



The Caregiver

Newsletter of the Duke Family Support Program

"We are a bridge to understanding your options"

Volume 30, Issue 2

Fall 2011

INSIDE THIS ISSUE:

Oral Hygiene Make a Difference.....	3
Welcome Bobbie.....	5
A Different Vow.....	6
Through the Eyes.....	8
Belvedere.....	9
Down Memory Lane.....	11
Have You Heard About?.....	16
New Online Help.....	17

Duke Family Support Program

Lisa Gwyther, MSW, LCSW
Bobbi Matchar, MSW, MHA
Cheryl Copeland

The Caregiver is co-sponsored by the:

**Joseph and Kathleen Bryan
Alzheimer's Disease Research
Center (ADRC)**

**Duke University Center for the
Study of Aging and
Human Development**

**Funding for this newsletter is
provided by the North Carolina
Division of Aging and
Adult Services**

**Caregiver subscriptions are available
free to N.C. residents.
Call 800-646-2028.**

**View this newsletter online at
www.dukefamilysupport.org**

Caring: The Conversation Changes

The Caregiver newsletter, in its 30th year of continuous publication, features first-person reflections on caring told with love and humor, in full acknowledgement of devastating loss. As Thanksgiving approaches, perhaps it's time to listen with gratitude to how conversations about caring might change.

- Our readers are contributing stories for a future book honoring those living with Alzheimer's and related disorders (see p. 5).
- People living with Alzheimer's are telling their own stories of caring for each other.
- Communities are thinking beyond disability access or senior-friendly, moving to become more genuinely inclusive, flexible and tolerant.
- Artists, writers and experts from all fields are joining individuals with Alzheimer's to expand opportunities for creative expression, social or civic engagement, physical exercise and intellectual stimulation regardless of level of cognitive impairment.
- New free online experiential programs, like timeslips.org, offer fresh fun ways for people living with Alzheimer's to connect and create new stories with family and friends.
- Individuals living with Alzheimer's describe quality of life and relationships, retained pleasure in beauty and moments of connection despite frustration with functional loss.
- Person and family-centered services and consumer-directed services are becoming the language of aging, disability and long-term support programs.
- There is humor, hope, faith and resilience. Affected families acknowledge that living with Alzheimer's implies grief and loss, but conversations about caring are no longer limited to burden, hopelessness and helplessness.

Let's savor moments of fun, faith and belonging as we gather this season,

Lisa

Duke Family Support Program

Box 3600 Duke University Medical Center
Durham, NC 27710
800.646.2028
919.660.7510
www.dukefamilysupport.org

National Alzheimer's Association

225 North Michigan Avenue, Suite 1700
Chicago, IL 60601-7633
312.335.8700 800.272.3900
www.alz.org

**Alzheimer's Association, Western
North Carolina Chapter**

Main Office
3800 Shamrock Drive
Charlotte, NC 28215-3220
800.272.3900 (24/7 Helpline)
www.alz.org/northcarolina
Email: infonc@alz.org

Satellite Offices:

Asheville, Cherokee, Greensboro and Hickory
800.272.3900 (24/7 Helpline)
www.alz.org/northcarolina
Email: infonc@alz.org

**Caregiver Education Conferences
800.272.3900**

Sylvia, NC, First United Methodist Church
November 14, 2011

Murphy, NC, First Baptist Church of Murphy
November 15, 2011

Arden (Asheville) NC, Biltmore Baptist
Church
November 17, 2011

**Alzheimer's Association, Eastern
North Carolina**

3737 Glenwood Avenue, Suite 100
Raleigh, NC 27612
800.272.3900 (24/7 Helpline)
www.alz.org/nc
Email: info@alz.org

Alzheimer's North Carolina, Inc.

1305 Navaho Drive, Suite 101
Raleigh, NC 27609
919.832.3732 or 800.228.8738
www.alznc.org;
Email: info@alznc.org

**Caregiver Education Conferences
800.228.8738**

Lumberton, NC, Southeastern Agricultural Ctr.
Thursday, November 17, 2011

Kill Devil Hills, NC, Ramada Plaza
Monday, January 23, 2012

Goldsboro, NC, St. Paul Church
Thursday, February 23, 2012

Oral Hygiene Makes a Difference

By Brenda L. Plassman, PhD, Professor, Department of Psychiatry and Behavioral Sciences
Bryan Alzheimer's Disease Research Center, Duke University Medical Center
and Bei Wu, PhD, Professor, School of Nursing and Global Health Institute, Duke University

There is much focus on prevention of general health problems such as hypertension and diabetes that increase as we get older. But oral health problems also increase in frequency as individuals get older and these problems are often overlooked. Oral health problems include caries (cavities), plaque on the teeth, loss of teeth, dry mouth, and periodontitis (bleeding and inflammation of the gums). Poor oral health can cause pain as well as impairment of important functions such as speaking, chewing, and swallowing. There is also growing evidence that oral health problems may be linked to other health conditions such as diabetes, cardiovascular disease and stroke. The association between oral health and diabetes may be two-way. Individuals with diabetes are at greater risk of periodontal disease, characterized by persistent swollen, red or bleeding gums. But serious periodontal disease may also affect the body's ability to control glucose and may contribute to the progression of diabetes. In addition, some research has shown that periodontal disease may also increase risk of heart attack and stroke.



