The Caregiver

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Duke Family Support Program

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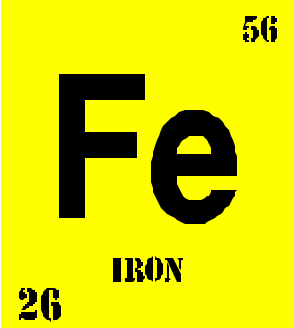
Alzheimer's Association ***Western Carolina Chapter*** 3 Louisiana Avenue Asheville, NC 28806 828-254-7363 800-522-2451 **http://www.alz.org/wnc**	**For Outside North Carolina:** ***National Alzheimer's Association*** 919 N. Michigan Avenue, Ste 1000 Chicago, IL 60611-1676 312-335-8700 800-272-3900 http://www.alz.org

NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS

Eastern NC Alzheimer's Association – Community Workshops (for families, volunteers and clergy) April 19th – Dare Co., June 7th-Craven Co.; Facility Training – 2 Day workshop (for professional caregivers) April 23rd, May 14th, October 15th, November 5th. Activity coordinator training – June 28th, August 2nd, September 12th, October, 18th; Bowlathon: Saturday, May 11th; Memory Walk – Saturday, October 5th, Annual Education Conference – November 7 - 8.

Western Carolina Chapter Alzheimer's Association – Early Stage Support Group – September 2002, a program that runs for 6 consecutive weeks in Charlotte. It is intended for the person with dementia and his or her caregiver. Prescreening required. April 25 – Understanding Behavior: Rockingham; April 30th Education conference featuring P. Murali Doraiswamy, M.D. of Duke, Charlotte: Beginning to Cope free classes for new family caregivers offered monthly in Asheville, Hendersonville, Hickory, Lenoir, Spindale and Taylorsville.

RESEARCH UPDATE



IRON OVERLOAD: GENETIC AND ENVIRONMENTAL FACTORS IN ALZHEIMER'S DISEASE

Donald E. Schmechel, M.D.--Professor and Director
Joseph and Kathleen Bryan Alzheimer's Disease Research Center
Duke University Medical Center

The occurrence of Alzheimer's disease (AD) in a family member, friend, or oneself is often accompanied by the question – why did this happen to me at this age? The answer, as it is for many age-related chronic diseases, *eventually* will be precise and knowable combinations of genetic risk factors and environmental conditions that develop over years to decades.

A new genetic factor for AD is the iron overload gene, called the hemochromatosis or Hfe gene. [Sampietro et al., "The Hemochromatosis Gene Affects the age of Onset of Sporadic Alzheimer's disease." Neurobiology of Aging 22(4):563-8, 2001.] The Hfe gene is named for the pathological changes of increased iron stores in the liver and other tissues. If an individual has a double dose, that is, one from each parent, of this normal variant (gene), it sometimes causes a disease known as hemochromatosis or "bronzed diabetes."

The Hfe gene clearly interacts with environmental factors such as the amount of dietary iron intake, liver injury such as hepatitis and alcoholism, and, although more rarely, blood transfusions. The Hfe gene's *proposed* relationship to the risk of developing AD is new.

To consider this newcomer, it is useful to remember the presently known genetic landscape. Studies at Duke in 1993, which have now been confirmed elsewhere, demonstrated that normal genetic variants or alleles of a common cholesterol transport gene, apolipoprotein E (APOE), altered the *average* age of onset for AD when *large* groups of individuals were analyzed. The higher risk allele, APOE*4*, is present in double copy in roughly 2% of people and in single copy in roughly 20-30% of people. Most people (60%) have double copies of the neutral variant APOE*3*. Few persons have the "super" genetic profile of one copy each of APOE*2* and APOE*3*. To put this in context, for each of the many thousands of human genes, one copy or version of each gene is inherited from each parent for a total of two copies per gene.

The APOE gene is potentially "silent." However, when the APOE gene is combined with other genetic susceptibility genes or environmental factors, the combination results in ***earlier*** age of onset of AD (10 years earlier per each inherited APOE*4* allele). Demonstrated environmental factors that strongly interact with APOE are head injury and cardiac surgery (CABG). Other environmental factors that *increase* the risk of AD in humans and mouse models include high dietary fat and cholesterol, and early menopause in women. Other factors that may *decrease* the risk of AD are the use of non-steroidal anti-inflammatory drugs (NSAIDs), a common treatment for arthritis, and the use of hormone replacement therapy in women. The interaction of these environmental factors with APOE is less clear.

