



Dementia: The Disease and New Hope For Treatment, Part I. by Diane Walker, R.N., M.S.

Dementia is a general category of brain disorders that can affect a person's ability to think, speak, reason, remember and move (1). The diagnosis and its manifestations have a profound impact on millions of adults and their family members every day. This article will present a general overview of the diagnosis and will be available to you in two installments. The second installment will appear in our Fall 2004 Edition and will focus on care giving strategies and available resources.

Overview - More than four million older Americans been diagnosed with some stage of dementia. Although much of the literature has focused on Alzheimer's disease, which accounts for approximately 50% of dementia diagnoses, there are other causes, some of which are much more treatable than Alzheimer's.

Dementia usually develops in adults sixty-five (65) years or older, affecting about 10% of older adults. The number of individuals affected increases to about 50% of adults 85 years of age or older. The number of people affected by dementia is rising as the general population ages, and estimates are the number will quadruple by 2050. (1,2). Chronic, untreatable forms of dementia progress through a series of stages characteristically described as mild to severe with increasing loss of function. The progression may take from three to twenty years depending on the form of the illness.

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You Can Count On the National MS Society for Help and Hope by Peter Kennedy

For more than 50 years, the National MS Society has provided help and hope to those with multiple sclerosis across the nation: help through its client programs which make daily life better for people with MS and their families, and hope through our promising national and international research programs.

The National MS Society has long been the leading provider of programs for people with MS, their family and friends. Through its network of 83 local chapters, it provides a wide variety of free services including: resources and information, living assistance, equipment loans, educational programs such as seminars, online and teleconference learning; employment counseling, and symptom management sessions and information. The Society also focuses

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Looming Crisis As Elders Give Up The Wheel by Diane Walker

Is there anyone who doesn't remember the rush they felt slipping behind the wheel of a car and stepping on the gas for the first time? Well, *giving up* the right to drive is attracting more attention these days as increasing numbers of drivers on the road are over 65. Attention now focuses on: the how the aging process makes older drivers less safe; warning signs; safety tips and how to talk with aging parents about giving up their keys. This is happening because drivers over 70 have a higher rate of fatality and many states now

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Jean Griswold Invited to Mentor and Inspire

By Dot Folz, Ed.M

Despite her pressing duties as Founder, CEO, as well as Director of the Chestnut Hill, PA office, when Jean Griswold was asked to share with entrepreneurs of the future and to contribute to a national project on ethics in America, she welcomed the invitations with her usual aplomb.

The mentoring took place at the Wharton School of the University of Pennsylvania. As an Entrepreneur in Residence, Jean Griswold joined nine other entrepreneurs who represented the full range of industries and life experiences in lecturing and providing consultation to the students. "Regardless of their direction, service or product, all of the students shared the courage to take a risk and launch their own business," she commented. "Sharing the story of how one tragic event became the galvanizing factor for beginning *GRISWOLD SPECIAL CARE* seized the attention of each new entrepreneur, and opened the door for the aspiring entrepreneurs to share their dreams aloud. An entrepreneur must have a dream and a passion for doing something about that dream – then they must act." Jean Griswold has been re-appointed and will continue mentoring in the fall.

On the heels of her appointment to Wharton, Jean Griswold was invited to contribute to the book, *Dream Again America*. The book originated with the nationwide project, *The Content of Our Character* founded in 1998 at Duke University's Kenan Institute for Ethics. It will incorporate hope and vision for future leaders.

Jean Griswold, who was nominated as an exemplar of ethical leadership, has been asked to not only share the story of the amazing evolution of the delivery of needed homecare services from her dining room table to a multi-million company but also to compose a letter of inspiration for generations to come.

About the project, Jean Griswold said "Contributing to a publication that will encourage and inspire ethical leadership in future generations is an awesome responsibility. However, because I have lived it, it is easier to articulate. Have a dream. Work hard to achieve it. Put people ahead of profit, and service ahead of success. Therein lies great satisfaction." The book is set for release in Spring 2004.



Veronica Willard Appointed Arthritis Foundation Board Member

By Dot Folz, Ed.M

Ms. Veronica Willard, National Quality Assurance Manager for *GRISWOLD SPECIAL CARE*, has been named to the Board of Directors of the Eastern Pennsylvania Chapter of the Arthritis Foundation. The Chapter serves over 20 counties, including the five-county Philadelphia area, making the public knowledgeable about arthritis and the importance of appropriate treatment, and by helping people take



personal control of their arthritis through self-help classes, warm water and land exercise programs and support and education groups. The Board's mandates are numerous, including: to develop programs designed to provide better diagnosis and treatment for persons in the area who are

suffering with arthritis and other rheumatic diseases, to help integrate programs of investigation within our area, and to assist local fund raising efforts.

