

The CAREGIVER

*A Bridge to Understanding
Your Options*

Newsletter of the Duke Family Support Program

Volume 32, Issue 2

Fall 2013

NC PROJECT C.A.R.E. MOVES STATEWIDE

Project C.A.R.E. (Caregiver Alternatives to Running on Empty) uses a family consultant model to provide comprehensive support for caregivers. Specialized family consultants offer home visits, care planning and ongoing support as needs change. Project C.A.R.E. helps reduce family caregiver stress so that people with dementia can remain at home for as long as possible.

Project C.A.R.E. is now available to residents in all 100 NC counties, rather than 36 original counties. The focus is on families caring at home for someone with Alzheimer's or a related disease, particularly those families in rural areas with few other resources. This specialized family consultation is available through successful partnerships among the NC Area Agencies on Aging, the NC Family Caregiver Support Program, the NC Division of Aging and Adult Services and Alzheimer's family consultants based in Asheville, Durham and Greenville NC. These regional specialized family consultants, working with local and regional family caregiver support specialists, offer personalized education, referral and monthly follow-up. In keeping with new visions for long-term services and supports, Project C.A.R.E. goes beyond addressing the immediate needs of the individuals with Alzheimer's to tackle the health and social risks to the families providing such invaluable community-based care. NC Project C.A.R.E. supports family strengths and capacity while acknowledging real risks to these families from running on empty.

To learn how you or someone you know can access help from NC Project C.A.R.E. go to <http://www.ncdhhs.gov/aging/ncprojectcare.htm>, or find the NC Family Caregiver Support Program Specialist in your region at <http://www.ncdhhs.gov/AGING/fchome.htm>. For toll-free information, call Bobbi Matchar, MSW, MHA at the Duke Family Support Program at 800-646-2028.



In August 2013, NC tragically lost its visionary innovator, leader and passionate advocate for Project C.A.R.E with the death from cancer of Len Erker of Weaverville, NC. We join his wife and nine children in mourning his loss, but we honor his legacy with this statewide expansion.

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Duke Family Support Program

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Caregiver subscriptions are available free to N.C. residents. Call 919-660-7510 or 800-646-2028.

View this newsletter online at www.dukefamilysupport.org

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 800-646-2028
 919-660-7510
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National Alzheimer's Association

225 North Michigan Avenue, Suite 1700
 Chicago, IL 60601-7633
 312-335-8700
 800-272-3900 (24/7 Helpline)
www.alz.org

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

3739 National Drive, Suite 110
 Raleigh, NC 27612
 800-272-3900 (24/7 Helpline)
www.alz.org/nc (for support groups, other events and more information)
 Email: info@alz.org

Walk to End Alzheimer's Eastern, NC

- New Bern: October 26, 2013
- Wilmington: November 16, 2013

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

3800 Shamrock Drive
 Charlotte, NC 28215-3220
Satellite Offices: Asheville, Greensboro and Hickory
 800-272-3900 (24/7 Helpline)
www.alz.org/northcarolina
 (for support groups, other events and more information)
 Email: infonc@alz.org

Poker Face Charlotte: A Charity Masquerade Ball:
 October 25, 2013

Ashe County Memory Breakfast: November 8, 2013

Purple Sunday: November 10, 2013

Walk to End Alzheimer's Western NC

- Asheboro: October 26, 2013

Alzheimer's North Carolina, Inc.

1305 Navaho Drive, Suite 101
 Raleigh, NC 27609
Satellite Offices: Wilmington and Greenville
 919-832-3732 or 800-228-8738
www.alznc.org (for support groups, other events and more information)
 Email: info@alznc.org

Caregiver Education Conferences

- Lumberton: November 13, 2013, See their website
<http://www.alznc.org/index.php/alzheimers-conferences-workshops>
- Raleigh: November 21, 2013 Springmoor Life Care Retirement Community's Annual Dementia Conference, contact joyce.eisele@springmoor.org
- Goldsboro Family Caregiver Workshop: February 2014
- Wilson Full Day Caregiver Education Conference at Barton College: March 2014

New to the Duke Family Support Program: Dean Fox

Dean Fox of Greensboro, NC will be working with the Duke Family Support Program for three days a week during this academic year. Dean is in his second and final year as a graduate student in the Masters in Social Work (MSW) Program at the University of North Carolina School of Social Work in Chapel Hill. In addition to his MSW degree, Dean will graduate in May with a Certificate in Aging, an interdisciplinary program for graduate students and professionals interested in expanding their involvement in aging.

Dean is working with families of people with memory disorders and he is assisting with the Early-Stage Alzheimer's Education and Support Program. He is also continuing to work part-time at Charles House Daytime Eldercare Center in Carrboro. Watch for his newsletter feature story in *The Caregiver*, Spring 2014 issue. Welcome Dean!

TOMMORROW

New Direction in Delaying or Preventing Alzheimer's Disease: The TOMMORROW Study

By Kathleen Welsh-Bohmer, Ph.D. & Brenda L. Plassman, Ph.D.
Bryan Alzheimer's Disease Research Center, Duke University

If Alzheimer's disease (AD) research has taught us anything over the last 30 years, it is this: the disease is extraordinarily complicated. We have come to understand that a number of fundamental cellular mechanisms go awry early in the disease, beginning likely in midlife before symptoms are apparent. Ultimately, over a period of decades, two proteins (amyloid and tau) begin to accumulate abnormally resulting in toxicity and cell death. We are now able to diagnose AD earlier in the course of the disease, but finding a treatment, to either cure or prevent the disease, has proven much more elusive. We now believe that an important key to success is in starting targeted treatment early before significant cell injury has occurred. Identifying people at this silent stage of disease is tricky. It requires a strategy to identify people who are at risk of developing the disease within a few years.

A number of exciting drug prevention trials are starting this year with the same fundamental approach in mind: start early, identify normal individuals at high risk of AD, and try promising therapeutics in this group. The first of the studies to launch is the TOMMORROW study, a novel clinical trial designed to delay the onset of AD symptoms. The TOMMORROW study has its roots right here in the Triangle, conceived by an investigative team within the Joseph and Kathleen Bryan Alzheimer's Disease Research Center (Bryan ADRC) at Duke University.

The story begins with a genetic discovery in 2009

when a team of scientists led by Allen Roses, MD identified a gene called TOMM40, (this gene is where the TOMMORROW study gets its odd spelling), that interacts with APOE, another AD gene, to influence the timing of symptom onset in AD. In the 1990's, the Duke team had identified APOE as a major risk gene for AD. Combining both APOE and TOMM40 gene status, the team was able to predict risk of AD in nearly 97% of the individuals studied. This means combined information may offer a way to reliably identify individuals at high risk for AD, appropriate for a clinical trial to delay the onset of their symptoms.