It is important to understand that APOE is a "risk" or susceptibility gene. The presence of the APOE*4* gene does not mean that a person will develop AD. Therefore, testing for one's APOE genetic status is not recommended in persons with no symptoms of AD. The reason is clear. It is possible to have one or two APOE*4* alleles and *never* develop AD.

APOE risk factors are important beyond their use as individual predictors of disease risk. The overall genetic and environmental risk of AD is extremely high in industrialized countries. This overall risk should encourage certain personal decisions about the use of alcohol, tobacco, dietary choices, and control of adverse medical or emotional factors that may increase the likelihood of adverse aging of the heart, lungs, and brain.

There is a variant or mutation of the Hfe (iron overload) gene identified as C282Y. Studies have now demonstrated an apparent earlier onset of AD (5 years on *average*) for the many persons carrying the C282Y gene. This age of onset effect compares to an apparent *average* effect of 10 years per APOE*4* allele for acceleration of AD onset for the many persons carrying APOE*4* alleles. The Hfe gene frequency is two times more common in Western Europeans than in Africans, African Americans, or Asians. Roughly 10% of people carry a single variant copy of the Hfe gene (C282Y 'mutation') and roughly 0.5% carry the double copy.

Another even more common "milder" variant of the Hfe gene, H63D, is carried by 20-30% of people and is now under study. Similar studies in humans and animals are being carried out at the Bryan Alzheimer's Disease Research Center (Bryan ADRC) at Duke to analyze the effects of Hfe gene variants, dietary iron overload, and reduction of iron stores on AD. The Bryan ADRC is currently studying several patients with double Hfe copies on iron depletion through phlebotomy. Phlebotomy is equivalent to regularly donating blood. Patients are counseled to reduce dietary iron intake as part of an attempt to convert to a heart-wise, low saturated fat /cholesterol diet.

Most American diets are over-charged in saturated fat and iron content. However, it is important to note that dietary iron or supplements may be necessary at times (Even an Hfe C282Y carrier can become iron deficient.). The relative risk of men and women may be different. A higher use of iron supplements and higher rate of iron loss during reproductive years may affect a woman's risk.

Iron excretion is limited at 1-2 mg/day through the intestine. This means that any genetic/environmental factor increasing iron intake (like the Hfe 282Y variant) will result in increased iron stores. This is particularly true given the high amount of available and added iron in Western diets (usually 10-20 mg/day). The normal intestine only absorbs what it needs based on current "sensed" iron stores of the body. Excess iron in tissue is proposed to cause injury to the liver, pancreas, heart, and possibly the brain. This higher injury rate may be related to the high reactivity of iron and oxygen (oxidative stress).

The current theme for AD research is that specific, fairly common variants of two very basic genes that influence fat metabolism (APOE gene) and iron metabolism (Hfe gene) influence susceptibility to AD. The effect of APOE*4* is strong (10 years average earlier onset) and the proposed effect of the Hfe C282Y hemochromatosis allele is respectable (5 years average earlier onset). Both genes are undoubtedly environmentally modulated – APOE*4* by previous brain injury and possibly long-term dietary fat and Hfe C282Y by liver injury such as hepatitis and by long-term dietary iron intake. Even persons with double copies (homozygotes) of these variant genes are usually clinically "silent" or symptom-free during most of their lives. It is highly likely that even the "bad" variants, APOE*4* and C282Y, confer some selective advantage to humans in adverse or harsh dietary conditions during development of the brain (APOE*4*) or low iron intake (C282Y and H63D variants of Hfe).

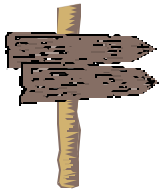
Our current long life spans and surplus of dietary fat and iron may now expose us to new environmental conditions for which our genetic background is not suited. It remains to be demonstrated whether persons with these "special" variants need ***long-term dietary modulation*** (like low iron for Hfe variants), ***intermittent protection during periods of environmental stress*** (such as after head injury or CABG operation for APOE), or ***specific long-term medications***.

The good news is that the Hfe gene is a well-studied gene with potential control through diet or phlebotomy. Also, the Hfe gene is well understood compared to the complex APOE*4* gene whose effects and remediation are still under study. New studies are examining the relationship of APOE and Hfe together and the exact "signature" of the subset of AD persons with iron overload. The aim of these new studies is to formulate evidence-based recommendations for diagnosis and treatment. Eventually, specific recommendations will be based on precise knowledge of personal genetic risk, environmental history and exposures.

The 17th Annual
Joseph and Kathleen Bryan
Alzheimer's Disease Research Conference

February 13-14, 2003

Durham Marriott at the Civic Center



Knowledge is power,
but enthusiasm throws the switch.