One subgroup of the older adults who are at particularly high risk of having poor oral health is individuals with cognitive impairment. Individuals with advanced dementia symptoms have been shown to have poorer oral health than cognitively intact older individuals (Chalmers, Carter, & Spencer, 2003). However, there is emerging evidence that individuals with less severe cognitive impairment also have worse oral health than those with normal cognition. One study has shown that individuals with mild dementia have a higher number of missing teeth than individuals without dementia (Kim, et al., 2007). Our own work has shown that individuals with cognitive impairment, not dementia (CIND) have more plaque on their teeth than older adults with normal cognition (Wu, et al., 2011). CIND is often viewed as an intermediary state between normal cognition and dementia. Other studies have shown that poorer performance on cognitive tests is associated with higher rates of dental caries, periodontal disease, and missing teeth (Noble, et al., 2009; Wu, Plassman, Crout, & Liang, 2008). While lower cognitive scores do not always equate to cognitive impairment, these studies provide further evidence of a link between poor cognition and poor oral health.

The most straightforward explanation for the association between cognitive impairment and oral health is that oral hygiene tasks, like other daily hygiene tasks, decline as cognitive impairment becomes more severe. Oral hygiene tasks include brushing teeth, cleaning dentures, and flossing. Consistent with this explanation, preliminary results from our own research conducted in West Virginia have shown that compared to cognitively normal older adults, individuals with dementia were less likely to brush their teeth twice a day or to see a dentist twice a year (Wu, et al., 2010). To date, there have been a few small oral health intervention studies that have focused on oral hygiene behavior among individuals with moderate-severe dementia in long term care facilities. These studies have shown that training nursing assistants to regularly help residents with routine oral hygiene tasks results in striking improvement in oral health within a period of weeks to months (Frenkel, Harvey, & Newcombe, 2001; Jablonski, et al., 2011).

Research findings suggest that the decline in oral health may be present among individuals with CIND and mild dementia, not only among individuals with advanced dementia. One explanation for this is that indivi-

(continued on page 4)

Oral Hygiene Makes a Difference (continued from page 3)

duals with CIND and mild dementia brush their teeth less regularly or may be less thorough in their toothbrushing. For many daily activities, a family member may provide assistance or reminders to an individual with cognitive impairment. However, oral hygiene tasks are often neglected as part of this assistance. Yet, reminders from family members to brush their teeth and guidance on doing it thoroughly may be very beneficial in maintaining oral health among individuals with cognitive impairment. The importance of routine daily oral hygiene, such as regular and proper toothbrushing, for the prevention of plaque build-up is well established. Plaque control can lessen or prevent more significant problems such as dental caries and periodontal disease and the complications resulting from these diseases such as pain, infection, and oral functional loss. Thus, educating individuals with cognitive impairment and their family members on the importance of good oral hygiene and teaching them good oral hygiene behavior could make a major contribution to the prevention or delay of the oral health problems seen with progressive cognitive decline.

Researchers at Duke are in the planning stages of an intervention study on improving oral health among individuals with mild dementia. This study will work with both individuals with dementia and a family member to educate them on the importance of good oral hygiene and to teach them ways to improve oral health for individuals with dementia. The goal is to focus on oral hygiene behaviors that can be maintained to ensure good oral health of the individual with dementia over time. This is just one more step to improving the health and quality of life of individuals with dementia.

- Chalmers, J. M., Carter, K. D., & Spencer, A. J. (2003). Oral diseases and conditions in community-living older adults with and without dementia. *Spec Care Dentist, 23*(1), 7-17.
- Frenkel, H., Harvey, I., & Newcombe, R. G. (2001). Improving oral health in institutionalised elderly people by educating caregivers: a randomised controlled trial. *Community Dent Oral Epidemiol, 29*(4), 289-297.
- Jablonski, R. A., Therrien, B., Mahoney, E. K., Kolanowski, A., Gabello, M., & Brock, A. (2011). An intervention to reduce care-resistant behavior in persons with dementia during oral hygiene: a pilot study. *Spec Care Dentist, 31*(3), 77-87.
- Kim, J.-M., Stewart, R., Prince, M., Kim, S.-W., Yang, S.-J., Shin, I.-S., et al. (2007). Dental health, nutritional status and recent-onset dementia in a Korean community population. *Int J Geriatr Psychiatry, 22*(9), 850-855.
- Noble, J. M., Borrell, L. N., Papapanou, P. N., Elkind, M. S., Scarmeas, N., & Wright, C. B. (2009). Periodontitis is associated with cognitive impairment among older adults: analysis of NHANES-III. *J Neurol Neurosurg Psychiatry, 80*(11), 1206-1211.
- Wu, B., Plassman, B. L., Crout, R. J., Caplan, D. J., Boone, M., Wiener, M. A., et al. (2010). Oral health disparities among elders with and without cognitive impairment. *Journal of Dental Research, 89*(Special Issue A), Paper 129572.
- Wu, B., Plassman, B. L., Crout, R. J., Kao, E., Boone, M., Caplan, D. J., et al. (2011). *Cognitive impairment and oral health in older adults*. Paper presented at the Alzheimer's Association International Conference on Alzheimer's Disease.
- Wu, B., Plassman, B. L., Crout, R. J., & Liang, J. (2008). Cognitive function and oral health among community-dwelling older adults. *J Gerontol A Biol Sci Med Sci, 63*(5), 495-500.

WELCOME, BOBBI MATCHAR

A New Voice of the Duke Family Support Program



Dear Readers,

I'm Bobbi Matchar -- the new staff person with the Duke Family Support Program. Although my title is Program Specialist, most people refer to me as "the new Edna." But your beloved Edna Ballard's shoes are way too big for me to fill, so just think of me as the new social worker.

