

# The CAREGIVER

*A Bridge to Understanding  
Your Options*

Newsletter of the Duke Family Support Program

Volume 33, Issue 1

Spring 2014

## AN INVITATION TO FAMILY CAREGIVERS

AARP North Carolina, in cooperation with local and regional aging agencies, invites family caregivers of older adults and adults with disabilities to a free forum.

### You Are Not Alone - Family Caregiving in North Carolina



A forum will be held at three locations in the state from 1:00 to 4:00 p.m. with registration from 12:30 to 1:00 p.m.

- April 29 in Goldsboro at Peggy M. Seegars Senior Center, 2001 E. Ash Street, 27530 (free respite care will be provided on-site for care recipients of caregivers attending forum). To register for this forum call 1-877-926-8300 or go online to <http://aarp.cvent.com/GoldsboroForum>.
- May 1 in Eden at The LEAF Center (Fellowship Hall), 211 N. Oakland Avenue, 27288 (free respite care will be provided on-site for care recipients of caregivers attending forum). To register for this forum call 1-877-926-8300 or go online to <http://aarp.cvent.com/EdenForum>.
- May 5 in Charlotte at Tyvola Senior Center, 2225 Tyvola Road, 28210. To register for this forum call 1-877-926-8300 or go online to <http://aarp.cvent.com/CharlotteForum>.

Each forum will include a presentation by Lisa Gwyther, Director of the Duke Family Support Program and nationally known expert and author on family caregiving issues, followed by a discussion of local resources to assist family caregivers. Each participant will receive a free copy of the *North Carolina Family Caregiver Guide* and will have the opportunity to share information about the challenges and rewards of caregiving and what changes are needed to support family care.

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**Duke Family Support Program**  
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Call 919-660-7510 or  
800-646-2028.

View this newsletter online at  
[www.dukefamilysupport.org](http://www.dukefamilysupport.org)

**Duke Family Support Program**

Box 3600 Duke University Medical Center  
 Durham, NC 27710  
 800-646-2028  
 919-660-7510  
[www.dukefamilysupport.org](http://www.dukefamilysupport.org)

**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](http://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](http://www.alz.org/nc)  
 (for support groups, other events and more information)  
 Email: [info@alz.org](mailto:info@alz.org)

**2014 Walk to End Alzheimer's Eastern NC**

- Fayetteville: September 6
- Triangle: September 20
- Johnston County: October 4
- New Bern: October 25
- Wilmington: November 8

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

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

**2014 Caregiver Education Conferences**

- Mooresville: May 6
- Hickory: June 19
- Arden: October 23

**2014 Walks & Events**

- Blondes vs. Brunettes Charlotte Game Day: May 3
- State Lobby Day, Raleigh: May 21
- Gastonia and Greensboro Walks: September 13
- Asheville, Kannapolis, Southern Pines and Winston-Salem Walks: September 20
- Burlington, Charlotte and Lake Junaluska Walks: September 27
- Mount Airy Walk: October 4
- High Point and Troutman Walks: October 11
- Asheboro and North Wilkesboro Walks: October 18
- Hickory Walk: October 25

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

800-228-8738  
*Main Office:*  
 1305 Navaho Drive, Suite 101  
 Raleigh, NC 27609  
 919-832-3732  
*Satellite Offices:*  
 Wilmington  
 910-686-1944  
 Greenville  
 252-355-0054  
[www.alznc.org](http://www.alznc.org)  
 (for support groups, other events and more information)  
 Email: [info@alznc.org](mailto:info@alznc.org)

**2014 Caregiver Education Conferences**

(see website for details)

- New Bern: May 20
- Family Caregiver Workshop - Southport: June 10
- Triangle Caregivers Conference - Raleigh: June 17 and Durham: June 24. See Conference website for details [www.trianglecaregiversconference.org](http://www.trianglecaregiversconference.org)
- Williamston: September 16
- Fayetteville: October 16

**2014 Walks & Events**

(see website for updates and other events)

- Craven County Walk: April 26
- Run to Remember (Wake Med Soccer Park): April 27
- Forsyth County Walk: May 3
- Tarboro Walk: May 17
- Wilmington Walk & 5K Run: June 7
- Martin County Walk: June 14
- Mount Airy Walk: June 15
- Galloway Ridge 5K & Chatham County Walk: September 13
- Devil's Ridge Golf Tournament: September 17
- Wilson Walk: September 20
- Washington Walk: September 27
- Triangle Walk: October 4
- Robeson County Walk: October 18
- Goldsboro Walk: October 25

# Do pesticides increase the risk of Alzheimer's disease?

Brenda L. Plassman, Ph.D. and Kathleen M. Hayden, Ph.D.  
Bryan Alzheimer's Disease Research Center at Duke University

Regular *Caregiver* readers know that both environmental and genetic factors contribute to the risk of Alzheimer's disease (AD). The search for environmental factors has intensified as it has become clear that the AD risk genes that have been discovered only account for a small part of disease risk in the population. The search for environmental factors has included physical activity, diet, head trauma (or traumatic brain injury), and cognitive activity, to name just a few. But so far, many of these factors have shown inconsistent results. Other risk factors have not been studied in great detail but deserve more attention. Among these are pesticides which are known to have negative health effects involving the nervous system. Much of the available evidence on the harmful neurological effects of pesticides is based on people who have been exposed to high levels of pesticides. We know much less about the long term effects of chronic low-level exposure to pesticides on AD risk. However, in some studies, exposure to pesticides has been shown to increase the risk of other neurodegenerative diseases such as Parkinson's disease (PD) and Amyotrophic Lateral Sclerosis (ALS).