To those who can dream
there is no such place as faraway.

ALZHEIMER'S 2002: WHAT'S NEW AND WHAT'S TRUE?
February 7-8, 2002

The Duke Faculty

Dr. Koltai Attix takes questions during a break.

Dr. Welsh-Bohmer offers new findings on risk and protective factors.

Dr. Schmechel takes questions during a break.

ALZHEIMER'S 2002: WHAT'S NEW AND WHAT'S TRUE?
February 7-8, 2002

The Guys and The Families" Perspectives

A daughter's perspective on her mother's mild cognitive impairment.

A moment of shared humor during "the guys" presentation.

"The guys" take a break after their presentation on living with the "related disorders."

"The guys' wives" have their own points of view.

ALZHEIMER'S 2002: WHAT'S NEW AND WHAT'S TRUE?
February 7-8, 2002

The Guest Faculty

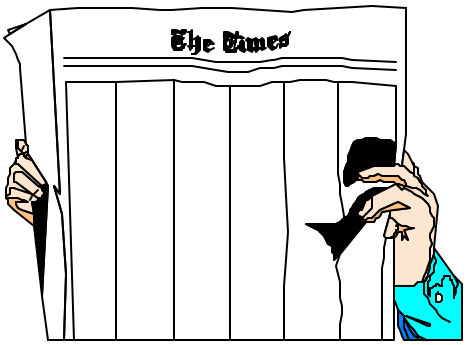
Dr. Ron Petersen of the Mayo Clinic presents new findings on mild cognitive impairment

Dr. Robert Green from Boston University addresses what participants "want" to know about genetics.

Penetrating questions for the morning panelists

Duke's Dr. Mark Newman answers questions about cognitive decline following bypass surgery.

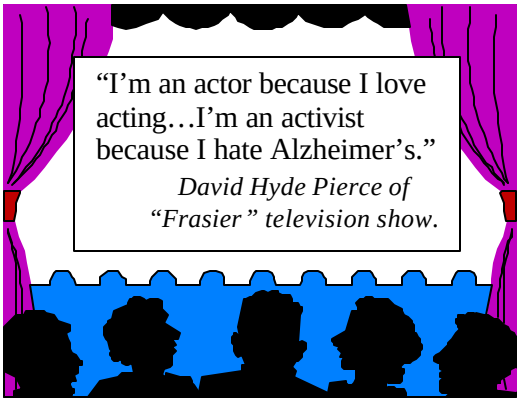
Dr. Hendrie from Indiana University points out differential risks of Africans vs. African-Americans.