While I may be new to you, I am not new to social work or geriatrics. My first job after moving to North Carolina in 1983 (yes, I am/was from up north) was as the social worker for a geriatrics research project at the Durham VA Hospital. Fast-forward about 15 years, three children and a newspaper career later, and I returned to social work. I ran outreach programs for seniors. While at that position I developed a passion for working in aging and a desire to do more. So I returned to graduate school for a second master's degree, this time in Health Policy and Administration at UNC's School of Public Health. My thought was that with a policy background, I would be able to take my skills and interests to a broader playing field and hopefully I could make a bigger difference in the lives of older people and their family caregivers. After graduating in 2006, I worked at the School of Public Health until this summer when I landed here in the Duke Family Support Program in what feels like my dream job.

I feel so fortunate to be working with and learning from Lisa Gwyther, our program director. Even better, I look forward to meeting more of you, our readers, and learning from you – you are on the front lines and you have much to teach me about family care. Feel free to contact me at 919-660-7509, 800-646-2028 or at bobbi.matchar@duke.edu.

I'm really happy to be here!

Bobbi

"How do I honor thee, let me count the ways."



Please join us in a special writing project honoring persons with Alzheimer's disease, whether you write a few sentences or a few paragraphs. Edna Ballard, Cornelia Poer, and Kathy LaFone are currently working on a booklet honoring persons who are courageously coping with this disease. It is also open to other family members (including children), friends, professionals, and anyone whose heart has been broken by Alzheimer's. **Write Edna L. Ballard, MSW, ACSW, Box 3600 DUMC, 200 Trent Drive, Room 3513/Blue Zone, Durham, NC 27710. For additional information, please call 1-800-646-2028 or 660-7510.**

A Different Vow

By Kate Arnold ©, Washington, D.C.*

"Do you know where my husband is? Because he's a good one and I'd hate to lose him." This is her third husband, so Holly, my 80-something-year-old patient, has room to judge. I tell her he's reading his book downstairs and she says, "He's such a patient husband." She asks this question every five minutes of her two-hour-long visit. She doesn't know what city she's in, but she know she's in love with her husband.

A year and a half ago, I was finishing my post-baccalaureate pre-medical program at Georgetown. I was twenty-four, taking physics with 19-year-olds, and trying to find a job for the year I would spend applying to medical school. In an effort to convince myself that the work was worth it, I read *Final Exam* by Pauline Chen, MD. Dr. Chen says that good doctors recognize when death is inevitable and then strive to make the transition to death more comfortable and peaceful. Believing her, I decided to spend my year learning how to be with patients with hard diagnoses. I got a job as a research coordinator for clinical trials for Alzheimer's disease, which is how I met Holly.

It struck me that Holly was so in love with her husband when she had lost touch with every other part of her life. In marriage vows, you promise to love each other forever. In over 50 percent of marriages, people are unable to keep this promise, and that's both frightening and depressing to people in their twenties considering marriage—myself included. And yet, as I watch my patients and their spouses face the hardest thing I can imagine together, in the process, they restore my faith in marriage as a sacred commitment. To love another in sickness and in health is a profound promise; and yet, it's the tip of the iceberg when Alzheimer's is involved. On your wedding day, you didn't promise not to get mad when your spouse forgets a dentist appointment, forgets your wedding anniversary, forgets how to converse, forgets your name. And if you're the one with Alzheimer's, you didn't promise to never give up and to do your best to fight the disease you'll eventually lose your life to. With a diagnosis of Alzheimer's, these are the vows some choose to make, spoken or unspoken. And patients who can do that save their marriages.

Interspersed throughout the struggle are funny moments, and the only way to keep your sanity is to laugh. The patients tend to be disinhibited and, given that most of them were somewhat proper 80-year-olds, the things they say can be unexpected. When I asked Mr. O'Farrell, my Irish patient, if he helps out with chores, he said, "Well, sometimes I'm an ass." Later in the visit, I asked him to address an envelope to himself and he wrote, "Mr. Wonderful." I made a copy of the envelope and taped it above my desk to keep me smiling. One caregiver, who's usually heartbroken at visits, laughed while telling me that on Valentine's Day, two beautiful bouquets arrived because her husband accidentally ordered flowers twice.

But the funny moments fade because they showcase how impaired the patients are becoming, and then it's back to reality. When I got the job, my boyfriend at the time asked me if I would be able to handle it. It was a valid question and I wasn't sure, but my goal was to learn to handle it and, I hoped, to learn to support patients and families facing Alzheimer's. I knew the job would make me cry, I knew sometimes I would feel heartbroken, and I knew I would often be emotionally overwhelmed.

**This article originally appeared in Today's Caregiver and it is used with the author's permission.*

(continued on page 7)

A Different Vow (continued from page 6)

And that's been true because just as there are funny moments, there are also powerful moments that grant you more insight than you ever wanted into what it's like to live with Alzheimer's. Like when Ralph told me Helen woke up disoriented one day, asking when it was time to go to school; and then sat on his lap and cried on his shoulder because she was disoriented and scared. Or a husband who simply stated that within two years, at the age of 54, his wife's mind will be "shot."

I never expected to be so emotionally engaged with my patients. When I started the job, I used to say hello and chat congenially; I now hug almost all of them. It might seem unprofessional, but I'm not their doctor. My job is to make coming to their study as enjoyable as possible. That's not my job description, but it's how I do the maximum amount of good. Now I'm invested in my patients' fights, while knowing they will most likely all lose.

My scariest moment came when I identified fully with one of my patients. I empathize with all of them. They tell me, after cognitive testing, that they're astounded and terrified at how easy the questions were and how they didn't know the answers. They read books about the progression of Alzheimer's and learn what will happen. But Martha was different; Martha was who I wanted to grow up to be. I would love to be her. She was tan, athletic, casually elegant, and ate healthy foods, but always caved when chocolate was involved. She had the family life I hope to have at her age; she had two grown kids, one granddaughter, and a husband who was in love with her. When I first met her, she was funny, light-hearted, kind, gregarious, and happy; but at 55, she has early onset Alzheimer's. At her last visit, Martha couldn't recognize the food on her plate. In the hall, she had trouble following me; and in the bathroom, she couldn't find the soap or faucet. I'm sure 15 years ago, she thought these would be the best years of her life. She had set herself up for it; it was time for her to travel and spoil her grandkids. Instead, she's slipping away. I looked at her and I wondered what she would have done if she had known this was coming and I felt overwhelmed. I could be her; this disease can happen to anyone and that's how I ended up at my mom's house crying.