A few studies have begun to point to pesticides as a risk factor for AD. One study from our research group, the Cache County Memory Study, has provided the strongest evidence linking pesticide use to risk of AD (1). Dr. Hayden, at Duke University, and colleagues

conducted this longitudinal population-based study in a group of 3,084 elderly people living in Cache County, Utah, an agricultural community. Information about pesticide exposure came from interviews with the study participants at baseline when they had no dementia symptoms. Cognitive status was monitored for up to 10 years after the start of the study. A total of 572 people (mostly men) reported being exposed to pesticides during their working life. The findings showed that occupation-related use of any pesticide was associated with a 42% greater risk of AD compared to those who did not report job-related pesticide exposure. In addition, the use of a specific group of pesticides called organophosphates was associated with a 53% greater risk of AD.

Most of the observational studies that have reported associations between pesticide exposure and risk of AD are based on occupational exposure to pesticides, such as farming exposure. But these chemicals are widely used in our environment; for example, they are used in the agricultural industry to control pests on crops and in the residential setting to control insects. Based on the most recent figures available, the United States used an estimated 1.1 billion pounds of pesticides in 2007. Thus, it is very likely that even people who have not worked in pesticide-related jobs have been exposed to pesticides. Along these lines, a recent study has brought this topic to the public's at-



## PESTICIDES *(continued from page 3)*

tention again. This new study published in the Journal of the American Medical Association (JAMA) Neurology in January, 2014 (2) examined the blood levels of a metabolite or by-product of dichlorodiphenyltrichloroethane (DDT) in 86 AD patients and 79 people without AD (controls). Despite the fact that DDT has been banned in the United States since 1972, the majority of people had evidence of DDT exposure in their blood. But strikingly, the people with AD had levels of the DDT metabolite that were on average four times higher than in controls and those with the highest levels of the DDT metabolite had a fourfold increased risk of AD.

One of the necessary steps when investigating the association between a potential toxic substance and risk of AD is to determine whether the substance is present in the brain tissue. There is a protective surface surrounding the brain called the blood-brain barrier that prevents many substances in the blood from entering the brain. If a toxic substance does not enter the brain, it is hard to make the case that it would increase the risk of AD. The researchers of the JAMA Neurology study examined the levels of the DDT metabolite in blood and in brain tissue and found that the levels in blood and brain tissue corresponded closely.

These studies provide preliminary evidence that pesticide exposure throughout life may increase risk of AD in later life. But this research needs to be replicated. A number of additional key questions need to be answered to better understand whether pesticides pose an increased risk of AD. Like many other exposures occurring years before dementia onset, information on pesticide exposure generally comes from personal recall of pesticides used – often decades earlier. Thus, detailed information on the type and amount of pesticides used has been lacking in most prior studies. But pesticide ‘use’ does not always equal pesticide ‘exposure’. Even among professional pesticide applicators, exposure can vary widely based on application method and use of protective equipment. Many other people may not regularly use pesticides, but they still may be exposed to them. Also, some people may use more than one chemical that has a neurotoxic effect, so it is hard to know which toxin is the risk factor. The difficulty in accurately measuring pesticide exposure poses a significant obstacle for the study of chronic exposures

over time. Finally, it is not known whether low levels of long term exposure are as detrimental as a few events of high levels of exposure.

Since pesticides are everywhere in the environment, and many stay in the body for a long time, one might predict that everyone has been exposed to a substantial ‘dose’ of pesticides. This prompts the question, ‘So why doesn’t everyone get AD?’ As with many other environmental exposures, a gene-environment interaction may play a role in who gets AD after being exposed to pesticides. This means that people with a certain gene may be at greater risk of developing AD if they are also exposed to a specific type of pesticide. On the other hand, people without that gene may not be at greater risk of AD even if they are exposed to the same pesticide. Some genes that affect the metabolism of pesticides in the body have already been identified, and these genes are candidates to investigate for interactions between AD and pesticide exposures.

As we hone in on new environmental and genetic factors that alter the risk of AD, we are reminded of how much we have learned about this disease in the past few decades. Thousands of genes have been studied and a number of these genes are thought to increase the likelihood of developing AD. New disease markers (biomarkers) have been identified that may help us diagnose AD earlier in the course of the disease. Many risk factors have been studied. The next steps are to learn more about the best ways to measure risk factor exposures and study their interactions with AD risk genes. Findings from these two steps should lead to interventions to ameliorate the effect of the risk factor among those genetically at greatest risk of developing AD if they are exposed to the risk factor.

### References

1. Hayden KM, Norton MC, Darcey D, Ostbye T, Zandi PP, Breitner JC, et al. Occupational exposure to pesticides increases the risk of incident AD: the Cache County study. Neurology 2010 74: 1524-1530.
2. Richardson JR, Roy A, Shalat SL, von Stein RT, Hosain MM, Buckley B, et al. Elevated serum pesticide levels and risk for Alzheimer disease. JAMA Neurol 2014 71: 284-290.

## Family Caregivers Advise Duke and UNC Researchers

By Dean Fox, Anna Beeber, Joe Clark, Gloria Dewey, Betty Frei, Maggi Grace, Lisa Gwyther, Kathy LaFone, Carol Land, Bobbi Matchar, Madeline Mitchell, Joan Peluso, Philip Sloane, Hongly Truong, Lynette Russell & Sheryl Zimmerman

Duke and UNC sitting at the same table. Seasoned family caregivers partnering with seasoned researchers. Unusual? Perhaps. But true of a recent research project that had family caregivers saying, “We felt valued as participants,” and researchers listening intently to the input from those, “in the trenches.”

There is growing interest in health services research in what is known as “consumer-directed research,” a process of involving individuals in shaping research from which the same individuals might benefit. Often this process involves conducting focus groups or includes one or two laypersons as advisors to research projects. In a unique application of consumer-directed research, a team of researchers from the University of North Carolina Cecil G. Sheps Center for Health Services Research (Sheps Center) and the Duke Family Support Program invited non-researchers to help in the development of a website for family caregivers. The website, Alzheimer’s Medical Advisor (AlzMed), is designed to help caregivers manage common medical problems and know when to seek medical attention for their relative with Alzheimer’s disease or related dementias.