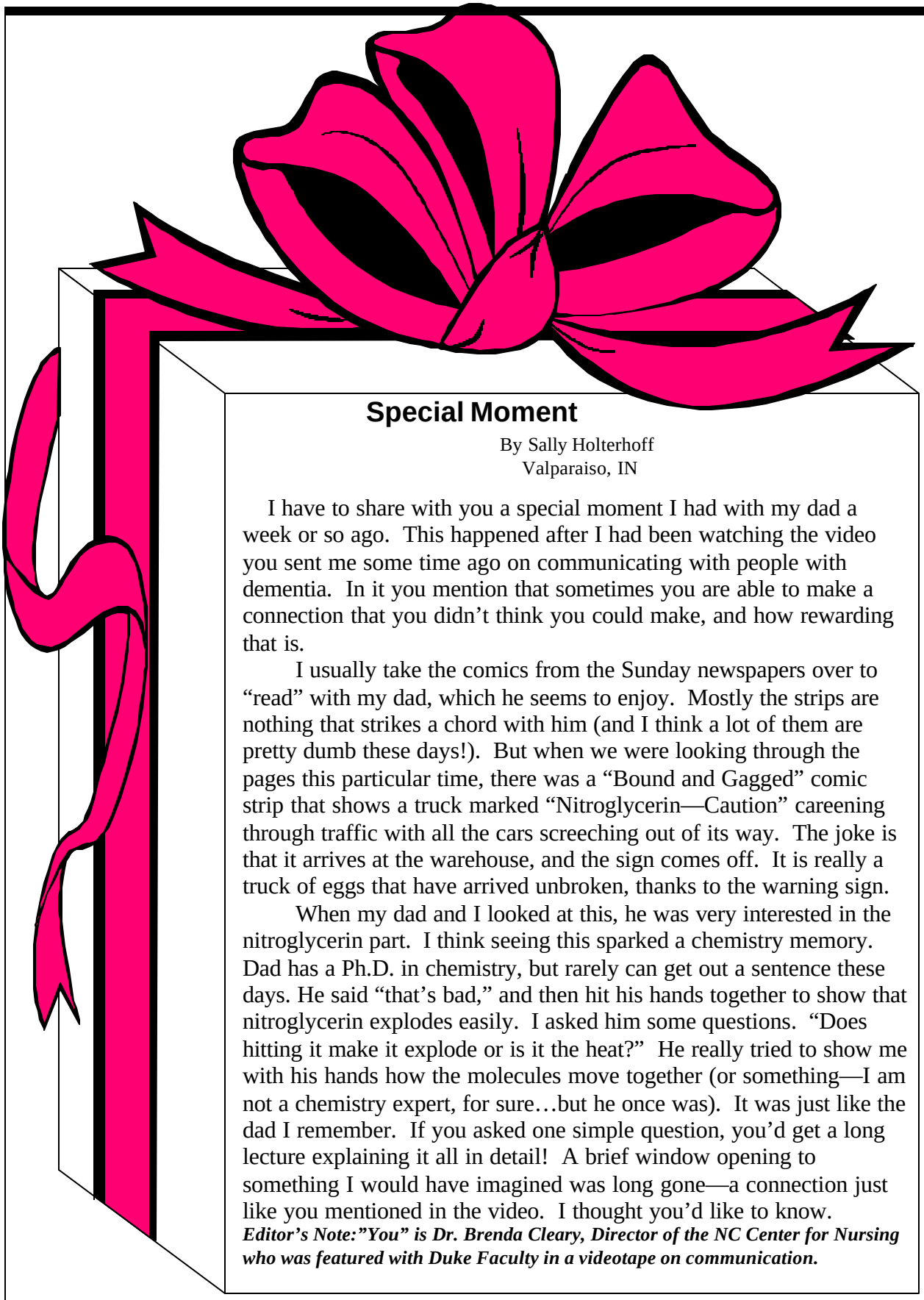


Breaking News About Medicare
From the Alzheimer's Association Medicare Advocacy Project

In a significant development, The Centers for Medicare and Medicaid Services recently issued a Program Memorandum, which prohibits the automatic denial of claims for medical services based solely on the diagnosis of dementia. A Program Memorandum provides specific rules and guidelines for the Medicare program. For years, Medicare has refused to pay for some medical services for beneficiaries with Alzheimer's disease solely because of their diagnosis. Beginning immediately, Medicare will not use the dementia diagnostic codes alone as a basis for determining whether Medicare-covered services are reasonable and necessary.

The new Program Memorandum explains that due to advances in diagnostic techniques, physicians and psychologists can diagnose individuals with certain dementias at the earliest stages of the disease. It makes clear that individuals with Alzheimer's disease may benefit from pharmacological, physical, occupational, speech and other therapies. Therefore, Medicare will cover evaluation and management visits and therapies if these therapies are reasonable and necessary for the Alzheimer's beneficiary. For example, if an individual with Alzheimer's disease has an unsteady gait and physical therapy is necessary, Medicare will pay for the individual's physical therapy. Medicare payment of medical services and procedures will be determined based on the individual assessment and needs of the Alzheimer's beneficiary, rather than denied solely because of the dementia diagnosis.





Special Moment

By Sally Holterhoff
Valparaiso, IN

I have to share with you a special moment I had with my dad a week or so ago. This happened after I had been watching the video you sent me some time ago on communicating with people with dementia. In it you mention that sometimes you are able to make a connection that you didn't think you could make, and how rewarding that is.

I usually take the comics from the Sunday newspapers over to "read" with my dad, which he seems to enjoy. Mostly the strips are nothing that strikes a chord with him (and I think a lot of them are pretty dumb these days!). But when we were looking through the pages this particular time, there was a "Bound and Gagged" comic strip that shows a truck marked "Nitroglycerin—Caution" careening through traffic with all the cars screeching out of its way. The joke is that it arrives at the warehouse, and the sign comes off. It is really a truck of eggs that have arrived unbroken, thanks to the warning sign.

When my dad and I looked at this, he was very interested in the nitroglycerin part. I think seeing this sparked a chemistry memory. Dad has a Ph.D. in chemistry, but rarely can get out a sentence these days. He said "that's bad," and then hit his hands together to show that nitroglycerin explodes easily. I asked him some questions. "Does hitting it make it explode or is it the heat?" He really tried to show me with his hands how the molecules move together (or something—I am not a chemistry expert, for sure…but he once was). It was just like the dad I remember. If you asked one simple question, you'd get a long lecture explaining it all in detail! A brief window opening to something I would have imagined was long gone—a connection just like you mentioned in the video. I thought you'd like to know.