Around the same time, other scientists found that a type of drug used to treat diabetes was also effective in improving memory and function in areas of the brain affected by AD in humans. In animals, the drug reduced amyloid deposition in the brain. Intriguingly, these positive effects were seen with very low doses of the drugs, nearly 55 times lower than the dose used in diabetes. The drug used in these studies, pioglitazone, is commonly prescribed for Type II Diabetes, so the safety profile is well known. And the very low dose needed in order to have a brain protective effect, helps to reduce potential safety concerns. Perhaps one of the most exciting features of this class of drugs for AD is that they appear to influence a number of cellular processes damaged early in the disease. This offers hope that if begun early in the disease process, the compound may have an effect in slowing down the disease.

We are now able to diagnose AD earlier in the course of the disease, but finding a treatment, to either cure or prevent the disease, has proven much more elusive.

TOMMORROW *(continued from page 3)*

The investigators working on the TOMM40 discovery entered into an alliance with Takeda pharmaceutical company which manufactures the compound pioglitazone. At the end of August this year, the study officially launched in the U.S. Over the next 2 years, 50 sites across Europe and the U.S., including a site at Duke and one in Kannapolis NC, will enroll and treat over 5800 cognitively normal adults, many of whom are at increased risk of AD due to their genetics. At the end of 5 years, we will have an answer as to whether we have successfully delayed the early symptoms of this horrible disease.

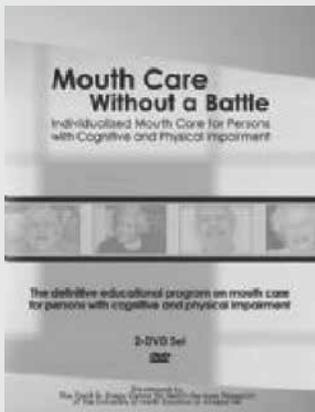
The promise of the TOMMORROW study is that it is taking AD treatment in innovative directions, providing a sensible strategy and a promising drug to

treat AD. Our hope is that we are writing the beginning chapter of a new book for a future without AD. We believe, at a minimum, a strategy of early intervention will put us on a path that takes us more rapidly towards solving this complex disease and will point to treatments that may delay and perhaps even prevent the disease altogether.

Those interested in being a part of the TOMMORROW Study or any of our other prevention studies can contact us by phone (1-866-444-2372) or visit our website (<https://adrc.mc.duke.edu/>).

Be a part of the solution and join us in the search to find a cure for AD. For today is the TOMMORROW we dreamed of yesterday.

NO MORE BATTLES



◆ Did you know that poor mouth care causes as many as half the cases of pneumonia in nursing home residents and other people with physical and cognitive impairment? Poor mouth care also leads to poor nutrition, both by promoting tooth

loss and by causing gingivitis.

Mouth Care Without a Battle®, a training DVD, provides basic mouth care techniques and strategies to care for people with cognitive and physical impairment. Researchers at the University of North Carolina at Chapel Hill developed and studied the outcomes of Mouth Care Without a Battle® and found oral health was significantly improved by the nursing assistants who provided mouth care in accordance with this program. Mouth Care Without a Battle combines best practices in oral hygiene with proven techniques to overcome resistance to care among persons with dementia and related conditions. The DVD has been distributed free of charge to all nursing homes in North Carolina.

For more information:

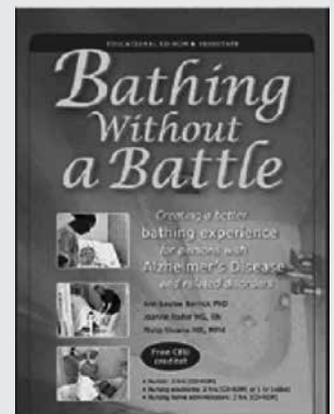
<http://www.mouthcarewithoutabattle.org/>

◆ Each day hundreds of thousands of people with dementia are bathed against their will. This battle that often occurs between people with dementia and their caregivers is in most cases preventable. Bathing can be made into a more humane, gentle experience for persons with dementia.

The Bathing Without a Battle DVD and program was developed using over 10-years of research into improving bathing for persons with dementia. The program combines person-centered techniques with simple, practical approaches to make showering, tub bathing, in-room bathing, and hair washing safe and comfortable for the persons giving and receiving care.

For more information:

<http://bathingwithoutabattle.unc.edu/>



INDIVIDUALS WITH ALZHEIMER'S MENTOR MEDICAL STUDENTS

By Darby Morhardt, MSW, LCSW
Cognitive Neurology and Alzheimer's Disease Center
Northwestern University Feinberg School of Medicine



Buddy Program participants at the Cognitive Neurology and Alzheimer's Disease Center, Northwestern University. Photo by Teresa Crawford.

"I think that as doctors, it may be easy to have the disease state overshadow everything else – and forget the reality of a disease as it affects the patient's life – and the lives of their loved ones. I truly believe that a program like this has enabled me to see the other side of the diagnosis – and will only enhance my ability to practice later on."

- Buddy Program Medical Student Participant

There is a growing concern over who will provide for the care of our aging population. As older adults increase in numbers in our society, there is a similar rise in the number of people with dementia. When coupled with longer life expectancy and increasing risk of Alzheimer's disease (AD), we can expect to see even greater numbers of people with dementia. Thus, there is a need for knowledgeable physicians with a sound understanding of clinically appropriate, and proper, dignified treatment for persons with dementia.

Unfortunately, studies show that healthcare professionals and physicians in particular, tend to have a negative attitude toward older patients and a lack of awareness regarding early diagnosis of dementia. Several studies conducted on the effects of programs bringing together medical students and older adults have shown to be beneficial for medical students in terms of their attitudes towards older people and aging; however, most of these studies have taken place in the clinical setting and have not specifically involved persons with dementia. There is also a gap in programs and services for diagnosed individuals in the early stage of dementia to meet their intellectual and social needs.

In an effort to change student perceptions while providing a meaningful role for persons with dementia, the Northwestern University Cognitive Neurology and Alzheimer's Disease Center (CNADC) developed The Buddy Program, an experiential learning and mentor-

ship program for persons with dementia and first year medical students. This article describes the program and the results of its impact on medical students.

The Buddy Program

The Buddy Program is rooted in the value and belief that persons with early stage dementia, in whatever ways their declining cognition is changing and modifying their functioning, retain the capacity to make meaningful contributions to society and others. In essence, the Buddy Program is based on relationship, conversation, dialogue, and reciprocity. It is about empowerment of the person with dementia in a world where they are at risk of being marginalized and disempowered as they lose cognitive capacity. The person with AD receives companionship and social interaction and the opportunity to mentor and the student, the recipient of that mentoring, has an opportunity to have his/her image of persons with AD shifted or transformed through this mutual relationship.

The program concept originated as a result of a physician who, after being diagnosed with AD, was no longer able to practice medicine; however, he knew he was still able to impart valuable experience and knowledge and 'mentor' a medical student. Simultaneously, we thought the student might benefit not only from the physician's experience and perspective, but might also gain a better understanding of the impact of cognitive

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BUDDY PROGRAM *(continued from page 5)*

decline on his life. The idea was for the student and person with dementia to be ‘buddies,’ sharing experiences rather than being engaged in a clinical or top-down relationship.