My mom and I were watching *To Gillian on her 37th Birthday*, which is about David, a man whose wife died two years ago, but every night he goes out to the beach where he can talk to her. Both David and all of my patients and their spouses have been robbed of the future they wanted. My patients and their families are losing the 20 years of vacations, new babies and quality time with each other they had expected to have. And they're living in a dual reality. The person they love is still right in front of them; and yet, their partnership is ending and every day that person is a little more gone. I cried on the couch and couldn't breathe for what everyone at work has lost and what they will lose.

What gives me hope is seeing my patients fight for their love. I never expected to learn so much about marriage; but watching my patients fight for their marriages has been my favorite part of the job. My parents got divorced when I was in third grade because, simply put, it just wasn't working. While I'm not second-guessing the decision, it's healing for me to see couples face huge obstacles together and win.

Martha and her husband John are terribly in love. Just as Martha's visit is ending, John walks into the room. He usually goes and works while she stays at the hospital, stopping by to have lunch from the cafeteria with her. As John walks into the room, they smile at each other and their eyes twinkle. John asks her if she's ready to go home, she says yes, and they get ready to go. Martha can't tell which shoe goes on which foot, so John helps. They joke as John puts her shoe on; and if a stranger walked by, he would surely think it was

(continued on page 8)

A Different Vow (continued from page 7)

an act of romance, not of necessity. John sees everything that's happening, but they've chosen to live together in good spirits despite the circumstances, and they convince me that it is better to have loved and lost than never to have loved at all. As they get ready to leave, his hand brushes her stomach with ownership and tenderness as he tickles her. With that one sign of affection, I see that they've won the battle. They will love each other until death do them part and that gives me hope.

Kate Arnold is attending medical school at Georgetown University; but before enrolling, she worked with Alzheimer's patients for a year as a research coordinator for clinical trials in Alzheimer's disease.

Through the Eyes of an Alzheimer's Patient

By Carolyn Haynali © 2005

As I look at you I am not able to tell you how I really feel
 But I want you to try to understand that I am still here
 Locked in my mind are feelings that I can't seem to let out
 I see you...as you are talking to me
 I see in your eyes that you expect me to respond back but I can't
 I can hear what you are saying but I can't tell you how I feel or what I am thinking
 So please look at me and see me the way I used to be
 I was strong, I was laughing and I smiled and I loved you
 Talk to me as if I can understand you
 Because even though I can't tell you
 I do hear you, I can see you, and I can feel your touch
 I still have feelings and can feel your love
 and see the pain, and the sadness in your eyes
 because you are not able to help me
 I am still here trapped inside this body
 But in my heart I have not left you
 I still love you even if I can't tell you
 So remember that I can see you through my eyes
 Some days it's like a puzzle and I am trying
 to fit the pieces together
 There are times I am not able to
 But be patient with me and look at me
 Through the eyes of this disease they call Alzheimer's
 Because I am still here and I can see you and
 I will always love you

Carolyn Haynali is the Founder of the Alzheimer's Disease Caregiver's Army. www.caregiversarmy.org.

Belvedere

By Margaret Toman © 2010, Garner, NC

“Today I threw the Christians to the lions but I got away just in time,” my mother announces as I pull into the parking lot at Applebee’s. Later I learn that she watched “Ben Hur” at adult daycare but today I don’t know that. I respond carefully, focusing on her lifelong appetite for grilled salmon. “I’m so glad you got away,” I say, “because I’m treating you to grilled salmon for supper. Would you like that?” “Oh yes,” she says, “I’ve never had it before!” As I help her out of the car I marvel at her resilience and her enduring beauty. She is 96. Together we have navigated the treacherous labyrinth of Alzheimer’s disease since her diagnosis 11 years ago. Tonight we are navigating the risk of an evening out.

My mother will die someday but my unruly heart goes right on loving her fiercely, wanting, despite all logic, to keep her forever. Love holds us to high standards, the most transcendently difficult of which is simply letting go.

Applebee’s has been our favorite spot since we moved to Garner five years ago. We dine there often and our bill has been paid on occasion by patrons both identified and mysterious. Beautiful, gregarious and kind, my mother has charmed and been charmed by, nearly all of Applebee’s waiters and waitresses. But we haven’t been there for awhile and BJ, our favorite waiter, is not working today. Yesterday’s heat wave has been replaced by today’s cold front and the air in Applebee’s is chilly. I don’t recognize our waiter, who smiles broadly then dashes off for menus we don’t need. I order our usual: grilled orange salmon, no potatoes, double order of vegetables (no butter), strawberry lemonade for her, unsweetened ice tea for me and a piece of caramel apple pie to split for dessert, with coffee. Our waiter hesitates for a moment before divulging that grilled salmon and caramel apple pie are no longer on Applebee’s menu. “How *could* they?” I protest. While the waiter and I commiserate over the uninformed decisions of distant management, my mother draws into herself as if being dragged by a malevolent force. The strange, growing absence in her eyes unnerves me. Grudgingly she chooses Crunchy Asian Salad, but her confusion and her litany of complaints notches up. She is cold, the seat is hard, the salad tastes funny, the fork is too heavy, there aren’t enough napkins, she doesn’t like this place. She’s licking hot fudge from a spoon when suddenly her face contorts with horror and she cries out, looking over my shoulder, “Those men are killing each other!” I turn around in my seat and see that a television at the bar is previewing a violent crime drama. I chastise myself: Why didn’t I think about the televisions at the bar? Why didn’t I insist on our usual window seat? I reach across the table and grasp her hand. “It’s alright, Sweetie,” I say soothingly. “It’s just a television program. You know I won’t let anything bad happen to you. Eat your dessert and we’ll go home. Everything is alright.” “I don’t want to sit here and be killed!” she snaps.