In speaking of the appointment, Ms. Willard commented "The Board is comprised of forward-thinking, talented, and committed individuals. In my position at *GRISWOLD SPECIAL CARE*, I observe first hand our work with many agencies and organizations that assist persons with disabilities including the devastating effects of arthritis. As a family caregiver myself, I understand the importance of support received from organizations such as the Arthritis Foundation. I look forward to lending my personal time and services to the Eastern PA Chapter of the Arthritis Foundation as they touch the lives of so many persons in our region". Ms. Willard has a bachelor's degree from Harvard University, and has completed post-graduate work at The University of Pennsylvania.

The Message Heard Around the World by Lori Griswold, Ph.D., M.S.G., Executive Vice President

MS Society *continued*

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on wellness and fitness programming, family services and events, leadership training and peer support. Nationally and locally, the organization is a leader in advocacy efforts focusing on legislative issues from research funding to voter rights.

The National MS Society is also known for its support of scientific studies into the cause, prevention and cure of MS, and spends more money on MS research than any other voluntary health organization in the world, totaling \$410 million since its founding in 1946. This investment is yielding significant advances in treating MS and in diagnosis, rehabilitation and symptomatic therapies.

All efforts are funded through a variety of special events including the MS Walk, the MS 150 Bike Tours, Women Against MS (WAMS), Leadership Class efforts as well as other initiatives.

For more information about the National MS Society, please call 1-800-FIGHT MS or visit www.nationalmssociety.org.

Looming Crisis *continued*

require age related screening after age 65. **Not enough attention**, however, has focused on the isolation, loss of independence and depression caused by the inability to drive. 7 million adults do not drive *today*—that number will reach 19 million by 2050.⁽¹⁾ Elders do not/are unable to use alternative public transportation services that usually are inadequate at best, particularly in suburban and rural communities where the elderly prefer to live. Family and friends may not be regularly available; the individual may not want to burden them or be too embarrassed to have to ask for help. The federal budget for transportation expires this year. Please contact your representatives to increase the funding authorized to private organizations to provide community-based transportation and accompaniment services like those offered by *GRISWOLD SPECIAL CARE*.

1. Larry Lipman. Crisis Expected As Seniors Give Up Wheel. Palm Beach Post. 2004.

GRISWOLD SPECIAL CARE is excited and encouraged to see the increased attention given to home and community based services. For many years, *GRISWOLD SPECIAL CARE* has worked nationally and locally to help consumers be heard who want to stay home instead of move into a facility. The message has been translated into some very exciting research and demonstration projects designed to enhance current state long-term care systems so that consumers can access home and community based services and also have more control over the services provided. We thought you might like to know about some of the federally funded grant initiatives designed to improve the current long-term care system by embracing home and community based services and consumer choice.

Since 2001, The Centers for Medicare and Medicaid (CMS) have funded over \$125 million to 48 states, 2 territories and Washington, D.C. A number of different research and demonstration grants are based on The New Freedom Initiative to “remove barriers to community living for people of all ages with disabilities and long-term illnesses.” Some of the grant categories include “Real Choice Systems Change Grants,” “Aging and Disability Resource Centers,” “Demonstration to Improve the Direct Service Community Workforce” and others. Please note that each state has different grants awarded based on their submissions and approvals. A few of the grants under the Real Choice Systems Change Grants include: 1) Money Follows the Person, 2) Independence plus Initiative, 3) Community Integrated Personal Assistance Services and Supports and more. As these titles reflect, the projects are taking a serious look at the current systems and how better to involve the consumer and his/her choices for services. Topics getting increasingly more exposure are consumer direction (increasing consumer involvement in services) and awareness to nursing home alternatives. For more information or to see what federally funded programs might be underway in your state or region please visit the CMS web-site at: www.cms.hhs.gov. You may also want to contact your state offices on aging, health or disabilities if you are interested in other possible initiatives that your state is pursuing in the areas of home and community based care and consumer choice. It is clear that the current demand for home and community based care and consumer choice will pale in comparison to what it will be like when the baby-boom population begins to need services. Since its inception in 1982, *GRISWOLD SPECIAL CARE* has had a consumer driven model of care and we are delighted to see initiatives that further include the consumer and his/her choice for home and community based services and look forward to “real choice systems change” within many states in the very near future. As always, *GRISWOLD SPECIAL CARE* continues to work on legislative and advocacy efforts on behalf of Clients and Caregivers. Please let us know if you have a message that you want to be heard. Please contact Dr. Lori R. Griswold at the Corporate Headquarters if you would like more information (1-888-777-7630 or e-mail: lori@griswoldspecialcare.com).