Editor's Note:"You" is Dr. Brenda Cleary, Director of the NC Center for Nursing who was featured with Duke Faculty in a videotape on communication.

Hartman Sings

Phyllis Mayo, Chaplain
Raleigh, NC

Do you ever wonder what is going through the minds of people with Alzheimer's (AD) as their verbal communication skills are diminishing? Frequently they struggle to make us understand what they are feeling or thinking, often to the point of frustration for both patient and listener. We, as listeners, can benefit from developing our skills at "hearing" people with AD in new ways. When we listen in new ways, this adaptive communication may bring new insights and, perhaps, new joys to all involved.

My friend, Hartman, has an outgoing personality that continues even as he becomes limited in verbal communication. For many years his standard response to the greeting, "How are you today, Hartman?" has been "Fifty-fifty and holding." Most days he still responds in the same way. Failure to respond with such familiar words may be an indicator that he is not feeling well, has not rested adequately, is frustrated or worried, or is simply having "one of those days."

Hartman likes to sing. Most fascinating is his choice of two songs he sings regularly: "Happy Days Are Here Again" and "Everything Is Beautiful in its Own Way." These songs provide a window to Hartman's soul that is otherwise mostly cloudy. Songs of "happy days" and "everything beautiful" reflect a certain contentment of soul and spirit. Though he may not be able to formulate sentences that express such feelings, the words of these songs springing from deep in his memory certainly convey a sense of happiness, security, satisfaction and peace.

Ecclesiastes 3:11 says "God has made everything beautiful in its time." According to Hartman's songs, there is still beauty in life even for those living with Alzheimer's disease.

"You've gotta dance like nobody's watching and love like it's never gonna hurt!

from Judy Ewens, Raleigh, NC

When Feelings Get in the Way: Why Families Hesitate to Get the Help They Need

By Edna Ballard, MSW, ACSW
Duke Family Support Program

"There is no thought or impression untinged by emotion…every perception is screened through an emotional lens."

--*Carroll Izard, Psychologist*
University of Delaware, 1994

"I don't want to be a bother."

"I should be able to do this myself. He's my husband."

"Getting help with this feels like another irreversible step."

"Can I trust these people to appreciate what a wonderful man he was."

"It will seem to her that I am giving up on her."

"I can't stand to think what this new step will mean to her and to me."

"I have put years of my life into taking care of her. What will I do if I give up this job?"

"It's too much effort to get relief for just a short time."

"He can't protect himself. It's my responsibility to protect his image, his dignity. You would not believe some of the things he does."

"I can't afford the service and I don't qualify for anything."

"It's so frustrating just trying to get information about services that might be helpful. Everybody has a different rule, a different requirement."

"The people who talk to you are not always nice. They can make you feel stupid and behave as if they are doing you a favor. Why should I put up with that?"

A field that has rested gives a bountiful crop.
- Ovid -

"This is a Test"

Are You Successful in Managing Feelings About Asking for Help?

By Edna Ballard, MSW, ACSW

How do you know when you are successful in managing negative feelings that interfere with getting the help you need and deserve? There are many indications of success. These are a few:

When you refrain from responding in anger when your mother says, *Jackie's mother doesn't have to go to the nursing home. Jackie takes care of her mother.*

When your sister says she can't help with your father because of her job and other obligations, and you find other concrete ways she can contribute, i.e. pay for respite to give you the break that she can't. You make sure she follows through.

When you use your 'respite time' for your benefit. *I miss not having time to leisurely read for the pure pleasure of it. Now, I look forward to going to the library on Tuesdays, with three whole hours. Just getting away does wonders for me.*

When you learn from others how to respond to those minor but recurring situations that are maddening without getting angry. *Jacob got to the point that he would not change into his nightclothes when it was time to go to bed. People at the support group finally convinced me that it didn't matter, to let it be. They were right. When it was no problem for me, it was no problem!*

When you accept that caregiving is not your life—it's something you do. *Just as my wife is more than a patient, I am more than a caregiver. This helps me in thinking about how I care for her.*

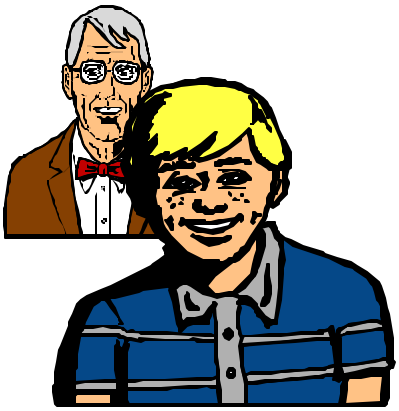
When you are able to request a different worker when the agency sends someone who is "cold and indifferent," and your wife refuses to cooperate with her.

