



# The Caregiver

Newsletter of the Duke Family Support Program

"We are a bridge to understanding your options"

Volume 29, Issue 1

Spring 2010

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## Duke Family Support Program

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The Caregiver is co-sponsored by the:

Joseph and Kathleen Bryan Alzheimer's Disease Research Center

Duke University Center for the Study of Aging and Human Development

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## Progress in Discovery for the Prevention of Alzheimer's Disease

Memory, Health, and Aging Program

Joseph and Kathleen Bryan Alzheimer's Disease Research Center

Duke University Medical Center

Kathleen A. Welsh-Bohmer, Ph.D.

Principal Investigator and Director

*From time to time, participants in the Memory, Health, and Aging (MHA) Program of the Joseph and Kathleen Bryan Alzheimer's Disease Research Center (Bryan ADRC) ask if their participation matters in the search to understand and treat Alzheimer's disease (AD). The short answer is YES, research participation matters. I would like to take this opportunity to share what the MHA Program is all about and to express a sincere 'thank you' to the many current and past participants.*



The ultimate goal of the MHA Program of the Bryan ADRC at Duke University Medical Center is to speed progress in discovery for the prevention of Alzheimer's disease (AD). Since the MHA Program began in April 2005, 539 participants from North Carolina have been enrolled. Of these participants, 30% are African-Americans, a population reported to have an increased risk for AD. For progress in the prevention of AD, the Bryan ADRC is committed to reaching and enrolling this at-risk population. Also, the National Institute on Aging (NIA), the funding source of the Alzheimer's Disease Centers (ADCs), has charged the ADCs to increase minority enrollment. Thus, the Bryan ADRC has taken special effort, such as its African-American Community Outreach Program and its successful partnership with First Missionary Baptist Church, Reverend Dr. James E. Brown, Pastor, in Jacksonville, NC, to reach the NC minority population. The Bryan ADRC recognizes the importance of research data representative of the population as a whole.

The Bryan ADRC and its MHA Program are part of a much larger research enterprise involving all of the 30 funded-ADCs. The research data including memory tests and biological samples collected through the MHA Program are submitted to the National Alzheimer's Coordinating Center (NACC).

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3737 Glenwood Avenue  
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email: info@alz.org

**Western Carolina  
Caregiver Education Forums**

May 6, 2010 8:30 AM - 4 PM  
Grace Ridge Retirement Community -  
Morganton  
May 7, 2010 9:00 AM - 8:00 PM  
NC Research Campus - Kannapolis  
May 13, 2010 8:30 AM - 4 PM  
Landmark Church of God - Statesville  
July 27, 2010 8:30 AM - 4:00 PM  
NC A & T State University - Greensboro

**Alzheimer's North Carolina, Inc.**

400 Oberlin Road, Suite 220  
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## Memory, Health, and Aging Program (continued from page 1)

In doing so, the ADCs are combining information in a uniform way to speed discoveries. The sum of the 30 ADCs becomes much greater and more significant for producing research findings.

Progress in discovery is already evident from the combined ADC initiative. The Bryan ADRC MHA Program participants have played a substantial role in the progress. As of February 1, 2010, the National Uniform Dataset (UDS) contains data from over 20,000 individuals from all ADCs. Of these individuals, 539 are participants in the Bryan ADRC MHA Program. An additional 200 individuals are participating in Bryan ADRC research through its Autopsy and Brain Donation Program. Participants in the Autopsy and Brain Donation Program agree to brain donation upon their death. Since the beginning of the Program in 1984, the Bryan ADRC has performed more than 1,000 brain autopsies and is currently following 200 living enrollees.

The information collected in this very large unified database does not contain any personal identifiers. Each ADC assigns unique numerical code identifiers to its research participants for use in submission of data to the national data repository. Only each ADC, under the Director's oversight, maintains the key to the code, which links data to an individual. All information that could possibly identify any individual is maintained under strict confidentiality and according to federal law. Thus, the combined uniform data allow scientific investigators world-wide, unparalleled opportunities to ask and answer questions related to AD and aging. In addition, scientific investigators have gained insights that have launched new collaborations in AD research. Over 200 studies have occurred as a direct or indirect result of the ADCs' unified database.

Examples of some of the most important discoveries/findings in the last several years that came from Bryan ADRC participants include:

- Using the clinical data collected from participants *without* memory impairment, the Bryan ADRC has developed a useful resource of neuropsychological information. This information will help investigators, now and in future prevention studies, to interpret the amount of change in test performance that is 'normal' to brain aging and that which is related to brain disease.
- From those participants who provided genetic material either from a blood sample or from brain donation, a number of studies have been published examining the role of genetics in successful aging and in diseases such as AD and frontotemporal dementia (FTD). Duke investigators, led by Dr. Allen Roses of the Duke Deane Drug Discovery Institute, reported a new gene that influences the onset of AD symptoms, a finding that if replicated in other studies, has significant implications in speeding drug development.
- Also important for drug development to prevent AD, are Duke initiated studies involving MRI brain imaging. Duke studies with the help of some Bryan ADRC research participants, have examined brain changes of aging and those associated with genetic risk factors for AD. These studies are providing useful markers or "targets" for drug development in AD, potentially shortening the necessary length of clinical trials by revealing more directly the impact of medicines on the underlying brain disease.

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## Memory, Health, and Aging Program (continued from page 3)

- In the subset of participants followed through autopsy, a number of studies have been published from the ADCs which suggest a role of preventable factors; importantly, vascular changes that arise from stroke and atherosclerosis, that contribute to the genesis of AD. Because vascular factors can be treated with medications and modified with lifestyle changes, the Bryan ADRC is now starting both drug and non-drug prevention studies based on these published studies.

*It is fair to say that science has come a tremendous distance in understanding AD since NIA funded the first five ADC's over 25 years ago. Although a cure for the disease is not as close as was naively envisioned 25 years ago, important strides have been made. The pace is accelerating through the combined information now available from the national coordinated effort. Working together, the ADCs – that is, the basic scientists, the clinicians, and most importantly, the participants - are making a difference as we advance toward the time when there will be effective prevention strategies and treatments for AD and other memory disorders.*

### *Publications:*

Browndyke, J.: Left Anterior Parahippocampal Gray Matter Volume is Inversely Associated with APOE Genotypic Risk in Healthy Seniors: Tensor-based Morphometry Data. *International Conference on AD Meetings (ICAD)*, 2009.