The Progression of Dementia *continued*

Dementia can have devastating financial ramifications for the affected person, for the nineteen million family members customarily providing most of the care, and for the society that loses the formerly contributing members now caring for someone with the diagnosis. Alzheimer's Disease alone costs the US approximately \$100 billion per year for care and treatment and costs businesses \$33 billion a year in lost worker productivity and benefit expenses. (2) It is estimated that the lifetime cost per person with Alzheimer's disease is \$174,000.

Causes & Potential Risk Factors - The cause(s) of dementia are not yet well known and the rate of progression varies with the type the individual manifests. We do know that a healthy brain has about 100 billion nerve cells that generate electrical signals. These signals are relayed from nerve cell to nerve cell. Chemicals called neurotransmitters help the signals move easily between the nerve cells. The transmission of electric impulses results in our ability to think, remember and feel. (3) Persons with dementia develop an inability to transmit electrical signals between nerve cells over time and the number of functioning nerve cells progressively diminishes.

The three most common types of dementia are Alzheimer's disease (AD), Lewy body dementia and vascular dementia. In AD the nerve cells in certain locations of the brain actually begin to die over time. The amount of neurotransmitters produced by fewer nerve cells is subsequently diminished and progressive symptoms of brain malfunction develop. The brain tissue of adults with AD contains abnormal clumps and irregular knots of cells called plaques and tangles. It is believed that deposits of plaque form between the nerve cells and cause them to die. Research is being conducted to determine if genetic mutations of certain proteins in the brain cause the development of these plaques and tangles. Profound inflammation has also been found in the brain tissue of some individuals with AD, but the role this plays in the disease is unknown. (1) Lewy body dementia is characterized by microscopic protein deposits found in deteriorating nerve cells. If the deposits in the brain are widespread, the individual manifests the signs and symptoms of AD over time and may also have hallucinations and significant fluctuations in alertness. (1) Vascular dementia results from either extensive narrowing of the arteries that supply blood to the brain or from multiple small blockages of blood to areas of the brain caused by clots and called "mini-strokes". In this form of

dementia, the appearance of symptoms can be either very abrupt or mimic the slow progression found in AD. (1)

Other forms of dementia can result from Parkinson's or Huntington's disease, head trauma, endocrine disorders, the long-term effects of alcohol, cardiovascular disease, nutritional deficiencies, immunologic disorders and other degenerative diseases. Some of these causes are treatable and may even be cured, such as hydrocephalus, certain brain tumors and infections of the brain like encephalitis, meningitis, HIV/AIDS and syphilis. (1)

The risk factors for AD, in particular, may include age, heredity, environment, level of mental activity, head injury, certain hormone replacement therapies, high blood pressure and high cholesterol. Women are more at risk for developing the disease because they live longer than men. There is a slightly higher risk of developing AD if a parent, sister or brother has the disease. Some studies suggest that higher education and remaining mentally active throughout life, especially later in life, may reduce the risk of developing AD. Women using a combination of estrogen and progesterone replacement therapies appear to double their risk of developing AD. (3)

Certain disorders like delirium and depression may mimic the symptoms of dementia but are treatable. (1) Depression can occur independently and may manifest many of the same symptoms as early dementia. Depression also sometimes accompanies the early stages of dementia when the individual realizes the severity and prognosis of the condition. Delirium, unlike dementia, results in a severe but short-term state of confusion and can be associated with fevers and drug reactions.

Screening and Diagnosis - One of the foremost impediments to getting early treatment for Alzheimer's disease is the assumption that forgetfulness is a normal part of the aging process. Spouses, children and friends who observe the following early warning signs of AD need to encourage the person to be screened and evaluated by a clinician: recent memory loss that affects job skills; difficulty performing familiar tasks (cooking, laundry, changing bed linens); problems with language (forgets common phrases or simple words in conversation); disorientation to time and place (forgets the way home); poor or decreased judgment; problems with abstract thinking (how to balance a checkbook); misplacing things; changes in mood or behavior (rapid

Why Use An Agency Anyway?