Other patrons stare. I am stunned, embarrassed, sad, and angry—with the disease, with myself, with her. I have sacrificed everything—financial security, social freedom, community involvement, a sense of future. But I chose this road and I would do it again. My mother will die someday but my unruly heart goes right on loving her fiercely, wanting, despite all logic, to keep her forever. Love holds us to high standards, the most transcendently difficult of which is simply letting go. But today I am tired of plumbing new depths and heights of myself. Frustrated and fed up, I help my mother to the car, reflecting on the cruel,

(continued on page 10)

Belvedere (continued from page 9)

diabolical force that is Alzheimer's disease. Like five million plus other people in this country, she is trapped in a strange world she can neither describe nor escape. I don't know what to do.

We drive across the shopping center and park outside of PetSmart. Dogs and their owners come and go and I point out this poodle, that lab, those cocker spaniels. My mother brightens just a little with each wagging tail, then sinks inward again. I am about to give up when a woman cradling a dachshund puppy emerges from a truck close by. I have learned to rely on the kindness of strangers and I get out of my car. "Ma'am," I say, testing the waters with my warmest smile, "that is the *cutest* thing I have ever seen!" She beams and introduces me to Belvedere, who wriggles with delight and licks my hands. I explain how things are and we walk to my car and place Belvedere gently on my mother's lap. She absorbs the puppy into herself, pressing its soft warmth to her breast. Closing her eyes, holding her head down close, she murmurs softly. Belvedere squirms contentedly and relaxes. I think they have both gone to sleep when my mother suddenly raises her head and looks squarely into my eyes. She releases a dazzling smile, her eyes sparkling like emeralds. "I love you," I say. "I love you more than Orville Redenbacher, Johnny Walker, Russell Stover or any of those guys." Sometimes I add a long string of names to this mantra but in this moment I can recall only three. "I love you too!" she says heartily. Belvedere wriggles and licks her cheek. His owner smiles, our eyes meet and for a moment the four of us are embraced in grace, redemption, healing and love.



As we drive home, my mother chatters happily and non-stop about everything. Nothing she says makes any sense but when we are almost to our turn, she announces, "I want some dessert! I haven't had any dessert." I don't remind her of the dessert shooter she just devoured. I check my vanishing funds. "Well alright, let's do it!" I say. We laugh all the way to McDonald's.

Margaret Toman is a freelance writer and Alzheimer's advocate who volunteers for Alzheimer's NC. She lives with her mother in Garner, NC.

Down Memory Lane

In an art exhibit on Alzheimer's, a writer finds shades of her own past

By Nancy Stearns Bercaw © 2010, Burlington, VT*

My father knew it was coming. Alzheimer's disease had been on his radar ever since his own father died of the mysterious malady. Witnessing the catastrophic deterioration of a man whose mind had been sharp enough to work for General MacArthur in prewar Manila, my frightened father, Beauregard Bercaw, decided to become a neurologist. Perhaps the practice, and pursuit, of medicine could stave off what he believed was a genetic inevitability.

Beauregard's fear reached epic proportions as he approached middle age, and he began to experiment on himself with supplements. By the time he was 60 — which was 12 years ago and before dietary supplements were so commonplace — my father was taking 78 tablets a day.

He tracked down anything that offered even the slightest possibility of saving brain cells and killing free radicals: Omega-3s, -6s, -9s; Vitamins E and C, ginkgo biloba, rosemary and sage; folic acid; flax seed; and many substances I had never heard of. He drank nothing but green tea, swore off sugar and even stopped using shampoos that contained sodium lauryl sulfate, which he called "toxic."

Beau spent hours a day doing math. Even when I was visiting the home he shared with my stepmother in Naples, Fla., he'd sit silently on his leather recliner with a calculator in his hand to verify the accuracy of the long math he factored by memory.

What are you saving your mind for, Dad? I often wondered. *I'm here now, waiting to talk with you.*

But my father wasn't interested in idle chatter. His prime pursuit was the solitary game of problem solving. Medicine and math had solutions; they just had to be found. The answer to Alzheimer's was somewhere in his head ... or so he thought.

On one of the occasions when I was visiting and he was doing equations, Beauregard looked up and stared at me.

"Promise me something, gal," he said, as if he were reading a paper to the Southern Clinical Neurological Society, an organization he founded and presided over for years.

"Anything," I answered my father, who had once mortgaged our house to buy the first MRI machine in our town. He later filed an antitrust lawsuit against the hospital where he worked when the administration decided radiologists had the right to interpret test results instead of neurologists. My father lost that battle but gained the respect of his colleagues — even the radiologists — for his scientific passion.

"Swear on your grandmother's Bible that you will put a gun to my head if I wind up like my father."

**This article originally appeared in Seven Days, a Vermont independent newsletter. Used with permission from the author.*

(continued on page 12)

Down Memory Lane (continued from page 11)

He was dead serious.

How do you answer a man who watched his own father wipe feces on the walls of their Virginia farmhouse? A man who couldn't tolerate seeing his loving mother bear the care-giving burden alone and sent his father to a respite home in Charlottesville, where he died a short time later? A father who blamed himself for his own father's death and was now asking me to kill him if the disease repeated itself despite his best mathematical and pharmaceutical efforts?