Longstreth, W.T. Jr., et al.: Associations between microinfarcts and other macroscopic vascular findings on neuropathologic examination in 2 databases. *Alzheimer Disease & Associated Disorders*, 23(3):291-4, 2009.

Roses, A.D., et al.: A TOMM40 variable-length polymorphism predicts the age of late-onset Alzheimer's disease. *The Pharmacogenetics Journal*, advance online publication 22 December 2009.

Weintraub, S., et al.: The Alzheimer's Disease Centers' Uniform Data Set (UDS): the neuropsychologic test battery. *Alzheimer Disease & Associated Disorders*, 23(2):91-101, 2009.

## **SAVE THE DATES!**

**It's the 25th Annual**

**Joseph and Kathleen Bryan**

**Alzheimer's Disease Research Center Conference**

**February 10-11, 2011**

**Sheraton Imperial Hotel & Conference Center**

**4700 Emperor Boulevard**

**Research Triangle Park, NC**

## A Family's Perspective—Bryan ADRC 2010 Conference Participation

Erin Pratt, Duke Medicine Office of News & Communications

When Melanie York found out about the Bryan Alzheimer's Disease Research Center's Conference, she thought it would be beneficial to her as the primary caregiver for her mother. After researching the conference, she decided that it would be most beneficial for her family to attend as well.

York, her husband, sister and brother all attended the 2010 conference and found it a valuable experience.

"This is sort of a new situation for me, so it was a real eye-opener as far as the level of research and data that are available," said York's brother, Jeff Young.

He liked that the conference provided him with a lot of free handout materials, including books, magazines and course materials.

"The information is definitely that, which I can utilize if there is something that I want to refer back to," Young said.



From York's perspective most of what her family had been dealing with revolved around crisis management – solving hard problems and stressful situations. The conference provided the opportunity for her family to bond in an environment with other families who were in the same situation.

"One thing I really liked was sitting at lunch with a family in a similar situation and talking with them. There were also practitioners at our table who commented. That was really helpful."

York and her family split up for the afternoon sessions. "We actually went and sat down afterwards and as my sister says "debriefed" about everything we had just learned," Young said.

"Being an hour away, I am not as directly involved with my mother's care, as my sister, Melanie. So, she is the one who probably found the conference most beneficial, particularly the part about possibly developing local support groups. Before the conference, I really had no clue about the physiological aspect."

York says that she will definitely attend the conference again, even if her whole family cannot make it.

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"This is what learning is. You suddenly understand something you've understood all your life, but in a new way. "

—Doris Lessing

## Early Diagnosis and Then What?

Lisa Gwyther, MSW, Director, Duke Family Support Program and Education Director, Bryan ADRC

**Editor's Note:** The above title was chosen by Dr. Philip D. Sloane of UNC-Chapel Hill for his panel presentation at Duke's 24<sup>th</sup> Annual Bryan ADRC Conference in February, 2010. Although *The Caregiver* has offered information of value to family and professional caregivers for over twenty-eight years, since 1992 and for this issue, we feature the perspective of the person with an early stage memory disorder. For this issue, we also include information specific to the unique needs of those with younger onset diseases. We believe these perspectives of those living with Alzheimer's and related diagnoses should inform person and family-centered services and support programs.

### Wise Words from Persons with Early Stage Memory Disorders

"Our value lies in what we are, not in our ability to recite the recent past."

A man living with AD

"What I am finding is there is no one "right" thing to do or say. Life is easier if we just trust, love, be open and accept each other for who we are. And, if we don't know for sure what to say to someone with dementia, we should ask, listen and just be. We need to stop looking for "the right thing" and start talking to each other about what meets both our needs."

Richard Taylor, Ph.D., author, *Alzheimer's From the Inside Out*

"Accept there is a problem, mourn what is lost and embrace what you still have"

David Anderson, South Australia

"The sleeping and time sense thing is huge for me. I'm not aware of the passage of time, I rarely am able to sleep at night, and often feel compelled to sleep in the late afternoon. Before dusk, I get this restless, anxious feeling that seems to come from a very primal place. It reminds me of many nights at the farm, watching the birds flit about and twitter around the trees as they settle in for the night. I feel the way I think they must feel."

Carole M. from *BAI Beacon*, [www.banneralz.org](http://www.banneralz.org)

"The hardest part for me is the denial that others reflect back to me when I mention my diagnosis. I'm not imagining it – it's not normal absent-mindedness...It took me three hours to get to my friend's house. I arrived in tears, and he just laughed. I was humiliated."

*Alzforum* 2006

"I was healthy, exercised, ate right and had a photographic memory until age 46. When I started to forget, I blamed it on the stressful job. Diagnosis was a relief. Five years later, I live a somewhat normal life but 'normal' changes daily. I'm not as outgoing, self-sufficient, engaging and definitely not the life of the party."

Kris, GA. 2008

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## Early Diagnosis and Then What? (continued from page 6)

“I want to go to lunch with friends, complain about the local sports teams and talk about the same stuff they do.”

Los Angeles Early Stage Forum, 2007

“Everything takes longer for the words to register and make sense....Holidays – Tis the season to be stressed, perplexed, implode and explode...I am tired – tired of confusion, losing things, forgetting and being frustrated at my own inconsistencies – why can’t I follow simple instructions?”

C. Hollinshead blog, *Asheville Citizen Times*

“How do I want to be treated? I want to be treated well, just like normal. Alzheimer’s isn’t my whole life. I want to be included. I am more than memory or a diagnosis. I wonder, Am I a case? I thought I was just one of the Ramblers.”

Tommy Thompson, NPR1996, Original member of the NC Red Clay Ramblers

“I get tired of asking when or what is going to be, but I don’t want to keep my mouth shut all the time. I want to be part of something. We people with Alzheimer’s actually do wonder how things happen and why. We want things to be like they used to be – it hurts like h---. Being dense is a big part of it – it’s a very come and go disease. My little dog helps – he doesn’t talk back or tell you you’re crazy.”