Nine family caregivers of older adults with dementia were invited and agreed to participate in AlzMed’s Family Caregiver Advisory Panel. One caregiver described the project as, “a really nice partnership.” Their work on developing the tool took place during the first year of this five-year project, funded by the

National Institute of Nursing Research. The next four years will be devoted to testing the product with at-home caregivers, evaluating its usefulness and ultimately making it available to the public. As an unplanned outcome of their experience, all nine family advisors and six of the core research team members consented to co-author this article, participating in individual interviews with a graduate student about their perceptions of the role of the Advisory Panel and their contributions in the initial development of the website.

*“participating in efforts to help other caregivers was something my husband (who has dementia) really believed in when he was still able to talk...it served to allow me to honor my husband’s earlier efforts to help others.”*

All family advisors provided care for a person with dementia. They were invited because they represented a range of experience. The group included two daughters providing care for a parent, six women providing care for a husband, and one man who was widowed but had provided care for his wife. The relatives for whom they provided care ranged from early to advanced dementia. Most were diagnosed with Alzheimer’s disease, but some had several other forms of dementia. Two of the caregivers did not have regular online access, and thus did not consider themselves “computer literate.” The research team consisted of faculty and staff from the Sheps Center at UNC and the Duke Family Support Program; they included physicians, nurses, social workers and health services researchers. Participants from both sides quickly grew to know and respect each other. A caregiver commented that, “they (researchers) were genuinely interested in what we thought.” Another said that the

## FAMILY CAREGIVERS *(continued from page 5)*

researchers were “open to everything everyone said, just like you hope people would be. We felt valued as participants.” And one researcher said, “The caregivers were committed to us; we got to know them well; they felt comfortable speaking up.”

Over the course of six monthly meetings, the family advisors were intensely involved in shaping the development of the materials in ways big and small. Both researchers and caregivers agreed that the work changed from what was originally proposed, and they primarily attribute the changes to suggestions from the family advisors. According to one researcher, “It’s a much different thing than what we thought we were going to do originally. They made it clear that the strategy for problem-solving medical situations is much different than what we professionals expected.” Another researcher admitted, “It changed so much. I never would have anticipated how much...definitely for the better.”

Caregivers participated for different reasons, but some consistent themes emerged in interviews. Several simply participated because they were asked and felt honored to have been invited. Others hoped to gain valuable information to improve the care they

caregivers.”

One woman explained it this way – “participating in efforts to help other caregivers was something my husband (who has dementia) really believed in when he was still able to talk...it served to allow me to honor my husband’s earlier efforts to help others.”

The family caregivers were minimally compensated for their time. These payments were intended to make it clear that they were experienced advisors and full members of the project team, not research subjects. No caregiver participated solely because of the financial incentive, however, all nine said they would participate again, even if no compensation for their time was offered. One caregiver said that being paid showed that the research team respected their input and that they had been recruited, “to do a job.” Most felt the payments were something extra – “icing on the cake” – and many were surprised to be compensated. As one said: “When they first told us, I said ‘Are you serious?’ I would have done it no matter what. I felt honored.”

One family advisor appreciated that the researchers were not looking for “confirmation or rubber stamping” but rather were genuinely interested in using sincere

*“I was pleasantly surprised by how much the project changed direction in a positive way, working with the (family) advisors generated more versions, more effort, and more work. But always the feeling that we were getting better.”*

could provide. Most hoped their input would benefit other caregivers or individuals with dementia in the future.

“I felt like if there’s anything I can do to help anyone, it was my duty to try.”

“Participating in the project was consistent with efforts I had made previously to be of help to others.”

“I feel like there is a need for Alzheimer’s disease help for people.”

“I thought I might learn things that would be helpful to me; maybe I could learn to help other

feedback from the advisor panel. Both caregivers and researchers agreed that significant improvements were made to the concept, content and design because of this genuinely collaborative approach.

Simplification was a significant theme of the caregivers’ recommendations. The original language of the website was viewed as too academic. As one caregiver said, “We said you’ve got to make it simpler. Make it clear; use fewer words. It was University jargon. That isn’t what people like us need.” The researchers agreed. “We like to think we know how to word

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## FAMILY CAREGIVERS *(continued from page 6)*

things in lay language that people will understand,” one said, “(but) the advisors pointed out ways that we were talking about things that were more formal than everyday language...they helped change the tone of what we were doing.” In addition, the layout of the website was adapted to be more intuitive for caregivers and more accessible on smaller devices, because some of the family advisors pointed out that they often use tablets and other portable technology.

In addition to simplification of language and layout, the content of the website changed considerably. The advisors suggested which medical topics are most pressing to caregivers, and priority topics were developed first based on their feedback. They placed a priority on non-emergency medical situations, saying that if the situation were an emergency, they would call 911 rather than access the website. In addition, family caregivers wanted specific, step-by-step problem solving guides for particular situations. Many caregivers mentioned having a relative or close friend who works in a medical field and whom they would call about medical concerns; so the researchers developed a guide they could use to organize information before calling.

The work of the Family Caregiver Advisory Panel led to the development of a website that is more accessible, easier to navigate, and more effectively organized around what concerns actually matter to caregivers than it would have been without their input. One researcher summed it up saying, “What was great, from the (research) team’s perspective, we focused on topics that never would have occurred to us, designed things in a way that we wouldn’t have come up with. So they really shaped the product. What we had originally envisioned is not where we ended up.” Another researcher said, “I was pleasantly surprised by how much the project changed direction in a positive way, working with the (family) advisors generated more versions, more effort, and more work.

But always the feeling that we were getting better.” In that way, involvement of the advisory panel was a huge benefit to caregivers who will use the tool, and this benefit was expected.

Another positive outcome was the knowledge gained by the family caregivers. Some family members said they learned something at each meeting, and that their oversight of their family member’s medical condition improved as a result. Caregivers learned from the professionals, but sometimes they learned as much from each other. As one said, “Just knowledge, practical knowledge, and hearing about how others had actually dealt with things we were talking about. I was thrilled to be included, so I could learn, have some background. I had never seen Alzheimer’s disease before. The whole thing is a big new world. I was, and am, eager to learn as much as I can.”