"Swear to me," he said again. My father taught me to shoot on the farm where he grew up. He collected guns and kept them under lock and key. Everything was in place to make his wish a reality.

I put my hand on the aging, leather-bound King James Bible that had belonged to my great-grandmother Nannie Dunlap and my grandmother Nancy Scott.

8	6		2					
			7					5 9
				6		8		
	4							7
		5	3					
	2						6	
		7	5	9				

"I swear," I said, promising only because I knew it would bring him comfort.

"Good," he answered, then set down the Bible and picked up a Sudoku puzzle book. "Want some pomegranate juice?"

A few years later, my father and his wife Nora came to Vermont for a visit. Beau lugged a wheeled suitcase full of supplements into my house. He stayed up late the first night parceling out his pills for the week into Dixie cups: one heaping cup of supplements to be served with every meal.

"Gal, you should be taking these, too," he declared one morning.



"Why?" I asked. "Because you are my genetic clone."

When I was very young, people would say, "You look just like your father." To which I would always respond, "But I am a little girl!"

Our physical resemblance and similar character traits were uncanny. We were a pair of tall, big-lipped, blue-eyed, loose-jointed, freckle-skinned, must-nap-in-the-afternoon, angst-ridden, globe-trotting Bercaws. Except for XX and XY chromosomes, nearly everything about us was a perfect match.

I wondered about the *apolipoprotein E e4 (APOE)* gene found on chromosome 19, which can indicate a predisposing genetic risk factor. Did I get that from my father, too?

Everyone inherits a copy of some form of *APOE* from each parent. *APOE e2* is relatively rare and may even provide some protection against the disease. *APOE e3* is the most common and appears to play a neutral role in Alzheimer's disease.

(continued on page 13)

Down Memory Lane (continued from page 12)

“Those who inherit one copy of *APOE e4* have an increased risk of developing Alzheimer’s,” explains the Vermont Alzheimer’s Association website. “Those who inherit two copies have an even higher risk, but not a certainty. Scientists do not yet know how *APOE e4* raises risk. In addition to raising risk, *APOE e4* may tend to make symptoms appear at a younger age than usual.”

I was only 34 when my father and Nora came to visit that summer. I didn’t want to be consumed by worry, as he had been all his adult life. What I wanted was to take them to the Shelburne Museum to show them a quilt exhibit and the famed Round Barn. I wanted us to stroll the grounds as if we didn’t have a care in the world. Couldn’t I think about Alzheimer’s later, maybe a decade or two down the road? Nope.

We did enjoy a beautiful day at the museum. Beau was fascinated by the Round Barn. “I never saw one like this in Virginia,” I recall him saying. I later sent him a Warren Kimble print to remember it by.

In exchange, my father sent me the very expensive *APOE* genetic test kit and instructed me to have the blood drawn at my physician’s office, but to have the results sent directly to him. Turns out that I carry the *APOE e3* gene — the neutral one, which means I may or may not get Alzheimer’s. My father is an *APOE e3* carrier, too.

And now Beauregard has full-blown Alzheimer’s. A year ago, he had a CT scan that showed “brain atrophy consistent with the disease.” He looked at the film himself as he was wheeled out of the room — before the radiologists even had a chance — and was confused by what he saw. *Whose brain is that?*

The symptoms have been compounding ever since. Beau can’t remember when he last ate, so he eats all the time. The big man is now big-bellied, too. His supplement regime — forgotten, for the most part — has been replaced with a combination therapy of the prescription drugs Namenda and Aricept. Nora must put the pills in his hand and watch him swallow. She has to stop him from taking them again a few minutes later.

Beau can still do Sudoku puzzles and read books on his Kindle. He just can’t remember what day it is or which words he most recently uttered. His nap schedule — formerly 20 minutes after lunch, even when he practiced medicine — has increased to twice a day, for two hours at a time.

A few weeks ago, after spending six months in Singapore with my son and husband, I went to Naples to help Beau while Nora had surgery. For the entire first day I was there, my father hugged me every time he saw me come around a corner. “Gal, it’s so good to see you,” he’d say. These hugs were long, drawn-out embraces, quite unlike the sideways, one-armed versions he used to give.

I fed him. I gave him the pills. I cleaned up his “accidents.” I let him eat Skinny Cow Ice Cream Sandwiches. (I temporarily lost him in the grocery store when he struck out on his own to find them.) I watched FOX News with him. (That one hurt.) I napped when he napped. I took him on daily visits to see his wife at the hospital, and stopped him from calling her every five minutes from home. I got the newspapers before he woke up so he wouldn’t wander outside alone. I wondered what happened to the calculator that had always been by his chair. Long math was long gone. The remote control was his device du jour.

(continued on page 14)

Down Memory Lane (continued from page 13)

While Beau watched a baseball game one afternoon, I walked into his den and eyed the wall of supplements he used to take — bookcase after bookcase of pills with names like “Memoral” and “Sharp Mind,” along with the standard vitamins and minerals. They were now brutal reminders of how valiantly he had fought to stave off this disease. It seemed symbolic that they were all past their expiration dates.

I rested my hand on the gun cabinet on my way out. *Not gonna need any of you, either.*

Several mornings during my caretaking time with him, I enlisted Beau to walk to the local coffee shop. The only thing he’d say on these walks was “The hibisci are in full bloom.” Every time he said it — there were dozens — I ruminated on whether the plural of hibiscus is, in fact, hibisci. I felt better thinking about innocuous things than the gravity of the situation.

On my final day in Naples, we took one last walk together. Beau didn’t mention the hibisci, though they were still blooming. I noticed his gait was off, and for a second I thought he might be having a stroke.