Cary S. Henderson, PhD. 1994, Author of *Partial View* (1998)

### Voices of Alzheimer’s Disease—Key Issues Identified by the Alzheimer’s Association Early Stage Task Force

- Stigma, social isolation, marginalized relationships
- Missed or late diagnosis (especially younger onset)
- Dissatisfying relationships with doctors
- Eligibility for and results of clinical trials
- Dependency, credibility, driving
- Staying engaged, opportunities for legacy and advocacy

### Voices of Persons with Dementia: Things that Help us Through Tough Times

- Humor
- Perspective “It’s good to be alive”
- Thankful for the good and positive—much to enjoy and it could be worse
- Don’t be too quick to judge
- Luck and good timing
- Perseverance
- Marry the right person
- Effective Communication

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## Early Diagnosis and Then What? (continued from page 7)

- Don't hold things in
- A good dog
- Make plans to look forward to

Perspectives newsletter, 2010  
(See resource list below)

### Try These Sources for Early Stage Memory Disorders

Social Security recently added younger onset Alzheimer's to conditions under compassionate allowances giving those with the disease expedited access to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Click here for application checklist!  
[alz.org/living-with-alzheimer's-social-security-disability.asp](http://alz.org/living-with-alzheimer's-social-security-disability.asp).

*Living Your Best with Early Stage Alzheimer's Disease* (2010) by Lisa Snyder. Outstanding new book for those living with early-stage AD.

*What Happens Next?* A free mailed or downloadable pamphlet written by and for people with early stage memory disorders from Northwestern Alzheimer's Disease Center in Chicago. [www.nia.nih.gov/Alzheimers/Publication/WhatHappensNext.htm](http://www.nia.nih.gov/Alzheimers/Publication/WhatHappensNext.htm) or 800-438-4380.

*Speaking our Minds: What It's Like to Have Alzheimer's*, Revised Edition 2009 by Lisa Snyder.

*Perspectives – A Newsletter for Individuals with Alzheimer's or a Related Disorder*. Edited by Lisa Snyder and free email subscriptions from <http://adrc.ucsd.edu>.

*Voices of Alzheimer's Disease: A Summary Report on the nationwide town hall meetings for people with early stage dementia*. (2008). [www.alz.org/national/documents/report\\_townhall.pdf](http://www.alz.org/national/documents/report_townhall.pdf).

“Top Ten Ideas for Enhancing Quality of Life by Diagnosed Individuals and Families Living with Alzheimer's Disease and Related Dementias” by Darby Morhardt. *Alzheimer's Care Quarterly* 2004 5 (2):103-110.

[www.ftd-picks.org](http://www.ftd-picks.org): The Association for Frontotemporal Dementias.

[www.lewybodydementia.org](http://www.lewybodydementia.org): LewyBody Dementia Association.

[www.brain.northwestern.edu/ppa/treatment.html](http://www.brain.northwestern.edu/ppa/treatment.html): Helpful communication tools for persons with Primary Progressive Aphasia.

“From ‘not a big deal’ to ‘hellish’: Experiences of older people with dementia” by Wendy Hulko. *Journal of Aging Studies* 23 (2009) 131-144.

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## Early Diagnosis and Then What? (continued from page 8)

*Quality Dementia Care Series: Younger Onset Dementia: a practical guide.* From Alzheimer's Australia, JR Hodges et. al, February, 2009. Downloadable online.

*In our own words: Younger Onset Dementia.* A collection of very personal stories. Alzheimer's Australia. February, 2009. Downloadable online.

“Arts allow Alzheimer's patients to live in the moment” by Mary Brophy Marcus, *USA Today*. Available online, September, 2009.

[youtube.com/watch?v=LjD5IP7PxVO&NR=1](http://youtube.com/watch?v=LjD5IP7PxVO&NR=1) The Face of Alzheimer's & Alzheimer's: A Family Changed. African-American family early to late stage AD.

[youtube.com/watch?v=6ZhdQz7LTiQ](http://youtube.com/watch?v=6ZhdQz7LTiQ) People with Alzheimer's disease mentoring medical students. The Northwestern ADC Buddy Program.

[youtube.com/watch?v=OICOFHXOYO8&Feature=related](http://youtube.com/watch?v=OICOFHXOYO8&Feature=related). Eye to Eye Alzheimer's.

[www.alz.org/living\\_with\\_alzheimers\\_10269.asp](http://www.alz.org/living_with_alzheimers_10269.asp) Ten Tips for Keeping Your Independence from the Alzheimer's Association.

[www.pbs.org/wttw/retirementrevolution/2009/08/03/gary-and-diane-shelton](http://www.pbs.org/wttw/retirementrevolution/2009/08/03/gary-and-diane-shelton) Interview with Alzheimer's Association SC early stage advisor and his wife.

[www.alzheimer.ca/english/haveAD/advice-message.htm](http://www.alzheimer.ca/english/haveAD/advice-message.htm). *I have AD: Advice from Support Groups: A Message to Family and Friends from the Alzheimer Society, Canada.*

Participating in Activities You Enjoy – More than Just Fun and Games. Tips from the National Institute on Aging (Oct 2009).

Participating in Alzheimer's Disease Clinical Trials and Studies (September, 2009 Fact Sheet). National Institute on Aging.

Computer-based Cognitive Training for Mild Cognitive Impairment: Results from a Pilot Randomized, Controlled Trial by DE Barnes et al. *Alzheimer Disease & Associated Disorders* 23 (3): 205-210. September, 2009.

Selfhood in younger onset dementia: Transitions and Testimonies by Phyllis Braudy Harris and John Keady. *Aging and Mental Health*, 2009. email: [pharris@jcu.edu](mailto:pharris@jcu.edu).

*The Alzheimer's Action Plan* (2009 paperback family guide for early to moderate stages of memory disorders) by PM Doraiswamy and LP Gwyther with Tina Adler. (Honorable Mention Award, 2009, for consumer health from the American Medical Writers Association).

## SHADOWS

Ruth Smith, Raleigh, NC

Memories dart in and out of our minds. Some with clarity and others left in distress. Fleeting thoughts with failed connections. If not today, perhaps tomorrow, or surely someday soon connectors will burn brightly again.