The goals of the Buddy Program are to:

- Educate medical students about Alzheimer’s disease by increasing their knowledge base, heightening their awareness of skills and strengths that remain in persons with Alzheimer’s and familiarizing them with care/support issues and effective communication skills.
- Introduce students to research and practice opportunities in fields related to aging and dementia.
- Provide an opportunity for persons living with dementia to serve as a mentor to a future doctor.

Results

Since 1997, the Buddy Program has paired 167 students with persons with dementia. The ‘buddies’ plan an academic year of regular meetings (four hours a month) around mutually satisfying activities, such as visiting museums, attending concerts, sharing a meal or simply going for a walk. The students write a journal entry of their buddy visit following each activity. These confidential reports to the program director not only briefly describe the activity but also their mentor’s mood, behavior, and their own thoughts, perceptions and reflections about the experience.

Medical student scores on a Dementia Knowledge Test reveal modest, but statistically significant improvement. Their journal entries were analyzed qualitatively. Resulting themes included: students’ expressions of a heightened sensitivity and empathy toward persons with Alzheimer’s, a change in their preconceptions of dementia, and a developing awareness about how their communication affects the person with dementia and their relationship. For example, one student wrote, “My interactions with (my mentor and his wife) afforded me my first opportunity to talk about the disease to someone who has it. I realize that I need to be much more conscious of the things I say about the disease and how they may make my (mentor) feel. This skill of putting myself in my patient’s place and trying to understand things from his or her perspective is something

that I will continue to work on because I feel it will make me a more empathic physician.”

There was evidence of an increasing comfort over time as the friendship between student and mentor grew. For example, this student reflected, “The most important thing that I took from my time with (my mentor) was the idea that there is a benefit to slowing down the pace of one’s life from time to time. (My mentor) walked slowly, she spoke slowly. Our conversations certainly moved slowly; often, we would have the same discussion several times in one visit. And I began to adjust to her pace. I would like to say that I never minded this deliberate approach, and I was certainly never upset by it, but at times near the outset I would find myself moving a bit faster or trying to determine where her thoughts were going before she finished speaking, as if to move the walk or the conversation along at a speed closer to my own. But I soon realized that there was really no reason to do such things, and moreover, that in doing them, I was robbing us of a great benefit of our relationship.”

Students also conveyed recognition of the caregiver experience, from feelings of admiration to an understanding of the stress, burden and complex family dynamics that occur when caring for someone with dementia. One student, whose mentor was in her 50s offered these reflections, “Before this program, when I thought of Alzheimer’s, I thought of the patient. Now, I understand that this disease affects so much more than just the patient – and the impact on the caregiver is often overlooked. When I am a physician, regardless of whether I work with Alzheimer’s patients directly or not, I know that I will make the effort to ask about the caregiver... I can only imagine how difficult it must be for (my mentor’s husband) to watch (my mentor) go

through this and his life taking a turn in a direction that he did not ask for.”

Finally, and applicable to the program goal, students explained how they saw their buddy as a mentor, all they learned from them and how they will apply what they’ve learned in their practice. One student stated “My mentor has been an inspiration on how one should always view the good and positives in life...the Buddy Program has allowed me to gain a unique perspective

...the Buddy Program is based on relationship, conversation, dialogue, and reciprocity.

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BUDDY PROGRAM *(continued from page 6)*

and see a person, beyond a diagnosis or disease.” And another explained, “My mentor has primary progressive aphasia, but he is not defined by his diagnosis. He is a husband, a father, a grandfather, a teacher and an art

presented findings at the 2013 Alzheimer’s Association International Conference in Boston in July. Each program has inserted unique modifications while retaining the core program elements. This fall, the University

The idea was for the student and person with dementia to be ‘buddies,’ sharing experiences rather than being engaged in a clinical or top-down relationship.

aficionado. If you ignore these aspects of the patient, you are doing both the patient and yourself a disservice. Who the patient is affects their diagnosis. I will avoid making assumptions about how the diagnosis will affect a patient’s life. I will let patients tell me how they view their illnesses and how it impacts their lives.”

In summary, through this experiential program, first-year medical students were exposed to the human side of medicine in addition to the science behind dementia. The Buddy Program gave them an opportunity to interact with a patient outside of the clinical setting. For many students, this was their only encounter with individuals with dementia. If students did have experience with individuals with dementia, it was typically with persons in the advanced stages. Participating students were able to grasp the concepts of the disease as it affected the patient, their families, and the everyday activities and challenges they faced. It also provided the diagnosed person with the opportunity to teach beginning medical students the importance of seeing a “patient” as a human being, and not as a disease. Results revealed the program helped to shape the future doctors’ interest in the person with the potential to provide effective, comprehensive, quality care to the individual living with an Alzheimer’s disease diagnosis.

Eager to share this program with other National Institute on Aging Alzheimer’s Disease Centers and medical schools, Northwestern wrote a replication manual with funding from the Glen and Wendy Miller Family Foundation, a foundation that has offered support for the Buddy Program over the last five years. The program has been replicated at Boston University, Dartmouth, and Washington University, all of whom

of Kansas and Albany Medical College are launching programs and the University of Wisconsin-Madison will begin in 2014.

Consider the dialogue below between a medical student and mentor when interviewed about their experience together:

Student – “(My mentor’s) love of Chicago has really rubbed off on me and we really hit it off right at the beginning, just talking about Chicago.”

Mentor – “I think it’s fun, especially if they are from out of town, that’s really fun. I like to share what’s going on in the city. I think it’s good because we’re still people and my challenge is to stay as normal, whatever that means, as possible and as independent as possible because to me that is what it’s all about.”

Student – “(My mentor) has really inspired me because of the optimism and the enthusiasm with which she lives every day. The purpose of the program was to give a person the experience with Alzheimer’s disease or another kind of dementia. It’s not really been about that for me. It’s been more about (my mentor) as a person. It’s been more about knowing her and understanding her and developing a relationship with her than it is dealing with a disease, which is not how I look at (my mentor), it’s not how (my mentor) is defined. It’s something else entirely.”

Mentor – “It’s a part of life.”

Student – “Yeah – it’s a part of life.”

There is “Something to Do” to Help People with Alzheimer’s Disease and Other Dementias and their Family Caregivers

By Katie Maslow, MSW

Senior Scholar in Residence, Institute of Medicine, Washington, DC

I was invited to keynote the first annual Dementia Care conference at the Alzheimer’s Association International Conference in July 2013 in Boston. I presented the findings from a recent review of the state-of-the-art in non-pharmacological treatments and care practices for people with Alzheimer’s disease and other dementias and their family caregivers. Perhaps it’s helpful to begin with my conclusion as I did in July.