“Are you OK, Dad? You’re walking funny.”

“I’m just trying not to step on the cracks,” he said, perfectly seriously.

I giggled. *Dear God, he thinks he’s a boy again!* He seemed especially distant that morning. Maybe he was back on the farm, or walking the halls of the University of Virginia. Wherever he was, he seemed happy there. But as we passed a particularly flourishing hibiscus tree, my father looked at me. *That look.* The one that means something big is coming.

“Gal,” he said, and then paused for a long while. “I sure appreciate you coming down to take care of me.” His voice quivered toward the end of the sentence.

I composed myself long enough to say, “It was a pleasure, especially after all you have done for me. Besides, you don’t need so much taking care of.”

My sunglasses masked my tears. As we walked on, my father would repeat this latest fixation every few minutes — with the same quiver in his voice in the exact same place. But each time, my emotions got bigger and my response got shorter, until I was the one who couldn’t find the right words.

Home in Vermont, a week before Father’s Day, I find myself back on Memory Lane at the Shelburne Museum. I’m sad down to my bones, as my dad used to say whenever a patient died.

I’ve come to the Round Barn to see “Alzheimer’s: Forgetting Piece by Piece,” a national quilt exhibit about the disease. With my first glance, I realize that a lot of other people are unraveling, too — victims, families, friends and caregivers. In fact, 5.3 million Americans are living with Alzheimer’s disease, and a new individual is diagnosed every 70 seconds. Nearly 11 million unpaid caregivers, like Nora, assist those living with the disease.

(continued on page 15)

Down Memory Lane (continued from page 14)

The Shelburne exhibit features 52 heart-wrenching quilted tributes, each partnered with a statement from the artist and a piece of information about Alzheimer's disease. The quilts are displayed so the accompanying facts are in chronological order — from diagnosis to death. It occurs to me that the Round Barn itself is the perfect metaphor for a disease that makes the mind spiral. The Shelburne Museum has put its own imprint on the exhibit by partnering with Vermont Public Radio and the national StoryCorps Memory Loss Initiative to share oral stories from local Vermonters who are living with the disease, and their caretakers.

I listen to one, and it's like I'm inside my father's head.

"I hope I can keep myself the way I am," says 79-year-old Robert Ferm to his wife, Sonja Olsen.

I hang up the phone at the listening station, and my hand is drenched with sweat. Fortunately, the museum has tissues placed throughout the exhibit.

The tapestries seem to tell my story, too — a patchwork that brings people together as things fall apart. In "Fading Memories," by Virginian quilter Linda Cooper, washed-out daylilies represent "the fading reality that Alzheimer's brings." On the borders, she's quilted sections of "normal neurons with occasional damaged nerves with the beaded amyloid plaques, seen in the disease pathology." The accompanying text explains how those sticky plaques clump together, build up between nerve cells and "block cell-to-cell signaling at synapses."

"The Crooked Path," by Diane Petersmarck from Illinois, depicts her father's winding, narrowing road to another world. Despite his shrinking reality, she feels "a tiny glimmer of joy" on those rare occasions "when he comes back to us." Like when she was sitting on her father's bed telling him she loved him. "I love you, too, Diane," he said out of the blue, hugging her.

One quilt in particular rips my heart to pieces. "What If I Can't Remember..." by Susan Gourley from Indiana, features a mass of unclear, floating and fading images representing memories (as well as her mother and aunt). Around the edges, Gourley has written questions mothers might ask when faced with the possibility of forgetting their own children. The last lines are "What if I never again have the chance to remember who I was and who you were to me? What if I cannot remember that I loved you?"

I head over to the "Wish Wall," where visitors can leave a message for a loved one with Alzheimer's disease. I pick up a piece of colored paper. Hibisci pink. And I scribble a message to Beauregard Lee Bercaw.

I will never forget you.

Author's update: My father has been moved to a memory care facility in Naples, Florida. He no longer remembers me, his gal, very well. He does still love to hold hands, though. I have written a book about him, called Brain in a Jar (not yet published), in honor of the fact that he once kept his father's Alzheimer's ridden brain in a jar on his office desk. I also keep a blog about Beau at <http://alzheimersdaughters.wordpress.com/>. The blog is called "Forget About It." I let my emotions out there big time!

Nancy Stearns Bercaw is a writer in Vermont. She has been published in newspapers from The Korea Herald to The New York Times.

Have You Heard About?

Aldrich, Joni James and Peterson, Neysa M. *Understanding with Compassion: Help for Loved Ones and Caregivers of a Brain Illness Patient*. CreateSpace, 2011. Written by wives focused on dealing with personality and behavior changes.

Aldrich, Joni James. *Our Daily Connection: A Journal for Brain Illness Caregivers to Share Facts, Fun and Feelings*. CreateSpace, 2011. A thirty-one day journal with tips and activities to encourage both the caregiver and care recipient to enjoy the day.

Cohen, Richard M. *Strong at the Broken Places*. Harper Paperbacks, 2009. TV producer, husband of Meredith Viera, and author profiles five people coping with chronic illnesses.

Doraiswamy, P. Murali, and Gwyther, Lisa P., with Tina Adler. *Living Well After an Alzheimer's Diagnosis*. St. Martin's Press, 2011. NEW, September 2011 e-book. Three chapters from the 2009 paperback, *The Alzheimer's Action Plan: A Family Guide*. *Living Well After an Alzheimer's Diagnosis* deals less with the technical details and more with the practical business of living with cognitive challenges.

Gambone, James V. and Travland, Rhonda W. *Who Says Men Don't Care? A Man's Guide to Balanced and Guilt-Free Caregiving*. CreateSpace, 2011.