Cross wires become exposed to belligerent voices heard and unheard of past remembrances. This path is destructive..what next? Passage of time, games, fun, sorrow. Where/who are loved ones? Slowly, recognition of Alzheimer's invades our lives.

Shadows, sun shining through trees after a soft fallen snow presenting shadowy reflections. Precious memories and there are many. Keeping our focus on the now, trusting our memories to safe keeping lest, we too, forget.

Failing to record our relationship, my husband once asked me where *I lived*. *Told me he had some children he would like me to meet. How many do you have? Five, he answered! I told him I had three, Barry, Bill and Kathy. In a distance, a firefly lit his eyes and he responded, I have some of those too.* Told him I thought they were ours while giving him a big hug.



Reflecting another memory, we were at Myrtle Beach for three days. Prior to leaving, Frank said to me “I have had a wonderful time down here with you. Are you going to tell my wife?” I responded, ‘no, are you?’, he said ‘NOT ME’! Another hug.

There is a song with words, “Through it all, through it all, you learn to depend on the Lord.” Faith is all sustaining in trusting God foremost.

Without direction and support from the staff at the Duke ‘Caregiver’, we all suffer during this journey.

Be blessed!

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“When we're young, we think these things only happen to other people; as we get older, we realize we are those other people.”

—Vladimir Nabokov

## A Daughter's Journey with Alzheimer's

Terri Payne, Durham, NC

Caring for someone with Alzheimer's Disease is a journey filled with changes, losses and transitions, traveling with someone who enjoys the ups and downs of the ride, but forgets the "trip" soon after it ends and needs many helpers to go along so she will make it through safely. There are periodic remembrances of events from the past (sometimes sprinkled with errors), celebrations of life events that are enjoyed, but quickly forgotten and caregivers who continually look for vestiges of the person who used to be.

My mother turned 90 years old in January 2010. Our family ALZ journey with her began about five years ago. Her own journey was preceded by her helping our family care for an adopted aunt who was diagnosed in 1996; at that time my "aunt" was 86 years old. My mother, my Alzheimer's caregiver assistant, watched with us as my aunt slowly progressed further into memory loss and inability to care for herself without more and more assistance.

Decades earlier, my mother cared for her blind sister-in-law and her brother who came to live with our family before they succumbed to chronic illnesses and cancer. Mom was also the temporary caregiver for a great niece whose father was in the armed services and whose mother became ill and could not care for her young daughter.

After successfully facing these caregiver challenges, mother then began a decade-long journey caring for my disabled father and her own health began to deteriorate. They made the decision to move near us in Texas, leaving behind their life after 70 years in Virginia. Throughout these events in her life, she remained strong, charming and outgoing. She was often the "belle of the ball" at social events we held in our home.

Given this background it is not difficult to understand why the decision to place my mother – the family caregiver who prevented family members from moving to care facilities – was one of the hardest I have had to make. The medical decision for placement does little to ease the emotional pain we have experienced. Before mom was placed in the family care home in the spring of 2008, she was still crocheting lap blankets for disabled seniors, playing board games with our family, dressing quite smartly and baking delicious pound cakes and sweet potato "jacks" which she introduced to our friends as we relocated to cities across the U.S. (It was when we moved to NC that people knew of these turnovers!)

But she had also become less willing to take part in social events at our home, aware and frustrated that her memory was "bad", suspicious and accusing as she misplaced her wallet, jewelry, and periodically irrational or incorrect about events, dates and people. With great support of family and friends and paid caregivers, we could handle most of these changes. She was still very much the family matriarch, holding court, as our family life revolved more and more around her care and well-being. Finally my mother had to be hospitalized after particularly distressful behavior changes that caused her to lash out at my daughter.

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## Long Term Care Facilities: Getting Good Care There

Sabrina Jennette, Duke Family Support Program Intern  
University of North Carolina-Chapel Hill MSW Program

There are many Long Term Care (LTC) facilities, including adult care homes, assisted living and nursing facilities in N.C. providing a range of services to residents and families. Some of these services consist of nursing care, therapies, pharmaceutical care, and specialty care, including Alzheimer's and memory care units. In North Carolina alone there are over 400 nursing homes providing these services and more.

Long Term Care Facilities (LTC) are vital resources for families. For many individuals, it may no longer be feasible to remain in their own homes. Many of the residents need help with intimate personal care, help with eating, managing medications, and getting around. Almost half are cognitively impaired; and may have many chronic diseases. When issues such as staffing, treatment, safety, or neglect interfere with this care, and all other options for resolution have been considered, it may be time to file a complaint.

Individuals may not file complaints against LTC facilities because they do not understand their rights or the filing procedures. They may also be fearful of retaliation against their relatives, sadly, allowing potential harm to occur. Residents of nursing homes are among the most vulnerable of our population. Families and residents need to know their rights to quality care and safety so that they can advocate for themselves.

Before filing a complaint, consider...

- Initially, allow time for the resident and the staff to adjust to one another.
- Build relationships with those directly responsible for the resident's care and acknowledge when they do a good job.
- Be positive, professional, and present. Be involved in the resident's care without being demanding or adversarial.

- Communicate regularly and openly with staff. Remember, families are the experts on their loved ones.
- Document concerns when they arise - dates, times, and circumstances.
- Become aware of residents' rights.
- Advocate for relatives. If concerned about the immediate safety of residents, report to Adult Protective Services at your local Department of Social Services.
- Finally, give the facility an opportunity to investigate and resolve issues.

When filing a complaint, consider.....

- If no resolution is taken, put the complaint in writing.
- Learn and follow filing procedures.
- Seek help from an advocate or organization like N.C. Friends of Residents in Long-term Care.
- Move relative to another facility if no action is taken.

Families and residents need to advocate for themselves, but they do not have to do it alone. The Long Term Care Ombudsman Program is one organization that advocates for residents living in LTC facilities. They work with residents, families, staff, and public organizations to resolve concerns or complaints and ensure that residents' rights are protected.