We have effective non-pharmacological treatments and care practices for people with Alzheimer’s disease and other dementias and their family caregivers. There is “something to do.” Now we have to figure out how to make these treatments and care practices available to people who can benefit from them.

The state-of-the-art review was mandated by the first National Plan To Address Alzheimer’s Disease, which was released in May 2012. A white paper based on the review, *Translating Innovation to Impact*, is available online.¹ It shows that from 1993 – 2012, randomized controlled trials (RCTs), the gold standard of rigorous clinical research, conducted in the United States found positive results for 44 non-pharmacological treatments and care practices for people with Alzheimer’s disease and other dementias and their family caregivers. Many additional treatments and care practices are in various stages of development and testing in the United States and other countries.

A few examples of the treatments and care practices included in the white paper are:

- **The New York University Caregiver Intervention**, which provides in-person and telephone counseling for the primary family caregiver and other family members and close friends to reduce caregiver stress and depression and increase support and assistance from others.
- **Skills₂ Care**, which provides in-person training and support for the primary family caregiver to increase the caregiver’s skills and confidence in managing memory-related behavioral symptoms and reduce caregiver upset about the symptoms.
- **Savvy Caregiver**, which provides information and support for family caregivers in a group to help them understand more about Alzheimer’s and dementia and manage caregiving tasks more effectively and confidently.
- **Reducing Disability in Alzheimer’s Disease**, which provides exercise for the person with Alzheimer’s disease or other dementia and counseling for the primary caregiver about how to manage behavioral symptoms.

It is important to acknowledge that none of the 44 treatments and care practices included in the white paper work for everyone. That is understandable. People with Alzheimer’s disease and other dementias differ in many ways, including the disease, condition or combination of conditions that is causing their dementia, their stage of disease, and particular symptoms. They also differ in their life experiences, current care situation, other medical conditions, values, preferences, and goals. Their family caregivers also differ. It would be unreasonable to expect that any one treatment or care practice could work for all these different people and situations, but each of the treatments and care practices has been shown to have positive outcomes for some of these people.

Examples of the positive outcomes for people with Alzheimer’s disease and other dementias include reduced depression, greater understanding about their condition, greater involvement in meaningful activities, reduced behavioral symptoms, and delayed nursing home placement. For family caregivers, positive outcomes from the treatments and care practices include reduced stress, anxiety, and depression, greater confidence in their ability to manage difficult caregiving situations, greater satisfaction with the help they receive from other family members, and fewer hours of caregiving tasks and feeling “on duty.”

A few of the non-pharmacological treatments and care practices that have been shown to work for people with Alzheimer’s disease and other dementias are available in some communities across the country, but none are

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PREVENTING FALLS AND INJURIES: Tips and Strategies for Family Members

By Cathleen S. Colon-Emeric, MD

Falls are one of the most common problems that affect older adults, and their consequences can be especially devastating in people with dementia. According to the Centers for Disease Control, one in three adults over 65 years of age will fall each year, and the risk is doubled in those with dementia. More concerning, falls are the leading cause of injury death among older adults, and result in more than 2.3 million visits to the Emergency Department each year. Falls can result in pain, broken bones, worsened walking ability, and fear of doing pleasurable activities. After a bad fall, an older adult with dementia will often require a higher level of care such as a nursing home, at least temporarily.

There are several reasons why people with dementia are more prone to fall. Changes in walking ability and balance are common with Alzheimer's, vascular dementia, and Parkinson's disease. Medications to improve mood, behaviors or sleep in patients with dementia often increase fall risk. People with dementia may forget to use a cane or walker properly, or put themselves in risky situations because of poor judgment. Other conditions that increase an individual's risk of falls include poor eyesight, stroke, arthritis, muscle weakness, balance problems, nerve damage in the feet, and dropping blood pressure. Many individuals with dementia may have more than one of these risk factors.

Because so many different things cause falls, it requires a team to prevent them. As a family member, you are a critical part of this team. Here are some ways that you can help your family member avoid a fall.

Make sure shoes are well fitting. Both shoes and bedroom slippers should have thin, flexible rubber soles. Shoes without backs (flip-flops) and heels greater than ½ inch are dangerous.

Correct vision when possible. Make sure that glasses are clean and in good repair and that your family member wears them regularly.

Be on the lookout for dangers in the environment. Correct burned-out light bulbs, wet areas on the floor, furniture blocking doorways and other hazards as soon as you notice them. Remove throw rugs. Install bars near the toilet and tub/shower, and consider night lights, especially in the bathroom. The CDC has a great home safety checklist you can use http://www.cdc.gov/ncipc/pub-res/toolkit/Falls_ToolKit/DesktopPDF/English/booklet_Eng_desktop.pdf.

Involve your healthcare team. Ask your physician to review your family member's medications and to try to taper or stop those that may make him/her sleepy or light headed. Ask your provider if it is okay for them to take regular vitamin D supplements (at least 1000 IU daily) since low levels of Vitamin D are common among people with dementia and can result in falls. Ask if they should be tested for osteoporosis, because treatments for this condition will make them less likely to break a bone if they fall. Ask the nurse to check blood pressure both sitting and standing up to see if it drops more than expected.

Consider requesting a physical therapy evaluation if your family member has fallen, if they have trouble rising from a chair, or if you notice a change in his/her walking pattern. Balance and strength exercises or a cane or walker might help. Regular exercise is very important; try to encourage exercise at least 5 days a week, at least 30 minutes each time. (Exercising together is a great motivator.) Balance classes or Tai Chi are especially helpful in preventing falls, but any pleasurable activity is great.

Not all falls can be prevented, but with some detective work and practical changes you can make your family member as safe as possible.

Dr. Cathleen S. Colon-Emeric is a geriatrician in the Department of Medicine, Division of Geriatrics at Duke Medical Center. Her research focuses on fracture prevention in older adults.

SAFETY RESOURCES

Home Safety for People with Alzheimer's Disease website from the National Institute on Aging. This 40-page booklet for caregivers gives room by-room suggestions for creating a safer space for people with Alzheimer's disease. <http://www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease/home-safety-room-room>

Alzheimer's Association Safety Center. This website offers information about driving after a diagnosis with dementia, home safety, medication safety, wandering, and MedicAlert® + Alzheimer's Association Safe Return®. <http://www.alz.org/care/alzheimers-dementia-safety.asp>

Home Fall Prevention Checklist for Older Adults. Safety tips from the CDC. http://www.cdc.gov/ncipc/pub-res/toolkit/Falls_ToolKit/DesktopPDF/English/booklet_Eng_desktop.pdf

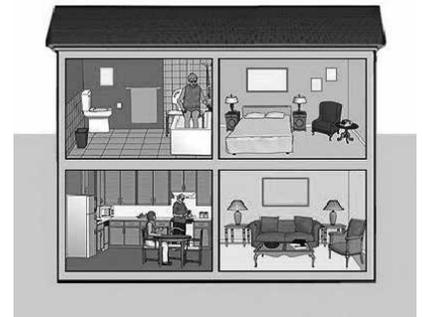
This Caring Home provides tips and tools to enhance home safety for persons with Alzheimer's and other types of dementia. Explore research-based solutions to home safety along with practical suggestions from family caregivers.

