunities to health care professionals in spring 2003.

Southeastern Wisconsin Chapter—8th Annual Conference on Alzheimer's Disease and Related Disorders, March 11–12, 2003, Milwaukee, Wisconsin

- Keynote address on diversity in the workplace
- Sessions include training in issues of diversity and caregiving

For More Information www.alzheimers-sewi.org or call 414.479.8800

Western and Central Washington State Chapter—18th Annual Education Conference, May 20, 2003, Seattle, Washington

- Keynote address on the experience of living with Alzheimer's
- Sessions include research developments in Alzheimer's, communication and behavior challenges, and panel discussions with people affected by early-stage Alzheimer's

For More Information www.alzwa.org or call 800.848.7097

in the news

Heston has Alzheimer's

Charlton Heston, 77, announced during a televised news conference that his doctors have told him he is "suffering symptoms consistent with Alzheimer's disease." In a videotaped statement played for reporters, the actor said, "For now, I'm not changing anything. If you see a little less spring in my step, if your name fails to leap to my lips, you'll know why."

Nancy Reagan: Memories

Former first lady Nancy Reagan said in a televised interview in September that the worst part of former President Ronald Reagan's Alzheimer's disease is that "there's nobody to exchange memories with." Nancy Reagan spoke with Mike Wallace on *60 Minutes II* about her life, past and present, with former President Reagan, now 91 and in the advanced stages of Alzheimer's.

Early-Onset Alzheimer's Brings Special Challenges

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Lockhart receives needed support by hosting daily chat sessions through Dementia Advocacy and Support Network (DASN) International, an on-line network founded and administered by people with dementia. "Some days are really difficult," says Lockhart, "especially when you wake up with a cloudy head and think, 'This is it.' Then the next day or two, your head is clear, and you try to remember that when a day like that comes, you just have to hope you get another one tomorrow."

Early-onset Alzheimer's accounts for approximately 10 percent of diagnosed cases, affecting an estimated 400,000 people in the United States. The basic issues surrounding Alzheimer's are compounded by an early-onset diagnosis, causing life transitions associated with the disease to arrive too soon. Financial challenges include the loss of income and insurance coverage, the possibility that a spouse must get another job or increase work hours to support the family, and the delay in eligibility for Medicare and other disability benefits. There are also added expenses for doctor visits, treatment, and care.

The emotional toll is even more burdensome. In addition to the frustration individuals experience when others don't understand what they're going through, there is often a sense of dread and uncertainty about what the future holds for them and their loved ones. People with early-onset Alzheimer's experience guilt about turning loved ones into caregivers and fear robbing children of their childhood because they often start watching over and protecting Mom or Dad. Self-esteem is affected because of the loss of mental capacity, job, or status in the community.

Information and understanding are essential to managing the disease and its effects. The Alzheimer's Association and its chapter network are committed to offering support for the early-onset community. Support groups provide valuable information and vital interaction, and the Association has over 20 related groups for people with early-onset Alzheimer's and their caregivers.

Elaine Silverio, coordinator of early-stage programs for the Association's Massachusetts Chapter, has facilitated an early-onset group for 10 years and finds early-onset individuals benefit greatly from this type of counseling. "People diagnosed with early-onset Alzheimer's are comfortable talking about their feelings and issues," says Silverio. "A support group offers them a safe place to be. They feel more in control of their disease by talking about it. Education empowers them."

Chip Gerber and his wife, Sharon, attended Association early-onset groups while living in the Cleveland area; since moving to Florida this year, they participate in a monthly gathering through the Central and North Florida Chapter. "The support groups have been indispensable for us," Gerber says. "We attend together, and have learned so much about the disease and its stages to help manage expectations, limitations, and priorities. I've met many friends who are going through the same experiences."

Patricia Hunter, MSW, family services director of the Western and Central Washington State Chapter, also believes in the importance of early-onset care partners participating in group support. For the past six years, Hunter has facilitated a caregiver-only group that helps family members understand they are not alone in their frustrations and challenges.

"Younger people with Alzheimer's and their families have special information and support needs," she says. "The level of support and mutual sharing that occurs within this group is fabulous. There is resource sharing, problem solving, emotional support, and friendship."

For More Information

Early-onset resource list through the
Benjamin B. Green-Field National
Alzheimer's Library and Resource Center
www.alz.org

DASN International
www.Dasninternational.org

Rita Hayworth Gala Raises Over $1 Million for Research

The Waldorf Astoria's Grand Ballroom in New York City was the setting for the Alzheimer's Association's annual Rita Hayworth Gala, which raised $1.3 million toward Alzheimer research. Princess Yasmin Aga Khan founded the gala 17 years ago in memory of her mother, actress Rita Hayworth, who died of Alzheimer's disease in 1987.

The gala theme was "The Lady from Shanghai," named for Hayworth's 1948 film with Orson Welles. Honored at the event was Margo Catsimatidis, founder of MCV Advertising Associates and co-publisher of the *Hellenic Times* newspaper. Over the past 10 years, she has been instrumental in the gala's success.

In between the evening's dinner and dancing, the Allman Brothers Band gave a special performance. Butch Trucks, the band's lead drummer, was presented with a special Caregiver Award. He and his father cared for Butch's mother, who died with Alzheimer's in early 2002.

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Advances Newsletter
Vol. 22 No. 4 Winter 2003

Advances is made possible in part through a grant from
MetLife Foundation
Working Toward an Alzheimer's Cure