Gross, Jane. *The Bittersweet Season: Caring for Our Aging Parents – and Ourselves*. Knopf, 2011. The original editor of the *New York Times* "The New Old Age" blog tells the story of her care for her mother over ten years, and how it affected her sibling and other family relationships.

Hamilton, Jane Meier. *Journey of a Lifetime: The Caregiver's Guide to Self-Care*. Infinity Publishing, 2010. Hamilton, a nurse for 35 years and family caregiver for 20 years, offers sensible, effective ways to cope with caregiver stress.

LeBlanc, Gary Joseph. *Staying Afloat in a Sea of Forgetfulness: Common Sense Caregiving*. Expanded Paperback Edition. Xlibris Corporation, 2011. A son shares his triumphs and hardships as the primary caregiver of his father with Alzheimer's disease.

McFadden, Susan H. and McFadden, John T. *Aging Together: Dementia, Friendship, and Flourishing Communities*. The Johns Hopkins University Press, 2011. The McFaddens contend that the only humanistic, supportive, and realistic approach is to find new ways to honor and recognize the dignity, worth, and personhood of those journeying into dementia.

Wayman, Laura. *A Loving Approach to Dementia Care: Making Meaningful Connections with the Person Who has Alzheimer's Disease or other Dementia or Memory Loss*. The Johns Hopkins University Press, 2011. Stories, tips, strategies from an experienced caregiver.

New Online Help

www.puzzlewithme.com/. Puzzles with images to spark a memory or start a conversation with someone with Alzheimer's. Ten percent of sales are donated to Alzheimer's Association International.

Medicare beneficiaries have choices when it comes to the quality of their providers. That's why the Centers for Medicare & Medicaid Services just launched the Quality Care Finder designed to help beneficiaries and their caregivers find better health care options. To find health care providers, facilities, health and drug plans, and equipment suppliers, and to make "apples-to-apples" comparisons of their quality, patients and their caregivers can go to www.Medicare.gov/QualityCareFinder or call 1-800-MEDICARE (1-800-633-4227) or TTY call 1-877-486-2048.

www.fda.gov. Information for older people about medicine, safety and ways to lower medicine costs. Call toll-free for free booklets 1-888-463-6332.

www.nia.nih.gov. Click on publications to access free publications—some online, others in print. Topics include Alzheimer's disease, caregiving, medications and others.

www.alzrisk.org/riskfactorview.aspx?rfid=2. Excellent current review of negative findings from antioxidant studies about reducing risk of Alzheimer's disease.

www.alzforum.org/new/detail.asp?id=2789. Last word from NIH on Prevention of Alzheimer's Disease with expert commentary reflecting little consensus.

www.ahrq.gov/consumer/safemeds/yourmeds.pdf. *Your Medicines: Be Smart. Be safe.* Includes wallet card for personal medications list.

www.metlife.com/assets/cao/mmi/publications/studies/2011/mmi-elder-financial-abuse.pdf. Important new report on elder financial abuse.

www.alzheimersreadingroom.com. Bob DeMarco has one of the best sources of shared experiential wisdom from families who care for and about persons with Alzheimer's disease.

www.aarp.org/money/budgeting-saving/info-06-2011/fs230-ten-facts-to-consider.html. "How Many Older Americans Live - Ten Facts to Consider."

www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2488. "New Fact Sheet: Caregiving with Your Siblings." Excellent tips and useful references from the Family Caregiver Alliance.

www.caring.com/articles/how-to-find-a-private-caregiver/ "How to Find & Hire a Private Caregiver." Excellent overview.

www.dementiacarecentral.com/videos. Short videos for families and care staff from N.C.'s Teepa Snow and Melanie Bunn.

New Online Help (continued from page 17)

www.alz.org/norcal/in_my_community_14292.asp and click Help & Hope downloadable link for free 15-page booklet, *help and hope for persons diagnosed with Alzheimer's disease and related disorders*. Basic practical summaries and brief messages from persons living with dementia offer meaningful reflections for those affected.

www.aboutalz.org. Five short videos including one for patients and families.

www.gerontology.vt.edu/docs/Gerontology_MCI_final.pdf. Free six-page pamphlet from Virginia Tech on Mild Cognitive Impairment (MCI) based on interviews with 99 persons with MCI and their families.

www.ahrq.gov/questions. New questions to ask your health care professionals about services, procedures, hospitals.

www.medicare.gov/caregivers. *Ask Medicare* has new tip sheets for family caregivers and care partners.

www.caregiver.va.gov/. Updated and helpful for older veterans.

www.timeslips.org. TimeSlips is an improvisational storytelling method originally designed for people with dementia and their caregivers, but anyone can use TimeSlips to read, write, and share stories with family and friends.

**Outdoorsmen for Alzheimer's Inc.
Presents Gift for \$12,500 to the
Joseph and Kathleen Bryan
Alzheimer's Disease Research Center
(ADRC)**



Ben Wolfe, pictured with Dr. Welsh-Bohmer, director of the Joseph and Kathleen Bryan ADRC, credits his late grandmother, **Bobbie Hunter Boney of Wilmington**, for much of his outdoors interest. However, Alzheimer's disease stole the final years from Boney, who was 77 when she died.

To honor his grandmother, Wolfe founded Outdoorsmen for Alzheimer's Inc. in 2005, a nonprofit group that hopes to make an impact by raising funds for Alzheimer's research in the state of North Carolina. Through private and corporate contributions and the support of members, the Outdoorsman made a generous donation of \$12,500 to the Bryan ADRC to help fund new prevention approaches to delay symptom onset and progression in Alzheimer's disease.

Through their donations they hope to bring the world closer to a cure for Alzheimer's disease.