Be assured that many LTC facilities do provide quality care. Issues may occur when there are changes in private ownership that may affect quality of care. Families report a range of

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## Long Term Care Facilities (continued from Page 12)

excellent care to very poor quality of care. It is important to do your homework before selecting a facility. Visit the facility, speak with the staff, residents and other family members. No one can know the future and incidents can occur even taking all precautions. It is reassuring to know there are procedures for handling situations if and when they arise. Learn these procedures and know residents' rights, as well as your rights as his/her family advocate or voice.



The link and number below is to the North Carolina Long Term Care Ombudsman Program where you can learn about residents' rights and how to file a complaint.

**<http://www.dhhs.state.nc.us/aging/ombud.htm> (919) 733-3983.**

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## A Daughter's Journey with Alzheimer's (continued from Page 11)

She was never "happy" about not coming back to live with us, but she "directed" activities at the family care home the first months, actively engaging in the home activities and still crocheting lap blankets. The owners and staff were patient and understanding as my mother's routine and adjustment was tested again when she experienced a Transient Ischemic Attack (TIA), and was hospitalized. She became more adamant about leaving the care home after the hospitalization, and our visits would remind her to pack and be on her way to her old life. We reduced and then increased our visits, but eventually she required a move to a secure, larger assisted living facility. Although feisty and still relentless in trying to get out the door, she does well with the routine there. Her disease continues to progress and I find myself missing our old conversations even more. We constantly ask ourselves if she would be more communicative in her familiar environment at our home. Currently, we are forced to anticipate yet another move with even less choice due to Medicaid constraints.

What have I learned? You can't plan enough for such a long and variable illness and you can't anticipate how you will feel or respond personally. Most important, I have learned not to be judgmental about other family members' or other family caregivers' decisions. We all do the best we can. The journey continues....

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"Memory is a way of holding on to the things you love, the things you are and the things you never want to lose."

—Kevin Arnold

## Avoiding Turbulence During Travel

Lindsay Penny, Bryan ADRC Intern

University of North Carolina–Chapel Hill MSW Program

While going through airport security recently, I overheard a woman pleading with a staff member. Her mother was struggling to follow instructions given by security personnel, and she was concerned that her mother would not be able to find her gate beyond the security checkpoint. Airport staff dismissed the daughter, offering no suggestions or solutions to the situation, and they left her mother to make her own way. Concerned for the family's predicament and disturbed by the staff's indifferent response, I found the older woman putting on her shoes and gathering her bags, and I ensured that she made it to her gate.



Navigating airports has become increasingly confusing, particularly with the increased security since 9/11 and subsequent events. Sadly, issues of ease and efficiency of travel have been ignored. An individual is required to pass through multiple check points and follow detailed instructions before reaching the gate, and this can prove challenging to travelers of all ages. These issues become even more complicated for frail individuals with cognitive impairment or memory disorders, all of which compound the confusing noise, activity, and stress, rendering successful navigation of the process almost impossible. In some cases, the presence or seriousness of an individual's memory impairment is not even detected by family until an incident occurs while traveling. Although in ideal situations, a

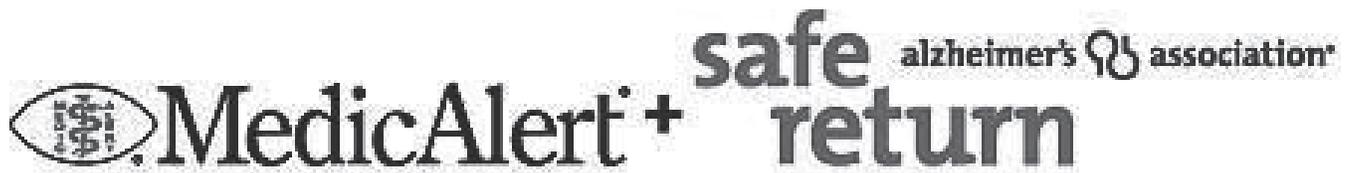
cognitively impaired individual would not be traveling alone, family and friends cannot always afford to accompany impaired individuals on planes. As I learned from this experience, airport staff cannot always be depended upon to help individuals with cognitive impairment successfully reach their destinations within the airport. The responsibility falls upon concerned family or friends.

There are several services for families eager to insure a person with memory loss reaches his/her destination safely. Unfortunately, these services are often not well-publicized. Families must find and arrange for these services in advance. Airlines do offer gate passes for family members wishing to accompany an elder to the gate, and these passes may be arranged as well when meeting someone

at the airport. Gate passes may be requested and issued at the check-in counter, but airlines may have different policies for individuals meeting an impaired adult at their destination. Family members are well advised to call the airline in advance for specific instructions. There may be an additional fee.

Caregivers who cannot accompany an individual with Alzheimer's through the airport should inquire about meet-and-assist services. Airlines usually offer these services for a fee and with pre-arrangement. An airline staff member will guide the individual from check-in to the aircraft and then from the arrival gate to baggage and the curb. Call the airline in advance to request, pay for, and arrange this meet-and-assist service.

(continued on Page 15)

**Avoiding Turbulence During Travel** (continued from Page 14)

**Live 24-hour emergency response service for wandering and medical emergencies**

Whether cognitively impaired individuals are traveling alone or accompanied by family, there is often a risk that they will become lost or separated in a structure as expansive and confusing as an airport. Because becoming lost is a potential risk, families should register for the Alzheimer's Association Safe Return/Medic Alert program in advance of any trip. Be sure to travel with access to the emergency response number. In an airport, a person should be reported missing immediately.

Successfully navigating airports is a difficult task, but with advance planning, families can help memory-impaired relatives have safe, successful travel.



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“You can’t cross the sea merely by standing and staring at the water.”

—Rabindranith Tagore

“Not the maker of plans and promises, but rather the one who offers faithful service in small matters. This is the person who is most likely to achieve what is good and lasting.”