A less anticipated benefit was the meaning this participation had for the family caregivers. One described feeling energized by each meeting and leaving with a sense of, “I can do this!” Most appreciated working on a unique project, feeling that their input was highly valued and that their

work would benefit other caregivers. Finally, several spoke about enjoying the company of working with fellow caregivers while developing an important tool. In the words of one participant, “there’s something really special about being with other caregivers. As strange as it may sound, it’s sometimes even fun... This is serious business, but the camaraderie was a really nice bonus.” The research team also enjoyed this unique partnership. One researcher admitted that including family caregivers, “made the meetings more interesting and more fun. Having real people participating made it an interesting and lively group.” It was a win for everyone – for Duke and UNC, for the family caregivers and researchers, and likely for the future care of individuals with Alzheimer’s disease.

*“there’s something really special about being with other caregivers.*

*As strange as it may sound, it’s sometimes even fun...*

*This is serious business, but the camaraderie was a really nice bonus.”*

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## Senior Fraud Alert: New Twist on Grandparent Scam

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The Elder Fraud Unit of the Attorney General's Consumer Protection Division is noticing a new twist in the way overseas scam artists are running the "Grandparent Scam." Whereas in recent years the scammers have claimed that they were the victim's grandchild vacationing overseas, and that they were facing criminal charges in a country such as Peru, Mexico, Spain or England for causing a terrible traffic accident, now some of them are claiming to be incarcerated in the local jail of the community where the grandchild actually resides. They claim that the persons they injured were foreign tourists who were traveling in a rental car here in the U.S. and that release from jail on bond will not be considered until thousands of dollars are wired to the injured foreign tourists, who have returned to their home country to recuperate. The payments usually are represented to be for medical care.

This new twist may stem from the fact that targets of the Grandparent Scam often will not believe that their grandchild has gone on an overseas trip, especially without telling them. Or, the victim might have spoken with the grandchild in question just hours or days before. Victims are more likely to believe, however, that their grandchild was just involved in a local traffic accident. One target was told recently that her grandson was in the local jail here in North Carolina. Another NC target was told that her grandson was in the local jail in his current town in New York state. In both instances the targets of the scams were told to wire \$6000 to individuals in Bogota, Columbia.

The other common features of a Grandparent

Scam appear to remain the same:

1. The supposed grandchild explains that his or her voice sounds different because of injuries sustained in the wreck.
  2. The supposed grandchild implores the grandparent not to tell his or her parents until he gets out of jail – and describes terrible conditions in the jail.
  3. Third parties claiming to be the grandchild's attorney or jailer will place calls to the grandparent, describe the grandchild's deteriorating physical or legal situation, and press them to wire money (or more money) immediately.
  4. The grandparent is told not to bother with calling the grandchild's cell phone number because it has been confiscated by jailers.
  5. Once money has been wired, the grandparent is called again and told that additional monies need to be wired because the medical condition of a victim has deteriorated, or a victim has died, or because the victims' rental car company wants to be compensated for damages, or because charges have been increased, necessitating more money for bail or attorney's fees.
- In the U.S., a person arrested because of an automobile accident cannot be held in jail until the other party's medical or property damage bills are paid.

Individuals or businesses who think an older adult is being targeted with this or any other type of cross-border scam should contact the Elder Fraud Unit of the Attorney General's Office, telephone 1-877-5-NOSCAM, and ask to speak with one of the Telemarketing Fraud Duty Agents.

*From The North Carolina Department of Justice,  
Consumer Protection Division*

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# Creative Ways to Help When Your Help Isn't Wanted

By Paula Spencer Scott

Excerpted from "Surviving Alzheimer's: Practical Tips and Soul-Saving Wisdom for Caregivers" (2014)

The number-one reason most older adults often refuse assistance is *fear of losing control*. (It's numbers two and three and four, too.) Aging parents are driven by a need for control, and their children are driven by a need to solve problems, get things done, tick items off a to-do list, and move forward. That disconnect can be crazymaking — for both sides.

These ideas can help you navigate this tricky dance in the earlier stages of Alzheimer's, when people can often continue to live independently, but require evermore support:

**1. Understand what "no" means.** Knee-jerk refusals are a natural response to the conflicts a parent may be feeling, coping with so many losses and threats, while perceiving others as interfering and creating more changes. Show empathy that you get where he's coming from: "You're right, it's a hassle..." "You've always done so much. What would be the worst part of that change for you?"

**2. Listen more than you act, at first.** Your goal is to help, not to fight about the need for help. Spend time together not with the aim of nagging or saying what you think should be done, but just relaxing and listening. You'll be able to achieve more if he doesn't feel like you're "taking over" or "intruding" because that's the only thing you ever want to talk about.

**3. Observe and record what you're dealing**

**with.** Get specific about where you see help needed. Make written lists of the problems (bill collectors are calling about unpaid bills, three car accidents, can't mow lawn, got lost last week, etc.). This keeps a more neutral focus on the needs at hand, not on you as a "meddler."

**4. Instead of making suggestions, ask questions:** "I know you don't want to move, but how do you think

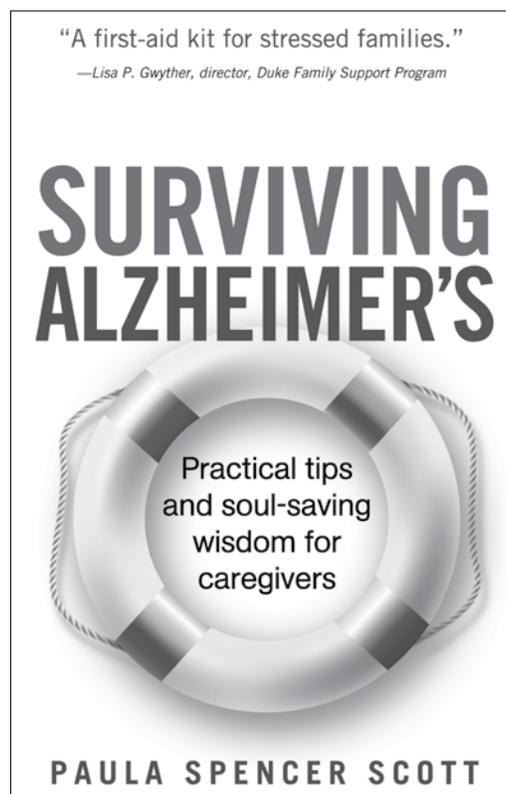
*we should handle upkeep on the house now that the doctor says you can't go up ladders?" "What do you want to do with all this extra stuff in the house?" "Why don't you make a list of pros and cons?"*

**5. Keep focused on the solution and the benefits.** "If someone helps with cleaning, I'll have more time to take you to lunch and the salon." "When your meals are brought to you, I won't have to worry as much, and you'll get your energy back."