<http://www.thiscaringhome.org/index.aspx>



Scams & Fraud: Protect Yourself – Don't Be a Target, NC Department of Justice.

<http://www.ncdoj.gov/getdoc/d2d5c385-bdaa-43dd-b1b5-6b1663003e6e/Scams-Booklet-4-2013-FINAL.aspx>



Safe Driving for a Lifetime. Download or order free safety guides from The Hartford, including, *We need to Talk: Family Conversations with Older Drivers* and *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving*. <http://www.thehartford.com/mature-market-excellence/publications-on-aging>

“Stop or Mom Will Shoot!” Home Caregiver Issues: Guns and the Elderly. Issues to consider about gun safety, the elderly and home caregivers.

<http://info.easylivingfl.com/blog/bid/259410/Stop-or-Mom-Will-Shoot-Home-Caregiver-Issues-Guns-and-the-Elderly>



Medications & Older Adults. Information and tip sheets from the American Geriatrics Society on medication concerns such as “Avoiding Over Medication and Harmful Drug Reactions” and “Medications Older Adults Should Avoid.” <http://www.healthinaging.org/medications-older-adults/>

Tips for Safely Surfing the Internet. How to find reliable advice on the internet that's safe to follow from the American Geriatrics Society Foundation for Health in Aging.

http://www.healthinaging.org/files/documents/tipsheets/internet_safety.pdf

Helping Seniors Avoid Scams

Telemarketing Scams

1. Place your home and cell phone numbers on the Do Not Call registry at 1-888-382-1222 or www.donot-call.gov to cut down on unwanted telemarketing calls. Go online anytime to verify that your phone numbers are still registered.
2. Never give out important numbers like your bank account, credit card or Social Security number to anyone who calls you.
3. Beware of scammers who call pretending to be a member of your family. They may claim to face an emergency while traveling and ask you to send money.
4. Your telephone's Caller ID feature can be manipulated. Scammers can make it appear that your bank, a charity, a government office, etc., is calling.

Sweepstakes Scams

1. Throw away unsolicited lottery or sweepstakes mailings that say that you're a winner. Foreign lotteries are illegal and the checks they send are fake, no matter how real they look.
2. Never send money to receive a prize, loan, or credit card. It's against the law to require you to pay to receive a prize or to charge an upfront fee for a loan.
3. Don't be pressured to buy something in order to enter a sweepstakes. You don't have to buy to enter and buying doesn't increase your chances of winning.
4. Don't put bank account or Social Security numbers on entry forms for sweepstakes or other contests.

Investment Scams

1. Never agree to invest in or buy something you don't understand.
2. Read all forms completely, and consult with a knowledgeable friend or trusted professional, such as a lawyer or an accountant, before you sign anything.
3. Don't make a quick decision about investment offers or changing insurance policies. When a loved one dies, avoid making major financial decisions or purchases right away.
4. Beware if a salesperson says "it's a special opportunity but you have to keep it secret," or urges you to "act now" while using phrases like "limited offer," "risk free" or "tax-free offshore investments."
5. Remember, all investments include some risk and you can't get something for nothing.

Health Care Scams

1. Avoid products that claim to be miracle cures or scientific breakthroughs, or say they contain a secret ingredient. Be skeptical of marketing that uses personal testimonials by consumers or doctors claiming "amazing results."

2. Products that offer a "no-risk money-back guarantee" often don't live up to that claim. Promotions that promise a free meal or lodging usually include a high-pressure sales pitch.
3. Don't sign up for any discount health or drug plan before checking with your doctor, pharmacist or the Attorney General's Office.

Home Construction and Repair Scams

1. Be very skeptical of unsolicited offers for home repairs, especially if the contractor comes to your door and says the job needs to be done right away. Don't let them pressure or scare you into paying for a phony repair.
2. After a disaster of any kind, beware of scammers who come to your home posing as government officials or insurance adjusters. Contact the government agency or your insurance company to verify before you let them inside or have work done.
3. When you need work done on your home, ask friends or co-workers for recommendations. Get written estimates from the contractors you are considering. Before hiring a contractor, check their references, insurance, and license.
 - General contractors (www.nclbgc.org or 919-571-4183)
 - Electricians (www.ncbeec.org or 919-733-9042)
 - Plumbers and HVAC (www.nclicensing.org or 919-875-3612)
4. When you select a contractor, get a written agreement that states clearly the exact costs, work to be performed and completion dates.
5. Don't pay before the work begins. Instead, make payments as work is completed. Never make a final payment until work is complete to your satisfaction.

Charity Scams

1. Research unfamiliar charities before you donate. Beware of fake and "sound alike" charities that try to exploit your sympathy for victims of a recent disaster.
2. When a charity calls, ask whether the caller is a professional fundraiser and find out how much of your contribution will go to fundraising costs.
3. Scam artists will pose as representatives of a charity and lie to get your money. Be wary of messages reminding you to fulfill a pledge that you don't recall making, and requests to make a second donation when you don't recall having donated before.
4. Do not send cash donations.

*From the North Carolina Department of Justice
For more information: 1-877-5-NO-SCAM (toll free)
www.ncdoj.gov*

MOM'S HANDS

By Mary Donnelley

There are lots of ways to say "I love you." Most of us say it in words, either spoken or written. Sometimes it's deliberately and carefully said, other times lightly and casually, as at the end of a telephone call. We say it to spouses, to children, to parents and friends. When we face the end of a life, we say it more often and more emphatically, making sure our loved ones get the message before their time is up.

Mom and I said it often to one another over the years. It never occurred to me that there would come a time when she wouldn't know how to say it, or wouldn't respond when I would say it to her. But she had dementia, and those words became lost along with most of the rest of her words. I could talk to her, I could even make her giggle, but I could no longer have meaningful conversation. So as my mother lost her words, I lost my mother. But here's the thing I learned through all of that: there are other ways to say "I love you" without using words. My mother said it to me with her hands.

Mom was seven when she fell and broke her arm. This was around 1920, and orthopedic medicine was a long way from where it is today. She spent a year at Johns Hopkins Hospital in Baltimore, far from her North Carolina home, enduring many operations and learning to live with a crippled arm. Everything she did from then on she had to do backwards. Imagine yourself, if you're right-handed, suddenly losing the use of your right arm, and having to learn all over again how to hold a pencil, to use a fork, to put rollers in your hair, to peel an apple – and do it all left-handed. She did it all admirably, if often awkwardly. The cumbersome, out-of-the-ordinary techniques she'd use to tie a bow or type a letter bore little resemblance to the way most of us do it. But somehow her bows came out right every time, and her typing speed was better than my own.