When you realize that you can't do it all yourself, and accept that the help you get will not always be up to your standards or "way of doing things."

When you are able to laugh with and enjoy the person as she is today and resist trying to make her do things she can no longer do. *My mother finds joy in the most simple things. When I enter into her world, I find laughter and peace too.*

When you no longer get upset when others say, "She looks fine to me." *Mother puts on her "best face" and does indeed look fine to family, neighbors, and even her doctor. I smile and realize that she is doing what we all do, putting on our best face, especially when everything else is slipping away.*

Success is knowing that there is never a perfect score, that the questions change without warning, and that the answers sometimes change.



Making A Difference
By Zachary T. Byerly, 2002
(great-grandson of Richard Godwin)

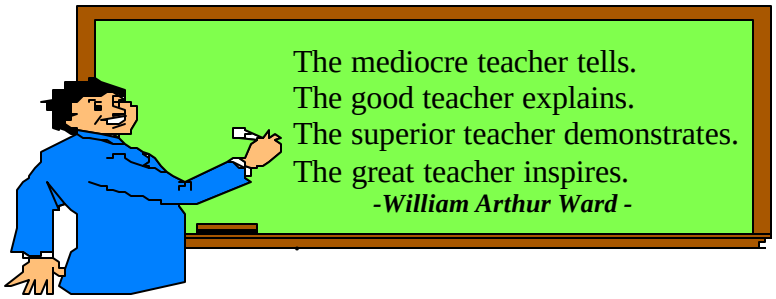
If I could do anything to make a difference in the world, I would make a cure for Alzheimer's disease. My great-grandfather has Alzheimer's. It is a disease that affects the brain. It has impacted my entire family.

My great-grandmother, grandmother, aunts and mom travel to take care of him. He has been placed in a nursing home for the last two years, and my great-grandmother has taken care of him for the past 11 years.

It is sad to see an 86-year-old man act like a two year old! Some days his brain says, "Blood sugar go high!" Three days later his heart might not beat right. In the mornings he might be able to walk some, and by 3:00pm he can't move! He sometimes acts like one of the Three Stooges. My great-grandmother still comes to the nursing home each day to dress and feed him.

I am a 7th grade student now, but I want to go to Wake Forest University someday to study medicine and gerontology. I might have to go to Duke University. The Duke Alzheimer's Clinic tested him and put my great-grandfather on a medicine that would slow the progress of Alzheimer's disease. Research and a cure could give people a better quality of life. I really want to eliminate the suffering that Alzheimer's disease causes!

Submitted by a proud grandmother,
Maxine Banther of High Point, NC



10 Ways to Help a Person Living Alone with Alzheimer's

1. Consider assisted living if the person cannot find food in the refrigerator or cannot take medicine correctly.

2. Keep groceries stocked and keep some already-prepared meals handy.

3. Alert police and fire department that the person lives alone.

4. Offer to drive, run errands, or have bills sent to your house.

5. Invite the person to dinner or to play cards (no rules) to combat cabin fever.

6. Ask neighbors to look out for the person (watch for lights on in the house or uncollected mail, call or visit frequently).

7. Offer rides to church or offer to take the person to choir practice.

8. Arrange doctor appointments and transportation for the person.

9. Perform a safety check on the house (furnace, hot water heater, wiring, smoke detectors, tripping hazards).

10. **Register the person in the Alzheimer's Association Safe Return Program.**

A Letter to Frank:

This letter was an assignment for a Grief Counseling session chaired by Roberta Wallace, LCSW. Having suffered Alzheimer's for 13 years, my husband Frank expired on July 25, 2001. I experienced grief in each stage as he progressed.

Dearest Frank,

Today is October 18th and it is gorgeous. A mixture of early Spring—blooming flowers to color the landscape, with cool nights of Fall. Another season in our lives! This morning I tried to capture the sunbeam that filtered through the trees resting on the glistening leaves. I sat at the breakfast table thanking God for His abundant blessings.

Andy walked down the driveway with me to get the daily paper lettered with war news. He is a portrait of devotion as his nose and mouth hair begin to gray adding a touch of sophistication to your namesake.

The church is sponsoring a Youth Rally for NC, SC and VA. A young family of three (from Fair Bluff) is visiting overnight with us on Friday. After Saturday breakfast, they return to the Rally.

My eye is healing from cataract surgery on October 8th, and I am so pleased. We tend to take so much for granted and eyesight is so precious.