**6. Propose "temporary" solutions.** "Why don't you try this for a couple of months and see how it goes for you?" "The firm offers a trial service for a month. The first visit is free, so what's there to lose?" One caregiver persuaded her parents to have

a geriatric care manager (who was referred to as a life coach) drop by daily while she was out of town. They enjoyed the help so much that the arrangement continued after the daughter's business trip ended.

**7. Mask the purpose of the help.** To help keep



*continued on page 12*

# My Father's Stories

By Carol Henderson

I'm heading off to visit my father in Philadelphia, a pilgrimage I don't make often enough.

These trips are exhausting though nothing much happens. Like an old dog, my 93-year-old dad sleeps – a lot. When he's awake and has something to say, his voice is barely a whisper and his thoughts come out muddled.

But I'm hopeful this time. I've got something that just might jumpstart a coherent memory bank.

Let me explain. When he called recently (my sister did the dialing) the conversation began the way it usually does.

"I'm so glad to hear your voice, Daddy," I said.

He mumbled something I couldn't understand.

Instead of saying, "What?" I've learned to move on, to tell him something, anything. That day I picked up the book I was reading, "Unbroken: A World War II Story of Survival, Resilience, and Redemption," by Laura Hillenbrand. It's about an American POW named Louie Zamperini, who, like my dad, was a track star and served in the Pacific.

"Dad," I said. "Did you know a guy named Louie Zamperini when you were training out in California?"

"Louie," my dad said, his voice suddenly crisp and loud. "Of course. We ran together."

"And he served in the Pacific during the war, Dad." "I know. I remember him. He was shot down. Survived in the water for weeks."

Delighted by my father's clarity, I named some Pacific islands from a map in the book. My father volunteered others.

He faded again, but at least synapses had fired.

When I visit I usually wheel Dad around the gardens

of his retirement community. He'll perk up at the names of flowers and trees and he enjoys listening to the birdcalls. My father was an avid gardener, an Olympic qualifying runner, a Princeton graduate, a WWII veteran, the father of three girls, and an unfulfilled public relations man. He's been a widower for almost a year.

On this trip, it's going to be cold and gray, probably not garden-gazing weather. He'll want me to park him in front of the television by the nurses' station.

"No, no!" he'll say, sometimes shouting it, if I try to take him to his room so we can "talk." He'd rather watch "Jeopardy," old movies, sitcoms, cooking shows, whatever. Ironic for a man who forbade television, and insisted on family conversation, when his daughters were young.

This time, with "Unbroken," I just might be able to lure him into his room, a lovely space with a portrait of his late wife, familiar furniture from my childhood, and lush plants.

My dad had served on the staff of Admiral Nimitz, whose title was Commander in Chief of the U.S. Pacific Fleet. I now have a large photograph of the admiral – it used to hang in my father's office – with an

inscription by his boss, the admiral, thanking my father for his WWII service.

"Dad," I'll say. "Louie was also honored by Admiral Nimitz."

Growing up, I paid little attention to the sagas my father told at dinner. I watched the candles burn and tried to remember to keep my elbows off the table. If I didn't he would poke them with his fork, and it hurt. I would wait, stony faced, until all the plates were cleared and I felt safe to ask: "May I please be excused?" His

*Growing up, I paid little attention to the sagas my father told at dinner... Now all these decades later, I'm going to read to him from "Unbroken." Hopeful he'll remember some of his tales and tell me again. I want to hear what I was too scared and distracted to listen to when I was a little girl...*

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# Transitions

By Margaret Toman

Through all the stages of my mother's Alzheimer's disease and the multiple challenges that have confronted us, many of the deepest transitions have been my own.

Like all caregivers of those with dementia, I have traveled with my mother through every stage of her illness, gradually lowering my expectations, adjusting hope, fine-tuning empathy and stumbling from denial toward acceptance, still an elusive destination. I still laugh but consistent cheerfulness eludes me. Outwardly, I am growing plump and gray like Velcro but without her vibrant purr. So much has changed.

Fourteen years ago, I was a single, older working woman of modest means active in civic and social activities, wearing out the hinges on my apartment door, living a lifestyle balanced between solitude and companionship, oblivious to the steady passage of time. Today I am an unemployed homeowner on social security, struggling to keep a roof overhead, sole caregiver for my 100-year-old mother who lives with me, and evolving as a writer, speaker and advocate for the ill and powerless. No one is more astonished than I.

My mother is still a beauty – even at 100, even with advanced Alzheimer's Disease, even though she anointed my right foot this morning when I transitioned her from bed to wheelchair, an event which would have appalled me once but which now earns her a soft chuckle and a comforting hug. Some say my decision to care for my mother at home was a leap of fiscal folly, a financial sacrifice too far, and it has turned out that they were right. It was also an affirmation of optimism, a declaration of love, a transition from fear to courage, and

a gift I wouldn't hesitate to give and receive all over again.