It was another busy morning: checking references, criminal background checks, taking calls from Clients. I was happy to see Carol when she walked into the office. As she handed me updates of her homemaker certification and fitness to work forms, it occurred to me to ask her about something which had been puzzling me recently. “Why do you work through us, Carol?” I asked. “Wouldn’t it be easier to find private clients yourself through the newspaper and not have to do things like meet our requirements and bring me your updated forms?” She smiled and asked me if I was trying to do myself out of a job. I said, “No, I’m just trying to understand why a person wouldn’t want to have a worker referred by an agency. There are things about it that just don’t make sense to me.” Carol nodded, “Oh, I’ve tried it a few times off and on. I don’t like it. I’m uncomfortable being on my own walking up to a house nobody but me has ever been to. There’s nobody for me to call if something goes wrong, or I get lost, or I’m sick. And I really like that the clients just automatically trust me.” “Well the trust thing is really more about who you are and how you present yourself, don’t you think, Carol?” She smiled again. “That’s nice of you to say and yes, I suppose some of it *is* me, but that’s part of why *GRISWOLD SPECIAL CARE* refers me isn’t it? Because I’m nice?” That made *me* smile. She continued, “No, what I mean is that they trust me because I’m with this office, I’m not just out there alone with no one watching over the clients. Folks know *GRISWOLD SPECIAL CARE* and recommend you. It’s like recommending me too. I have the *GRISWOLD SPECIAL CARE* name badge on so they trust me. I’m part of something important. That feels good. What parts don’t you understand?” “Well, I never understood why a client or family would risk having some stranger off the street answer their newspaper ad. How do they do all the work of checking references and criminal background checks and employment authorization documents? I wonder what they do when the person they hire no-shows or goes on vacation. What happens when there’s a problem with the person they hire, what can they do then? There’s no one to call for

help. The money they *think* they save on office fees they lose to unreliability and domestic employee taxes that they don’t risk when the worker referred by a reputable agency. *I worry* about workers who don’t want anyone checking up on their services or how things are going – why don’t those workers *want* to be with an agency? You know, like you, reliable and backed up and trustworthy.” Now we *both* smiled. “You just answered some of your own questions, now didn’t you?” Carol laughed. “Yes, I guess I did!” I finished her file updates, reminded her about the workshop coming up and told her I’d be out to see her and Mrs. Cleary next month. I thanked her for being reliable about getting her updates in to us and for being so good with Mrs. Cleary. As she left I realized that I did, after all, understand *exactly* why Carol was with us and why Mrs. Cleary was as well.

This account of an exchange between a GRISWOLD SPECIAL CARE case coordinator and Caregiver is partially fictionalized to protect the privacy of the persons involved.

Dementia *continued*

mood swings); changes in personality (suspicious or fearful), and loss of initiative [Adapted from the Alzheimer’s Association]. The signs and symptoms of the progression of dementia have been grouped into three generally accepted stages: **Mild**; memory loss, language problems, mood swings, diminished judgment and personality changes. **Moderate**; behavioral and personality changes, noticeably diminished capability in demanding situations, long-term memory affected, wandering, agitation, aggression, confusion and progressive loss of functional ability to self complete Activities of Daily Living (ADLs) and **Severe**; gait and motor disturbances, incontinence, and inability to perform ADLs. (4)

Several studies to rule out other diseases and conditions that can also cause these symptoms include: a thorough medical

history, basic medical tests, a mental status examination, neuropsychologic testing, and brain scans. These tests help rule out other organic illnesses which can cause or contribute to the symptoms being exhibited. (*See below*)

1. Mayo Clinic Staff. Dementia: It’s Not Always Alzheimer’s. Mayo Foundation for Medical Education and Research. 2003.
2. Patients and Caregivers: Alzheimer’s and Related Dementias Fact Sheet. American Assoc. for Geriatric Psychiatry. 2002.
3. Mayo Clinic Staff. Alzheimer’s Disease. Mayo Foundation for Medical Education and Research. 2003
4. Gonzalez, E. W. Caring for patients with dementia. Presented at Arden Courts, King of Prussia, PA. 2003.

Treatment for dementia and resource options are presented in the continuation of this article at our website www.griswoldspecialcare.com. You can also contact your local office to obtain a reprint of the article.

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Our website (www.griswoldspecialcare.com) includes a resource center that is designed to help make it easier for you to provide and arrange for care in the home. At this site, you will have access to past newsletter articles and other topics. Check the website regularly for the latest information. Here are some of the helpful features that are currently posted:

- ◆ A brochure to prevent falls at home
- ◆ The Caregivers Marketplace
- ◆ Just beginning to care for a loved one? Visit *Best Start* for tips
- ◆ Know someone *very special* who may to be a *GRISWOLD SPECIAL CARE* Caregiver? Visit *Caregiving* for more information.

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