—Johann Wolfgang Von Goethe

### Most Precious Valentine Ever

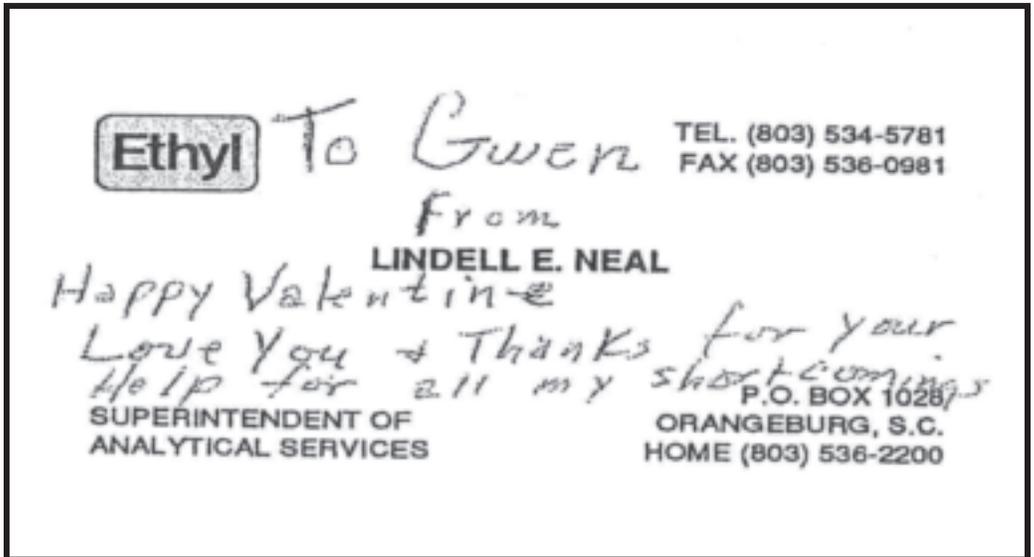
Gwendolyn Neal, Greenville, NC

This valentine story began in 1948 when my husband and I began dating. I was in high school and he had just graduated from the same school. We dated for three years and were married for 56 years before his death in 2008. He was diagnosed with Alzheimer's Disease in 2004, but it had been developing years prior to that. He was fairly far into this journey when he presented me with the best ever valentine. Valentine's Day 2006, I gave him a valentine and he said, "I couldn't get you a valentine." I told him I knew that but I wanted him to have one from me to let him know how much he meant to me. Then I went to another room before going to the kitchen to fix breakfast. When I walked into the kitchen, I noticed a little card on the table. I could not believe it. Some way his brain connected enough for him to

get one of his business cards out of the drawer. In the space above his name he wrote, "To Gwen From Lindell E. Neal (printed on the card). Then he proceeded to write, "Happy Valentine, Love you & thanks for your help for all my shortcomings." His job title, address and phone were already on the card. This was such a wonderful surprise. He was able to even think of getting the card out of the drawer, much less write what he did. I cried and cried and told him that was the Best Valentine I had ever received from him. This is one of the reasons I am upset when I hear someone say, "They don't know anything" because we don't know what they know. So many things are trapped in their brains. We need to work with what is possible and we never know when something wonderful will happen.

"We are shaped and fashioned by what we love."  
—Johann Wolfgang Von Goethe

"We should not be discouraged when our acts are small, when our acts are not grand, heroic things. We have to regain our belief in the power of what is small."  
—Alice Walker



# Check Your Medicines



**Bring a list or a bag with ALL your medicines when you go to your doctor's office, the pharmacy, or the hospital.** Include all prescription and over-the-counter medicines, vitamins, and herbal supplements that you use. If your doctor prescribes a new medicine, ask if it is safe to use with your other medicines. Remind your doctor and pharmacist if you are allergic to any medicines.



**Ask questions about your medicines.** Ask questions and make sure you understand the answers. Choose a pharmacist and doctor you feel comfortable talking with about your health and medicines. Take a relative or friend with you to ask questions and remind you about the answers later. Write down the answers.



**Make sure your medicine is what the doctor ordered.** Does the medicine seem different than what your doctor wrote on the prescription or look different than what you expected? Does a refill look like it is a different shape, color, or size than what you were given before? If something seems wrong, ask the pharmacist to doublecheck it. Most errors are first found by patients.



**Ask how to use the medicine correctly.** Read the directions on the label and other information you get with your medicine. Have the pharmacist or doctor explain anything you do not understand. Are there other medicines, foods, or activities (such as driving, drinking alcohol, or using tobacco) that you should avoid while using the medicine? Ask if you need lab tests to check how the medicine is working or to make sure it doesn't cause harmful side effects.



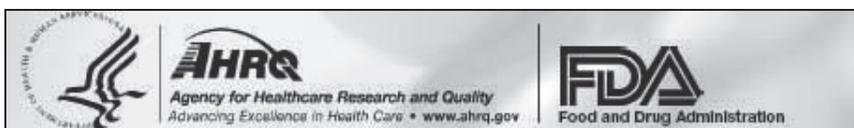
**Ask about possible side effects.** Side effects can occur with many medicines. Ask your doctor or pharmacist what side effects to expect and which ones are serious. Some side effects may bother you but will get better after you have been using the medicine for a while. Call your doctor right away if you have a serious side effect or if a side effect does not get better. A change in the medicine or the dose may be needed.

## Simple checks could save your life!

Visit: [www.ahrq.gov/consumer](http://www.ahrq.gov/consumer)

[www.fda.gov/usemedicinesafely](http://www.fda.gov/usemedicinesafely)

AHRQ Pub. No. 08-M044-A



(Replaces 07-M008-1)

April 2008

Food and Drug Administration

## Have You Heard About?

Carstensen, Laura L (2009). *A Long Bright Future, An Action Plan for a Lifetime of Happiness, Health, and Financial Security*. Dr. Carstensen sheds the myths and misconceptions about aging that stop individuals from adequately preparing for healthy, fulfilling, and financially stable long lives.



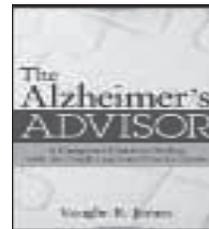
Donohue, Mike (2010). *From AA to AD, A Wistful Travelogue*. This is a story of Mike Donohue's journey, about the tools of AA explaining how they are key to abstinence and to a better life. It discusses the tool at work in his life and finally with acceptance of AD.