On weekday mornings before I take my mother to adult daycare, I feed her breakfast, usually a cup of Yoplait and a high calorie Ensure. She ingests it at a frustratingly glacial pace, peering at me over the straw. During these long feedings my eyes wander to

the backyard where birds flock to the feeders in the shifting light and dark of changing seasons. I recall that in her younger years my mother made wicked whiskey sours, wrote prize-winning poetry, painted watercolors, revered the silly and the profound, made room for difference, and never met a stranger. She had been a reporter, commercial artist, Angus breeder, prize-winning poet and salesman. Her depths and shallows were genuine. Anywhere she had never been was where she wanted to go. Once when we were exploring an old cemetery, I asked her what she would like as her epitaph. She threw back her head, eyes sparkling and said, "Tell them I had a good time!" She did.

I don't know when the shadow first loomed in her brain but I was chilled when we emptied boxes from her storage unit ten years ago to find that Alzheimer's had been there too, years before, jumbling her belongings in confused piles of unrelated items. Later I recalled her rambling tales, presented so entertainingly and authoritatively that everyone believed them, no matter how outrageous, but I knew them not to be true. I had never known my safety conscious mother to place a knife in the dish drain, blade side up, or to accuse children of stealing her jewelry. She was so dependably healthy, sturdy of spirit and heart, so authoritative, that even flashing signals didn't penetrate my oblivion. It was



*Photo of the author's mother, Lou M. Longest, taken in the late 1960s.*

*continued on page 12*

## TRANSITIONS *(continued from page 11)*

repeated falls and wanderings that finally found us in the office of a neuropsychologist. "Alzheimer's disease," he said. For weeks I wandered in the wilderness - a terrified and anguished only child.

When she has taken the last swallow of Ensure, I pull the straw gently from her lips and stroke her silver hair. She responds with a slight smile, still a celebrant in the deepest sense of that word, enlightened by a visceral joy in living. When I am with her, there are moments lately when joy and sorrow arrive in my heart simultaneously, forged by love into a gratitude that takes my breath away. Alzheimer's disease will claim my mother but it will never define or own her. Or me.

Later today I will meet an acquaintance for lunch who still has her own life, ample means, reasonable challenges, and no particular reason to mark the passage of time. If things go as usual she will ask at some point in our conversation, "How in the world do you do it?!" I will smile, lift a wicked whiskey sour in honor of my mother, and share a little D. H. Lawrence: "Love is having the courage of your tenderness."

That has been the greatest transition of all.

*Margaret Toman is the sole caregiver for her 100-year-old mother. She is also a writer, public speaker, caregiver advocate and community volunteer. Margaret and her mother live in Garner, NC.*

## SURVIVING ALZHEIMERS *(continued from page 9)*

an eye on her mother across the country, one woman enlisted local friends who stopped by on pretexts. One friend asked the mother to save the newspaper for her because she didn't subscribe; every day or so she'd drop by to collect them. Another friend asked for knitting lessons.

**8. Find the right inroad.** Your mother might not like the idea of a cook and maid because she's old and needs help, but she might get a kick out of a birthday gift for these services pitched as "pampering." Someone who never hired help but always follows clergy or medical advice might be open to someone coming in if it's "prescribed" by the right person.

**Keep in mind that it's hard to force anybody to do anything. You may have to live with decisions or living situations you're not thrilled with and wait for the proverbial other shoe to drop. This can be agonizing, especially as the effects of dementia begin to take hold.** You may be only able to do what you can preventatively, until things reach the point where finances, health, or physical safety are in jeopardy.

*Paula Spencer Scott is the author of *Surviving Alzheimer's*, a *Caring.com* contributing editor, and a *Met Life Foundation Journalists in Aging* program fellow. Four family members have had dementia. See: [SurvivingAlzheimersBook.com](http://SurvivingAlzheimersBook.com)*

## FATHER *(continued from page 10)*

answer wasn't always "yes."

Now all these decades later, I'm going to read to him from "Unbroken." Hopeful he'll remember some of his tales and tell me again. I want to hear what I was too scared and distracted to listen to when I was a little girl - those stories I never knew I'd want, someday, to know.

When I arrive he has just come out of the bath and I'm able to wheel him to his room without protest. I pull a chair up beside him and thumb through the book, showing him the accompanying photos and reading an occasional paragraph.

"POW's, yes, there was Frank and ..." he waves his arm, searching for more names. Other tidbits follow. Then I read my dad the two-page preface. His face

squishes up, his mouth turns down, and he begins to sob. He can't stop.

"I'm sorry, Daddy," I say. He places his long bony hands over the open book as though it were a sacred tome. His head nods up and down.

"Should I continue?"

"Yes," he whispers. No more words come from him, but as I read he grabs my hand and squeezes, his head bobbing with recognition.

It is my turn now to tell him his story.

*Carol Henderson is a Chapel Hill-based writer and teacher, who offers writing workshops all over the country. Her father died last year, at age 95, while she was with him. Visit her website: [www.carolhenderson.com](http://www.carolhenderson.com)*

## The Story of Joseph

*Editor's note: The author, Joseph, has his mother living with him and his wife, Mary, half the year; and she spends the other half the year with his sister, Maria, in Florida.*

My mother is back here now... for six months of my turn of caregiving to relieve Maria. Mom is now 96 years old, has dementia, is hard of hearing and understanding, living with COPD, and a patient of hospice. Yet, she shares a moment now and then of clarity and wit. Upon our arrival from the airport. Me: "Mom, do you know where you are now?" Mom: "The question is, Joseph, do you know where YOU are now? I happen to be in Manhattan." It's hard to describe the feeling you get from laughing with her in the car, then to watch her incessantly folding and refolding a Kleenex for five minutes. If I interrupt her, she responds by saying, "Let me finish this first."

Somehow, we make that work without too much upset to our mother. She has spent so much time in New York over these 27 years I've been back here that this has become her home as much as Florida. So we're fortunate the transitions aren't traumatic. But the travel itself is a bit upsetting... she gets confused with the hustle in the airport, security, wheelchairs and bathrooms. And now we have to travel with the portable oxygen concentrator in addition to the wheelchair assistance, but JetBlue gets us through quickly.