I plan to visit Roberta Wallace and friends on Friday. I also have volunteered to be a reading assistant in Ginny's second grade at Oak Grove School. We can still learn from our precious children.

Christi called from California last night. Seems the high school scholars on the West Coast are not as dedicated to learning as those in her previous classes in Florida.

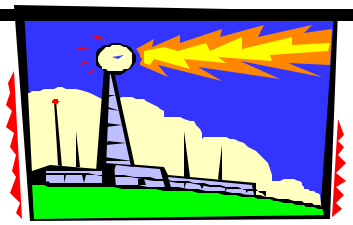
Carrie has been accepted at Bowling Green but she is considering Kent State and a couple of others. She would be near Matt at Ohio Northern University if she chose Bowling Green.

All of our loved ones seem to be doing well.

It's sleepy time for me but before I snuggle in, just know that as always, I love you unconditionally.

Ruth

Ruth Smith
Raleigh, NC



Have You Heard About?

Barrick AL, Rader J, Hoeffer B, Sloane PD. (2002) Bathing Without a Battle. Personal Care of Individuals with Dementia. Paperback (8-1/2 x 11), 162 pages, $39.95. Springer Publishing Co., Ed Schultheis, Sales Manager (212) 431-4370. Springer@springerpub.com.

Caregiver Support Kit. Aid caregivers in dealing with overwhelming responsibilities they face each day. To order a free kit call (800) 930-1357.

Carson, A. (2001). Circles of Care: How to Set Up Quality Home Care for our Elders. Boston, MA: Shambala Publications. $14.95 paperback.

Duffet, Dianne. (2001) Personal Medical Journal: Help your doctor help you. http://wwwmedicaljournalcanada.com. Toll free orders: 1-888-547-2389 or http://www.randominspirations.com.

Ellison GV and Young L. (2001) She Never Said Goodbye. www.aquariushousepress.com. Husband's account of his wife's early onset dementia.

Gwyther L, Ballard E and Pavon J. (2002) Steps to Success: Decisions about Help at Home for Alzheimer's Caregivers. Free booklets from AARP Andrus Foundation, Washington DC. Email: andrus@aarp.org or www.andrus.org. (800) 775-6776.

NEW

Hall, Geri. www.vh.org/patients/IHB/GeriatricEducation/Travel.html. 11 pages of travel tips, referencing Jan Moxley's original "Totebag and Toothbrush."

Lund DA and Wright SD. (2000). Respite Services: Enhancing the Quality of Daily Life for Caregivers and Persons with Dementia. Brochure/monograph available free from Dr. Lund in Salt Lake City, Utah. Phone (801) 581-8199, Fax (801) 581-4642 or on their website: www.nucs.utah.edu/gerontology.

NIA. (2001) Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease. NIH Pub# 01-4013. http://www.alzheimers.org/pubs/careguide.htm-19pp. Booklet (based on materials developed by Duke's Bryan Alzheimer's Disease Research Center) available to print off the web. Free single copies available from ADEAR (800) 438-4380.

Resource Directory for Older People (June 2001) Single free copies available from National Institute on Aging. (800) 222-2225 or email niainfo@jbsl.com. Lists agencies with phone, fax, email and websites.

Rhodes, LC. (2001) The Complete Idiot's Guide to Caring for Aging Parents. Indianapolis, IN: Alpha Books $16.95 paperback.

Simpson, Robert and Anne. (1999) Through the Wilderness of Alzheimer's: A Guide in Two Voices. Minneapolis, MN: Augsburg paperback. www.augsburgfortress.org. A minister living with Alzheimer's and his wife describe their differing perspectives in journal entries, conversations, letters and prayers.

Strauss, Claudia (2001). Talking to Alzheimer's: Simple Ways to Connect When You Visit with a Family Member or Friend. Oakland, CA: New Harbinger Publications. $12.95 paperback.

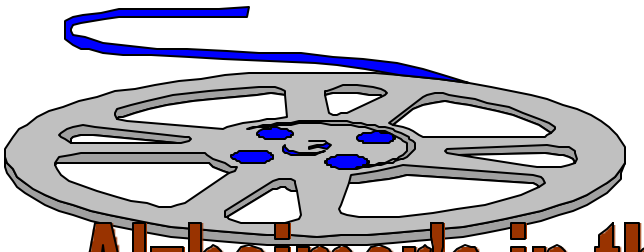
NEW

Excellent for church and volunteer respite training on communication with facility residents or persons living at home.

Zgola J and Bordillon G. (2001) Bon Appetit! The Joy of Dining in Long-Term Care. Baltimore: Health Professions Press. Paperback.