She was sensitive about that arm all her life. She never lost her "righthandedness", never became a natural "leftie." She often told me that she looked forward to going to heaven because she'd get her good right arm back. But it wasn't just the limitations of the arm that bothered her – indeed, she overcame most

of those with her wonderful optimistic attitude. It was the appearance of that crippled arm that bothered her the most. Once, when I was about 15, she was making me a beautiful party dress, and I was complaining about how I looked in it. She did something she very seldom did: she waved that arm at me and said, "How would you like to have gone to a dance with THIS?" I was ashamed, and I shut up – and I never forgot it.

She always wore long sleeves because of that arm. She always tried to hide it in photos, or keep a coat or jacket thrown over it. She assumed that it was the first thing other people noticed about her, and was always astonished when someone would say, "I never

knew you had that!" Many years ago, she asked me to shake hands with her. I did. She asked, "Does my hand feel strange to you?" Well, now that I thought about it, I guess it DID feel a little different from most other people's handshakes. She then explained that she had noticed strangers, when they first shook her hand, would quickly look down, curious to know what felt different. So she developed, over the years, her

characteristic greeting of extending her LEFT hand to people. It's unexpected, to be sure, but she was so lovely and gracious that people didn't seem to mind. I've even done it myself several times, and I always think of her when I do.

Most of us remember our mother's hands. They were the hands that stroked our cheeks, that dried our tears, that fed us ice cream when we had our tonsils out. They were the hands we played with while sitting quietly in church. They were the hands that gripped our arms tightly when we misbehaved in public, a firm but silent reprimand. They were the hands that showed us how to cross stitch and needlepoint, that served wonderful meals and arranged beautiful flowers. They were the hands that brushed our hair and set out tea parties and pinned on corsages. They were the hands that held us when our hearts ached from loss or disappointment.

My mother's hands did all those things, and did them beautifully. I loved that crippled arm of hers – it was a symbol of all she was, all she did, all she over-

...there are many ways to say "I love you" without using words. My mother said it to me with her hands.

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MOM'S HANDS *(continued from page 12)*

came. To her it was hideous, unsightly, an embarrassment; but to me it was a source of love and comfort and safety.

My mother's hands continued to speak to me, even as the dementia gradually took away her words. She would use fewer and fewer of them, and would often just make sounds or speak in nonsense. But here's what I discovered: hands don't get dementia. She would often reach her hand up to touch my face. I could put my head on her shoulder, and those hands automatically came up to wrap me in love, expressing wordlessly the message of motherhood well beyond what her mind could remember. It was like coming home. She was clearly saying "I love you" to me with her hands. What a gift.

People have asked me over and over during these last few years, "Does she recognize you? Does she know who you are?" Absolutely - maybe not with words, maybe not by saying "Here's my daughter Mary." But she knew me. So I would always answer them, "Yes - she recognizes me with her heart." And (I also could have said) with her hands.

My mother's face was beloved to me, as was her voice. I miss both of them. But it wasn't until I was going through a box of pictures last week that it suddenly hit me how much I miss her hands, how unique and extraordinary and special they were to me - and

how they had served to remind me that, even in the face of her deteriorated mind, my mother was still there.

So now I'm starting to notice other people's hands: my husband's - large, strong, dexterous; my friend Pat's - white and soft and delicate; Dr. Templeton's - quick and expressive. I will continue to treasure my friends and family, but I will also try to look for those unspoken things about them that make them who they are....starting with their hands. I will remember that there are many ways to say "I love you" without using words. And I will extend my left hand more often in remembrance.

Mary Donnelly's mother died last year, just shy of her 99th birthday. Ms. Donnelly wrote this piece to give at her mother's memorial service, which was held on her birthday. Ms. Donnelly lives in Asheville, NC.



Assisted living residences vary widely in terms of their services, costs, policies, staffing, and other features. Few people understand how variable assisted living is, and how choosing the wrong residence can impair quality of life. Assisted Living Comparison Experts was developed to provide objective information to help consumers find the best fit.

Assisted Living Comparison Experts' website includes information that dozens of organizations consider as important when choosing an assisted living residence. The website explains why this information is important, and allows users to search and compare residences based on this information.

The website features include:

- A free comprehensive directory of all assisted living residences in North Carolina
- Expanded search tools to help families specify which options related to services, costs, policies, staffing, dementia care, and other areas are important
- A user-friendly search feature that selects the residences that most closely meet one's needs and wants

Assisted Living Comparison Experts is a university-based non-profit and is not paid by assisted living providers or other companies. For more information: <http://alce.unc.edu/>

GRIEF AND THE HOLIDAYS: PLANNING TO WALK THROUGH HOLIDAY GRIEF AND SADNESS TOGETHER

By Rev. Dale Susan Edmonds, M.Div.

The challenge of holiday grief after a parent's death can feel insurmountable. You have managed through the end of life issues. You negotiated and handled services of remembrance and all the details that followed. Things finally began to settle down, and now it's time to plan for the first holidays.

Grief and the holidays can provide unexpected triggers for all kinds of strong emotions. People are often lulled into believing that the worst is behind them, when holiday grief "hits them" without warning.

The problem is that grief has its own timelines that can't be calculated, its own logic that can't be deciphered, and makes its appearances at will.

The temptation would be to go to one emotional extreme or the other -- denial or to go into hiding. Many families resort to going through the motions because they assume (often wrongly) that that's what everyone else wants to do. They don't want to make Dad even more uncomfortable, so they silently vow not to mention Mom, or the holiday grief they share, and go on with the family events "as usual".

Only there is no "as usual" any more. The gap that has been left is real. The roles have changed and therefore the "holiday rules" have to change, too.

Plan Ahead

What you want is to have conversation with Dad and with your brothers and sisters about the fact that this holiday is going to be radically different. Get a sense of where everyone is emotionally, and what they fear, dread or look forward to about the holidays. Don't expect immediate agreement about what should be done. Grieving is personal and takes different forms for everyone. Families DON'T grieve alike and that can be a source of tension and conflict.

Know what you need or want, check in with Dad and try to move forward from there with the negotiations.

Common Dilemmas

Dad is not very open with his feelings, so you're not really sure what he needs...

Write a note to him ahead of the holidays, and address the issues of holiday grief directly. Let him know that

1. You know that this is going to be a difficult time
2. You all will be missing Mom and you know he will be especially
3. You want to make sure that things are comfortable for him, so if he has an idea of what he does or doesn't want, you'll be asking.

Give him a couple of days to think about it... and then ASK.

Someone is afraid of "losing it"...

"Losing it" is OK, if that means not being in total control and having to deal with a feeling of intense and unexpected sadness. Grief is not something that we can set on a timer, be done, and wrap it up and put it away neatly. Grief is messy, hard, surprising and NOT welcome. Avoidance, hiding, denial, putting on a happy face to mask holiday grief may all seem useful in a specific instance, but they won't make the grief go away. It won't make the grief clear out any faster. And it won't make the journey any easier. But the only way to get it over with is to go THROUGH IT.