When we returned to Florida in July, she woke up on the second day terribly confused and in a panic over a sudden realization of memory loss. She told me, "I remember this house, but have no memory of living here. Where am I and where did I come from?" I asked her, "Mom, do you feel safe, secure, loved, comfortable, and cared for?" She answered, "Yes." I then told her, "Well, you have more than most people do and we only have the moment right now anyway. You are in Florida now after being in New York for six months." It seemed to squelch that initial panic.

Maria and I now both know how stressful caregiving

is. It's non-stop every day, many times a day. When Mom goes back to Florida, I suddenly don't have to worry about meals or time or anything except what I want to do that moment. Mary and I are easy with each other so we do what we like. But when my mother is here, I suddenly have to think about someone else and it's stressful. We are both helping Mom with medicine time, showers, layering her underwear with liners, telling her when to wash her face, doing her dentures, grooming her, balancing her diet to maintain weight, waking up and checking that she has the oxygen on properly, washing her clothes, dressing her to match clothing and earrings properly...the list is absolutely endless. Whatever I do for myself, I also have to do for her now. But she is slip-slip-slipping away. It is a slow grief of loss and is very strange. I'm guiltily relieved when she goes back to Florida; I'm overwhelmingly stressed when she first arrives. Mary is commuting out to Long Island at least a few times a week to care for her father... so I do have her

understanding of the invasion in our little apartment world.

So Maria and I have this caregiving to share. But I know that Maria has it much worse than me... she is depressed and has a very solitary life...hasn't gotten sick and tired of being sick and tired yet...so my mother is filling her life with purpose. I don't need caregiving for my purpose because when our mother is not here, there STILL aren't enough hours in the day to do what I want to do. Maria will be in a vacuum when our mother leaves us. I worry about that. This caregiving is tapping something caring in me I didn't think I had; but it also tells me that I only have so much energy and tenderness for it. Sharing the care is vital for both of us in different ways.

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*This caregiving is tapping something caring in me I didn't think I had; but it also tells me that I only have so much energy and tenderness for it. Sharing the care is vital for both of us in different ways.*

## *The MemoryCare Plays,* an Anthology of One-Act Plays on the Challenges Posed by Alzheimer's

As Alzheimer's disease and other types of dementia become increasingly prevalent, the dramatic arts can help provide needed insight and understanding into this looming societal challenge. Chosen by a juried panel from over 90 submissions from the U.S. and other countries, the three professionally crafted plays contained in *The MemoryCare Plays* anthology strive to dramatize the full impact of progressive memory disorders upon the individual, and to illustrate the richness and complexity of the caregiving relationship, with all of its challenges and rewards.

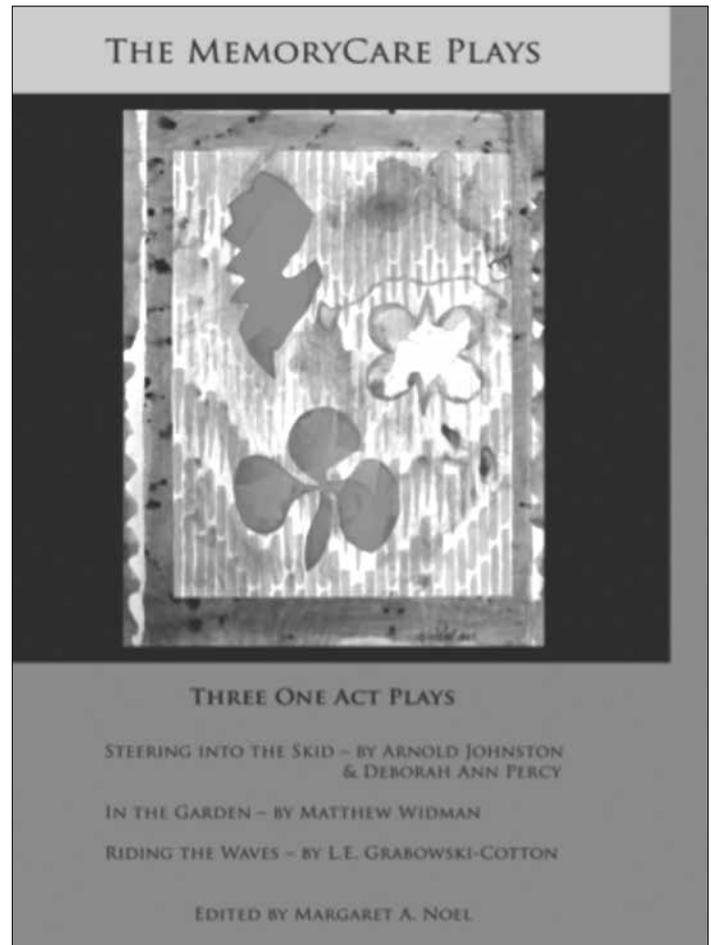
*The MemoryCare Plays* are edited by Dr. Margaret A. Noel, founder of MemoryCare, a non-profit charitable organization in Asheville, NC, that provides integrated services for persons with Alzheimer's disease and other dementias and their caregivers.\* The plays include *Steering Into the Skid* by Deborah Ann Percy and Arnold Johnston, *In the Garden* by Matthew Widman, and *Riding the Waves* by L.E. Grabowski-Cotton. Each work in this anthology is introduced by its author. The anthology is available through Amazon.com.

*Steering Into the Skid* is a perfect metaphor of a play, sweet and bittersweet. Letting go of driving is such an iconic stage in the progression of dementia; the authors have transformed that moment into a 12-month journey, with Amanda and Tim bound together on a trip through all the seasons of life.

*In the Garden* is meticulously and lovingly observed and written, capturing the father's erratic behavior and flights of poetry, and the struggle of his children to adjust and cope and hold on to lives that are forever changed.

*Riding the Waves* is lovely, with its gentle humor. It subtly reveals the tensions and cross-currents in the family, and the shape-shifting of the father and son gives us a window into Isabel's world, and into her daughter's confusion and frustration.