Zimmerman S, Sloane PD, Eckert JK. (2001) Assisted Living. Needs , practices and policies in residential care for the elderly. The Johns Hopkins University Press, 2715 N Charles Street, Baltimore MD 21218-4319. IBN# 0-8018-6705-3. $53.00 hardcover.

http://cancernet.nci.nih.gov. Comprehensive information about the many forms of cancer.
http://adrc.mc.duke.edu. Bryan Alzheimer's Disease Research Center.
www.forgivenessweb.com. Comprehensive forgiveness resource.
www.care-givers.com. Empowering caregivers website. See article by B. Witrogen McLeod on "Goodbye Grudge, Hello Good Health."
http://www.apdaparkinson.com. Official website of the American Parkinson Disease Association.
http://www.americanheart.org. American Heart Association. Resource for both heart disease and stroke.
http://www.arthritis.org. Arthritis Foundation. Provides information about arthritis as well as local chapter Arthritis Foundation branches.
www.stoppain.org/caregivers/index.html. Caregiver resource regarding pain management.
http://www.cancer.org/ American Cancer Society.
http://www.diabetes.org/. Official site of the American Diabetes Association.
http://www.hdsa.org/. National website for the Huntington's Disease Society of America.
http://www.nmss.org/. Web page for the National Multiple Sclerosis Society.
http://www.nof.org/. The National Osteoporosis Foundation.
http://www.stroke.org/. The National Stroke Administration.
www.aagpgpa.org. American Association of Geriatric Psychiatry. Information for both caregivers and care recipients.
www.familycareamerica.com. Familycare America. Comprehensive library of caregiving information.
www.oregoncares.org/caregiving/communication.html. Offers easy-to-understand communication tips for interactions between caregivers and physicians, caregivers and care receivers, and caregivers and family members.
www.wellspouse.org. Provides spouses of the frail elderly with a virtual support community.
www.nih.gov/nia/health/pubs/talking. (2000). *Talking with your Doctor: A Guide for Older People*. Patient-doctor communication.
www.health.harvard.edu/fhg/diagnostics.shtml. Great at explaining procedures and diagnostic tests like MRI brain scan.
www.unplannedjourney.com. Susan Miller's website. Information and support for those dealing with early onset Alzheimer's disease.
www.healthfinder.gov/. Top site on internet health information – now available in Spanish (Español).
www.hhs.gov/news/ . Health and Human Services press releases, fact sheets and other press materials.
http://www.centering.org/. Bereavement resource center.
http://pbscaregivers.org. Excellent caregiver links, outreach manual and stories to promote PBS Fall 2002 "And Thou Shalt Honor" 3 hour prime time miniseries on caregiving.
http:/www.carescout.com. A tool to find a nursing home.
http://webapps.urac.org/websiteaccreditation/portal/consumer/verify.asp. – reviews reliability of internet health information.
http://www.alzheimer.ca. See "I Have Alzheimer's Disease."



Alzheimer's in the Movies

The film *Iris* is about the life of Iris Murdoch (1919-1999), a prominent British lecturer and novelist who later suffered from Alzheimer's disease. The movie is based on the memoirs *Elegy for Iris* and *Iris and Her Friends* by Murdoch's husband, noted literary critic John Bayley. It depicts Bayley's life with Murdoch, from their first meeting at Oxford through their struggles with Murdoch's heartbreaking decline as Alzheimer's eroded one of the keenest minds in contemporary literature.

John Jager, executive director of the Alzheimer's Association's New York City Chapter, was among 400 attending the film's December 2nd premiere at the Paris Theater in New York City. He called *Iris* "the most honest cinematic depiction of Alzheimer's disease I have seen." Also in the audience were *Iris* stars Kate Winslet, Judi Dench, Hugh Bonneville, and Jim Broadbent, as well as the film's director, Richard Eyre, who told Jager that his mother had died with Alzheimer's. Jim Broadbent won the Best Supporting Actor" Oscar for his role as John Bayley. "At the conclusion of the screening there was a hush, a quiet moment before the audience broke out in appreciative applause. It was that authentic, and a beautifully crafted movie," said Jager.

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- Vincent Van Gogh -

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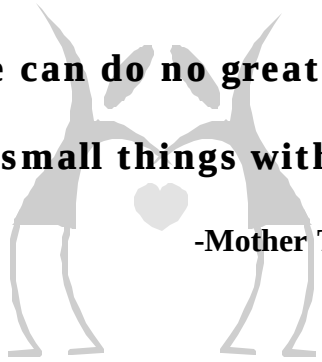

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only small things with great love."

-Mother Teresa-

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