Dad should be farther along than he is... what if he breaks into tears at dinner?

There is no such thing as being farther along. There is no timeline that he has to meet. Tears at dinner -- no problem. Acknowledge them. It's no cause for shame and you need to let him know. He's never been through anything like this, and neither have you. So unexpected things will happen. Uncharacteristic behaviors will show up.

I'm worried how this will affect the grandkids...

This is a great time to talk to them again about grief and build their sense of empathy. Ask about how they are feeling... what would make them uncomfortable... what they might fear. Again, valid feelings... emotions aren't wrong. Give them permission to write, draw or say what they are feeling. And let them know that people may be acting strangely, that's what grief does... and it's OK.

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GRIEF AND THE HOLIDAYS: *(continued from page 14)*

Be Prepared

Some family members may be more short-tempered than normal. There may be more arguments about small things. Some may be more boisterous than usual. Some may be more quiet and withdrawn than usual. Be prepared to keep yourself on an even keel. Get your rest, keep eating well. If you do drink, only moderately -- one or two drinks at most. You need to keep a clear head to navigate all the erratic emotions of holiday grief.

Redistribute the Roles Ahead of Time

Do you want to replicate traditions in this new reality without Mom, or do you want to do something entirely different this year and re-evaluate later?

Will we go to a restaurant or eat at home? Whose home? Will the meal be cooked or catered? Who will cook? Will the menu change at all? Who will make the dishes that Mom always made? Who will do the jobs that Mom always did? Be affirming of everyone's efforts. People will do their best, but it will never be "just like Mom did it..."

Figure Out How to Acknowledge Mom

What would work in your family?

- ...a toast before dinner?
- ...a special prayer?
- ...her picture in a prominent place?
- ...a tribute written and read by the grandchildren?
- ...telling funny stories of remembrance?
- ...putting on her favorite dinner music?
- ...singing a favorite song?
- ...looking at old photo albums and telling stories the children may not know?

Permission Granted

Give yourself and your family permission to be creative. There is no right or wrong way to be together in holiday grief. The key is to go through it and know that you are all going through it together no matter what method you choose.

Rev. Dale Susan Edmonds, M.Div. is an ordained minister, speaker and workshop leader. This article originally appeared in Rev. Edmond's website, Talk Early, Talk Often with Aging Parents, <http://www.talk-early-talk-often.com/>

Alzheimer's Caregiving Tips

Holiday Hints

Preparing Guests

Explain to guests that the person with Alzheimer's disease does not always remember what is expected and acceptable. Give examples of unusual behaviors that may take place such as incontinence, eating food with fingers, wandering, or hallucinations.

- If this is the first visit since the person with Alzheimer's became severely impaired, tell guests that the visit may be painful. The memory-impaired person may not remember guests' names or relationships but can still enjoy their company.
- Explain that memory loss is the result of the disease and is not intentional.
- Stress that the meaningfulness of the moment together matters more than what the person remembers.

Preparing the Person with Alzheimer's

Here are some tips to help the person with Alzheimer's disease get ready for visitors:

- Begin showing a photo of the guest to the person a week before arrival. Each day, explain who the visitor is while showing the photo.
- Arrange a phone call for the person with Alzheimer's and the visitor. The call gives the visitor an idea of what to expect and gives the person with Alzheimer's an opportunity to become familiar with the visitor.
- Keep the memory-impaired person's routine as close to normal as possible.
- During the hustle and bustle of the holiday season, guard against fatigue and find time for adequate rest.

From Caregiving Tips and Resource Lists, Alzheimer's Disease Education and Referral Center, National Institute on Aging, <http://www.nia.nih.gov/alzheimers/topics/caregiving#pubs> .

Have You Heard About?

Cole, Lon, 2013. *You Are Not Alone: Poems of Hope and Faith.* After being diagnosed with early-onset Alzheimer's, Cole says he began writing more poetry. This emotional collection will remind readers that there are others who share their experiences.

Hafner, Katie, 2013. *Mother Daughter Me: A Memoir.* Katie Hafner describes the year during which her mother lived with Katie and her teenage daughter. She touches on issues like intergenerational conflict, divorce, and questions of obligation to aging parents in this tale of healing.

Henry, William and Johns, Frank, 2013. *The Crown of Life Society.* Authors Henry and noted NC elder law attorney Johns turn fact into fiction for an appalling — but hilarious and sometimes heartbreaking — narrative about criminals scheming to steal from the elderly. Only available as an eBook.

Kardasis, Arlene, Larsen, Rikk, Thorpe, Crystal, and Trippe, Blair, 2011. *Mom Always Liked You Best: A Guide for Resolving Family Feuds, Inheritance Battles, and Eldercare Crises.* This guide book combines step-by-step advice with poignant examples to help adult families avoid and resolve common family conflicts.

Lohrman, Elaine, 2012. *Conversations with Nora: A Family's Journey with Alzheimer's.* Told through conversations between two women, this novel tells the story of two sisters coping with their mother's complicated experience of dementia. The novel is based on a true story and was nominated for a Pulitzer Prize.

Pereira, Elaine C., 2012. *I Will Never Forget: A Daughter's Story of her Mother's Arduous and Sometimes Humorous Journey through Dementia.* Pereira writes about difficulties during her mother's journey through dementia, but also emphasizes the more light-hearted aspects of her caregiving experience.

Prosch, Tim, 2013. *The Other Talk: A Guide to Talking With Your Adult Children about the Rest of Your Life.* This book offers tools to help initiate and guide conversations with adult children about long-term planning, before crises occur.

Shagam, Janet Yagoda, 2013. *An Unintended Journey: A Caregiver's Guide to Dementia.* Drawing on personal experience providing care for an aging parent, Yagoda has combined a practical approach with a personal and compassionate perspective to offer advice to those who want to prepare for the future.

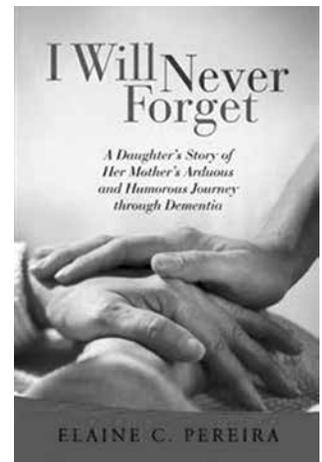
Simard, Joyce, 2013. *The End-of-Life Namaste Care Program for People with Dementia, Second Edition.* Simard details her program for dignified and comfortable end-of-life care for people with dementia, and offers step-by-step instructions for establishing this program in new or existing residential care programs.

Smith, Scott Taylor, 2012. *When Someone Dies: The Practical Guide to the Logistics of Death.* Having personal experience in making costly decisions after the death of a family member, Smith describes this as “the book he wished he'd had.” A guide to logistical steps to take after a death in the family, including topics like estate planning, making funeral arrangements, finances and more.