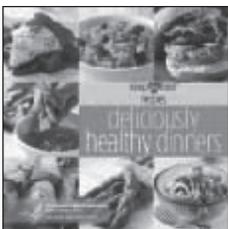
Fox, Judith (2009). *I Still Do: Loving and Living With Alzheimer's*. *I Still Do* puts a human face in front of the statistics, exploring the disease through Fox's intimate photographs and poetic writing. While the details of *I Still Do* are personal and unique, this deeply candid story of illness, aging, partnership, and loving is universal. This book has been selected one of the ten best books of 2009 by Photo-eye Magazine.

Hall, Julie (2007). *The Boomer Burden: Dealing with your Parents' Lifetime Accumulation of Stuff*. With fascinating stories and comprehensive checklists, professional estate liquidator Julie Hall walks Baby Boomers through the often painful challenge of dividing the wealth and property of their parents' lifetime accumulation of stuff.

James, Vaughn E (2008). *The Alzheimer's Advisor: A Caregiver's Guide to Dealing with the Tough Legal and Practical Issues*. A guide to the legal and ethical aspects of caring for a family member with Alzheimer's.



Kind, Viki (2010). *The Caregiver's Path to Compassionate Decision Making: Making Choices for Those Who Can't*. This book provides a method for facing tough choices in emotionally charged circumstances. It features practical tools for individuals and professional caregivers.



National Heart, Lung, and Blood Institute (2009). *Keep the Beat "Recipes: Deliciously Healthy Dinners"*. A brand new version of the popular *Keep the Beat* classic cookbook has 75 new deliciously healthy recipes, beautiful full-color design throughout, and original food photographs. The focus is on heart healthy dinner entrees and side dishes, influenced by Asian, Latino, Mediterranean, and American cuisines.

Nevin, Sean (2008). *Oblivio Gate*. Poems about aging, dementia and caregiving. Southern Illinois University Press.

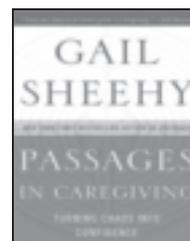
(continued on Page 19)

## Have You Heard About? (continued from Page 18)

Russo, Francine (2010). *They're Your Parents Too: How Siblings Can Survive Their Parents' Aging without Driving Each Other Crazy*. Written by a veteran journalist who chronicles life and how baby boomers live it, **They're Your Parents, Too!** offers information, insight, and advice you'll need to make productive choices as you and your siblings begin to assume your parents' place as the decision-making generation of your family.

Restak, Richard (2009). *Think Smart: A Neuroscientist's Prescription for Improving Your Brain's Performance*. In this book, brain expert Restak explains the latest scientific discoveries about our brain and gives readers strategies on how they can keep their most powerful organ in top condition and fight off its decline.

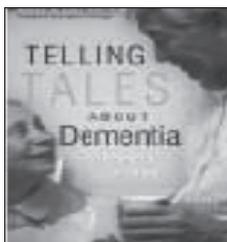
Sheehy, Gail (2010). *Passages in Caregiving: Turning Chaos into Confidence*.



Tadd, Marie (2009). *Happiness is Growing Old at Home*. With first-hand experience in helping a parent age gracefully at home, Tadd has written a practical, user-friendly book with warmth, wisdom, and a touch of humor. Presents guidelines, warning signs, and questionnaires to use in assessing and selecting quality in-home care, rehab, and hospice services.

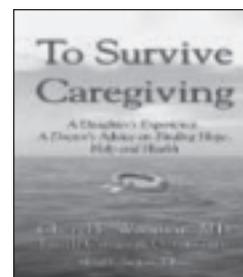
Thorndike, John (2009). *The Last of His Mind: A Year in the Shadows of Alzheimer's*. A bittersweet account of a son's final year with his father, and a candid portrait of an implacable disease.

Whiteside, Holly (2010). *The Caregivers Compass: How to Navigate with Balance & Effectiveness Using Mindful Caregiving*. A guidebook of tools that help caregivers to achieve emotional balance.



Whitman, Lucy (2009). *Telling Tales About Dementia*. This unique collection of personal accounts will be an engaging read for anyone affected by dementia in a personal or professional context, including relatives of people with dementia, social workers, medical practitioners and care staff.

Woodson, MD, Cheryl E. (2007). *To Survive Caregiving: A Daughter's Experience, A Doctor's Advice on Finding Hope, Help and Health*. An African-American geriatrician daughter's experience and perspectives on care for a parent with Alzheimer's. [www.woodsonctr.com](http://www.woodsonctr.com).



“Just when I was getting used to yesterday, along came today.”

—Greeting card

## New Online Help

[http://www.youtube.com/watch?v=IZa5m9kd\\_z4](http://www.youtube.com/watch?v=IZa5m9kd_z4) and here for the Resource Guide: [www.medicare.gov/caregivers/pdfs/Resource\\_and\\_Benefits\\_for\\_Caregivers.pdf](http://www.medicare.gov/caregivers/pdfs/Resource_and_Benefits_for_Caregivers.pdf). Ask Medicare is CMS' website for caregivers. It is as easy as logging onto [www.medicare.gov/caregivers](http://www.medicare.gov/caregivers) to help a friend or family member choose a drug plan, compare nursing homes, get help with billing, find local resources, and more.

[www.geriatricpain.org](http://www.geriatricpain.org), is a one-stop resource, offering best practice tools and resources concerning pain assessment and management in older adults in long-term care settings.

[www.brainworldmagazine.com](http://www.brainworldmagazine.com). New magazine published by the non-profit, international Brain Education Association for lay leaders. Includes resources and stories on healthy brain aging and Alzheimer's.

[www.suescoggins.com](http://www.suescoggins.com), "Me, Painting and Alzheimers" blog by an artist who displayed her work (prompted by her husband's young onset FTD) at the Bryan ADRC 23rd annual conference in 2009.

[http://www.alz.org/living\\_with\\_alzheimers\\_social\\_security\\_disability.asp](http://www.alz.org/living_with_alzheimers_social_security_disability.asp). NEW Social Security compassionate allowance available for earlier eligibility for young-onset Alzheimer's and other dementias. This is an advocacy victory for the Alzheimer's Assn.

<http://www.timegoesby.net/weblog>. Time Goes By is an excellent collection of weblogs, including some from the perspective of Alzheimer's family caregivers.