Summitt, Pat and Jenkins, Sally, 2013. *Sum it Up: 1,098 Victories, A Couple Irrelevant Losses, and a Life in Perspective.* Pat Summitt is the all-time winning coach in NCAA basketball history and a member of the Basketball Hall of Fame. In her new book, she tells her story of being diagnosed with early-onset Alzheimer's in 2011 and facing her newest challenge head-on.

Wallack, Max and Given, Carolyn, 2013. *Why Did Grandma Put Her Underwear in the Refrigerator?: An Explanation of Alzheimer's Disease for Children.* Written for children from a second grader's perspective, this book explains what it means to have a relative with dementia and explores the complex emotions that arise when families are affected.

Weisblat, Tinky, 2013. *Pulling Taffy: A Year with Dementia and Other Adventures.* Weisblat uses journal entries, history, family photos, and recipes to portray life with her mother, “Taffy”, during the last year of Taffy's life.



Online Help

Aging

http://www.americangeriatrics.org/press/video_channel/

The American Geriatrics Society's Video Channel has helpful videos on diabetes and fall prevention.

http://www.americangeriatrics.org/files/documents/ChoosingWiselyInsomniaAGS_ER.pdf

A brief report on insomnia and anxiety in older adults. Includes tips for better sleep and medications information.

Alzheimer's Disease and Related Disorders

<http://www.alz.co.uk/research/world-report-2013>

The World Alzheimer Report 2013, Journey of Caring: An analysis of long-term care for dementia. The report reveals that, as the world population ages, the traditional system of "informal" care by family, friends, and community will require much greater support.

<http://livingwithdementia.uwaterloo.ca/index.html>

A website prepared with input from people with dementia and family caregivers. It offers credible information about living well with dementia, and is designed to be user-friendly for users with little or no experience with computers.

<http://www.healthline.com/health-slideshow/best-alzheimers-dementia-blogs#1>

Healthline.com has created this list of the 25 best Alzheimer's blogs in 2013. Some are written by experts, others by caregivers, and several by individuals with dementia.

<http://americangeriatrics.org/files/documents/feeding.tubes.advanced.dementia.pdf>

This position paper from the American Geriatrics Society reports that evidence does not support the use of tube feeding for patients with advanced dementia.

<http://www.healthinaging.org/files/documents/ChoosingWiselyFeedingTubeAGS-ER.pdf>

An easy to read two-page report about feeding tubes for people with Alzheimer's disease. Discusses when you need them and when you don't.

http://alzheimersspeaks.wordpress.com/2011/09/25/from-his-window-a-song-about-alzheimers-disease/?goback=.gde_111042_member_255165121

A collection of videos of songs about Alzheimer's and related dementias, including one song used by Alzheimer's Disease International as an anthem.

<https://www.youtube.com/watch?v=1Z-Ugh-evN0>

In these short videos, an Alzheimer's disease researcher explains the history, diagnosis, biology, and progression of Alzheimer's.

<https://itunes.apple.com/us/app/balance-for-alzheimers-caregivers/id609839752?mt=8>

Balance is a tool for caregivers of Alzheimer's patients to coordinate care among multiple caregivers in real-time. Developed by the National Alzheimer's Center, a division of the Hebrew Home at Riverdale in the Bronx.

<http://livingwithalz.org>

Four new free documentaries about how families persevere in the face of Alzheimer's disease, by world-class directors.

Caregiving

<http://www.wellspouse.org/>

The Well Spouse Association is a national non-profit organization offering resources and peer-to-peer support for well-spousal/partner caregivers.

<http://www.caregiverstress.com/stress-management/family-caregiver-stress/>

Provides resources, articles, and videos related to recognizing and coping with stress related to caregiving.

<http://www.caregiving.com/store/products/after-the-diagnosis/>

Caregiving.com offers a free eBook, "After the Diagnosis," for caregivers of people recently diagnosed with a chronic or debilitating condition. It can be downloaded for free by clicking "buy now" on this website.

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Online Help *(continued from page 17)*



<http://suescoggins.com/blog/> This honest and emotional blog is written by a North Carolina woman whose husband was diagnosed with early onset Alzheimer's 14 years ago. It focuses on her experiences with caregiving, her art, and everyday life.

Planning, Insurance & Long Term Care

<http://www.theconsumervoice.org/piecing-together-quality-long-term-care/pdf> Offers national and NC-specific guidelines and fact sheets for navigating long term care, from choosing facilities to advocating for quality care.

<http://www.ncdoj.gov/getdoc/2818285d-f99a-4b91-ab75-5c1956a92f76/Scams-booklet--4-2013-%281%29.aspx> A guide to avoiding fraud and common scams, including a list of common scams. Published by the N.C. Attorney General's Office.

http://caregiver.org/caregiver/jsp/print_friendly.jsp?nodeid=849 This guide offers advice for deciding when it may be time to move aging parents out of their home, and for choosing among numerous options for where they might move.

http://www.pbs.org/newshour/bb/health/jan-june13/healthcare_05-30.html This is the first part of an occasional PBS series about long term care, the story of a daughter navigating the labyrinth of long term care for her mother in Arizona.

Products & Technology

<http://www.healthfinder.gov/StayConnected/> myfamily APP focuses on the preventive care benefits and services covered by the Affordable Care Act. Users can find customized prevention info and tips for family members, create personal health alerts, and keep track of medical check-ups and vaccinations.

SOMETHING TO DO *(continued from page 8)*

widely available. Important barriers to greater availability are lack of knowledge about the treatments and care practices among community service providers and agencies, lack of awareness among people with the conditions and their families, and lack of reimbursement or other funding for most of the treatments and care practices.

Addressing these barriers will require attention and persistence. One important first step is selecting and using better, more easily understood language and terms. The white paper uses the terms *treatments* and *care practices* instead of the more widely used term, *interventions*, a term that is unlikely to be either understood or acceptable to many people with Alzheimer's disease and other dementias and their families. *Non-pharmacological* is another troublesome term because it defines the treatments and care practices by what they are not; that is, they are not medications. We need a more positive term that encompasses the wide array of effective treatments and care practices and the kinds of positive outcomes that have been shown for them. Finding a better term for *non-pharmacological* has been surprisingly difficult.

The white paper concludes that the state-of-the-art in non-pharmacological treatments and care practices for people with Alzheimer's disease and other dementias and their family caregivers is much more advanced and more hopeful than has previously been reported. The glass is at least half-full. Now we need to figure out how to get what works to people who can benefit.

This is important. Millions of people are living with Alzheimer's disease and other dementias now. Certainly we all hope for pharmacological treatments that can prevent, cure, or delay onset or progression of these conditions. In the meantime, and for those who may not benefit from future pharmacological treatments, we have effective non-pharmacological treatments and care practices. We must make them better known and much more easily available to the people who need them.

¹⁷The white paper, *Translating Innovation to Impact*, is available at http://www.aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/TranslatingInnovationtoImpactAlzheimersDisease.pdf.