[oldwayspt.org/mediterranean-diet-pyramid](http://oldwayspt.org/mediterranean-diet-pyramid). Mounting evidence presented at the Bryan ADRC conference suggests the Mediterranean diet may reduce or delay risk of cognitive decline. This is the pyramid presented by Dr. Burke at the Bryan ADRC Conference.

<http://www.olderdriversafety.ca/consumer/index.html>. Older drivers "retirement" and safety tips.

[www.4070talk.com](http://www.4070talk.com). It is often difficult for older adults and their grown-up children to broach and discuss important topics that arise in later life, such as balancing independence and safety, managing money, and end-of-life issues. The goal of this website is to make it easier.

<http://www.youtube.com/watch?v=sIRb—Nauwk>. Powerful 6 min. PBS special on a woman with early stage AD.

<http://www.abanet.org/aging/pdfs/genlproxyguide2009.pdf>. Making Medical Decisions for Someone-Else: A How-To Guide (2009) from the American Bar Association Commission on Law and Aging.

<http://www.gilbertguide.com/articles/avoiding-surprises-services-covered/>. A comprehensive database of quality assessment tools, and vital, practical information on today's senior care issues.

<http://www.alzheimer.sk.ca/english/Just4Kids>. Children's information on Alzheimer's from Canada.

(continued on Page 21)

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**New Online Help** (continued from Page 20)

<http://www.ncdoi.com/Consumer/SHIP/SHIP.asp>. The Seniors' Health Insurance Program (SHIP) answers questions and counsels Medicare beneficiaries and caregivers about Medicare, Medicare supplements, Medicare Advantage, Medicare prescription drug plans, long-term care insurance and other health insurance concerns.

[www.icarevillage.com](http://www.icarevillage.com). See Alzheimer's and Memory section for articles and video for family caregivers.

<http://nihseniorhealth.gov/videolist.htm#falls>. New info on falls and prevention.

[http://www.youtube.com/watch?v=zLRYcj8hv58&feature=autoshare\\_twitter](http://www.youtube.com/watch?v=zLRYcj8hv58&feature=autoshare_twitter). Excellent Alzheimer's Association You Tube video—Voices of people with AD.

[thehartford.com/calmbeforethestorm/index.html](http://thehartford.com/calmbeforethestorm/index.html). *The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's and Dementia*. Important and helpful new book may be downloaded from the website above or ordered free in quantity from The Hartford, The Calm Before the Storm, 200 Executive Blvd, Southington, CT 06489.

<http://www.artistsforalzheimers.org>. ARTZ is Artists for Alzheimer's, an initiative of the Hearthstone Alzheimer's Foundation that draws on the support and collaboration of artists and cultural institutions, as resources to share, educate and inspire.

[www.aoa.gov](http://www.aoa.gov). New helpful information for families.

<http://www.nlrc.aoa.gov>. The National Legal Resource Center.

<http://nihseniorhealth.gov/exercise/foc.html>. New updated exercise site for older adults from the NIH.

[http://news.newamericamedia.org/news/view\\_article.html?article\\_id=be0e33ce58e5175830](http://news.newamericamedia.org/news/view_article.html?article_id=be0e33ce58e5175830). News article on Women and Retirement—'The Big Mistake.'

[theatlantic.com/magazine/archive/2010/03/letting-go-of-my-father/8001](http://theatlantic.com/magazine/archive/2010/03/letting-go-of-my-father/8001). (April 2010) by Jonathan Rauch. Powerful personal story of a son trying to care for his father suggesting that family care crises be "plucked from the realm of the person and brought into full public view."

[http://www.caregiving.org/data/emblem/CfC10\\_Final2.pdf](http://www.caregiving.org/data/emblem/CfC10_Final2.pdf). Caring for the Family Caregiver: A Place to Start—a 56 page booklet from the National Alliance for Caregiving.

<http://www.consumerreports.org/health/best-buy-drugs>. Safe and effective drug recommendations from Best Buy Drugs.

[www.lojack.com/safetynet/pages/resources.aspx](http://www.lojack.com/safetynet/pages/resources.aspx). Wandering and family caregiver resources and products.

<http://seeingalzheimersdifferently.blogspot.com>. Cathy Greenblat's interactive and positive photos with expert audio commentary on Alzheimer's around the world.

<http://www.easyforyou.info/index.asp>. Screen yourself for safe personally-tailored exercise.

<http://www.forltc.org/cms>. Friends of Residents in Long Term Care—new resources.

[www.KnowItAlz.com](http://www.KnowItAlz.com). Featured in *USA TODAY*—blog about family care for people with dementia.

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(continued on Page 23)

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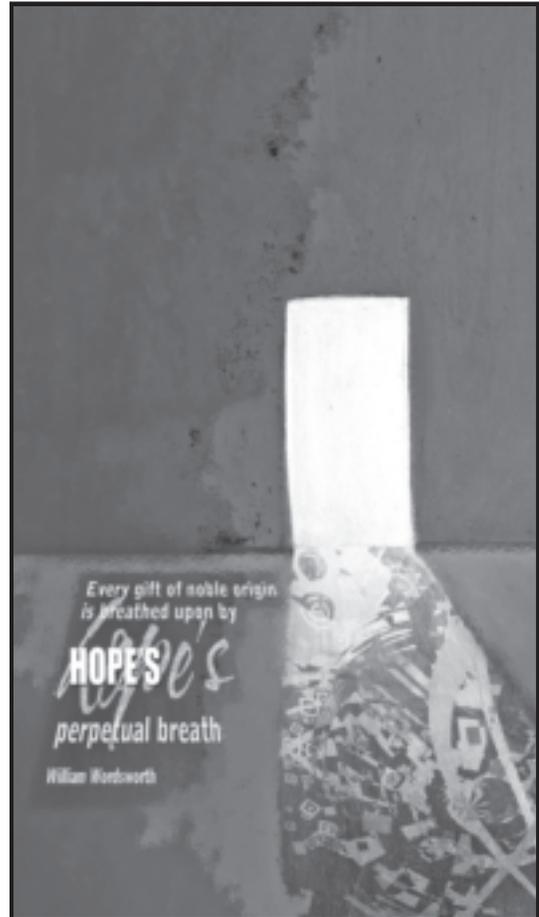
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—Apache Blessing

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