- David Hyde Pierce, (Tony Award-winning stage actor, best known for his role as the psychiatrist, Dr. Niles Crane, on the sitcom *Frasier*. Hyde Pierce is a well-known advocate for Alzheimer's research and services.)



All proceeds from this anthology will be donated to benefit families affected by dementia. Originally performed as a benefit for MemoryCare, the playwrights have generously agreed to allow MemoryCare to grant other non-profit organizations dedicated to dementia care the opportunity to utilize their work for educational, advocacy or fundraising events, provided that all profits raised from any such events will be applied to the care or support of persons affected by dementia.

\*MemoryCare is a team of physicians, nurses, social workers and volunteers helping individuals with Alzheimer's disease and other cognitive disorders live as fully as possible for as long as possible at home or in their preferred setting. The MemoryCare team focuses on equipping the caregiver with the resources they need as well as providing excellent care to the individual with the memory disorder.

# Bookshelf

**AgingCare.com, 2013.** *The Caregivers' Survival Guide: Family Caring for the Family.* A free guide for caregivers with advice on how to prepare legally, financially, and emotionally to care for a family member. Available only as an eBook at [www.agingcare.com/ebook](http://www.agingcare.com/ebook).

**Boss, Pauline, 2011.** *Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief.* Written for caregivers of people with dementia, this book offers suggestions for managing ongoing stress and grief. Dr. Boss gives hope to caregivers dealing with "ambiguous loss," the loss of a loved one who is here physically but absent psychologically.

**Cail, Mary M., 2013.** *Alzheimer's: A Crash Course for Friends and Relatives.* In this reader-friendly book, the author outlines how to respond to the challenges of dementia with compassion, comfort and help. Cail, an experienced counselor and support group leader, brings the voices of caregivers and persons with dementia to life with stories, sample conversations and simple strategies.

**Carpenter, Molly, 2013.** *Confidence to Care: A Resource for Family Caregivers Providing Alzheimer's Disease or Other Dementias Care at Home.* This handbook offers caregiving strategies for dealing with common dementia-related issues as well as advice for taking care of oneself. It includes personal stories presented with easy, practical tips and caregiving techniques from dementia experts as well as recommendations of other helpful resources.

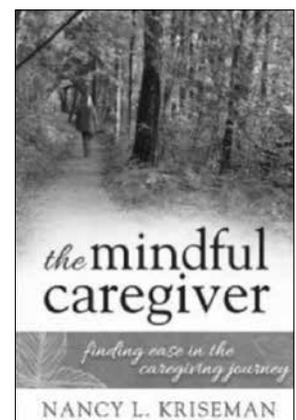
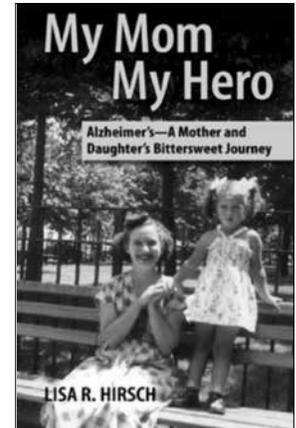
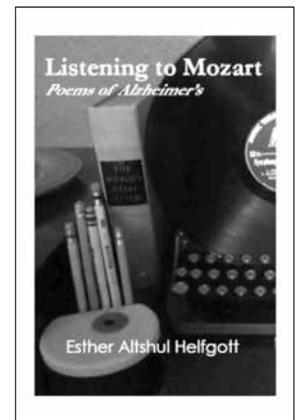
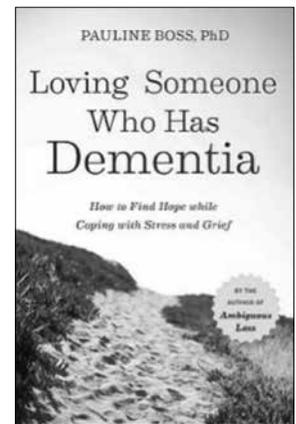
**Helfgott, Esther, 2014.** *Listening to Mozart.* Poet Esther Altshul Helfgott chronicles her last seven years with her husband, Abe, and their heart-wrenching journey with Alzheimer's. Her diary entries and poems show the tenacity of love and a visceral understanding of the need for compassion on this difficult path.

**Hirsch, Lisa R., 2013.** *My Mom My Hero: Alzheimer's - A mother and daughter's bittersweet journey.* When the author found out her mother, Ruth, had been diagnosed with Alzheimer's disease, her love, appreciation, and caring for her mother was transformed. To Hirsch's surprise, it brought her and Ruth closer together than they had ever been. This memoir tells that story through a series of entries from Hirsch's popular blog.

**Kriseman, Nancy L., 2014.** *The Mindful Caregiver: Finding Ease in the Caregiving Journey.* A geriatric social worker (with two previous national book awards on elder care) who cared for her mother through Alzheimer's disease, offers mindfulness techniques to honor the spirit and losses experienced with family care. Kriseman uses real stories to highlight two caregiving approaches, mindfulness and spirituality, to provide encouragement and inspiration for caregivers.

**Levine, Carol, 2014.** *Living in the Land of Limbo: Fiction and Poetry about Family Caregiving.* Drawing from a wide range of cultural backgrounds, this anthology of short stories and poems reveals the emotional experiences of men and women caring for family members with various chronic illnesses.

**Lipton, Anne M. and Marshall, Cindy D., 2013.** *The Common Sense Guide to Dementia for Clinicians and Caregivers.* This guide offers guidance from two specialists for clinical and family care of patients with dementia. It provides a detailed medical perspective on both non-Alzheimer's types of dementia and Alzheimer's Disease.



continued on page 16

## BOOKSHELF *(continued from page 15)*

**London, Judith, 2013.** *Support for Alzheimer's and Dementia Caregivers: The Unsung Heroes.* A book of 54 caregiver stories with suggestions for care. Each vignette contains comforting and nurturing messages for caregivers through repeating themes and provides tips for caregivers to take care of themselves.

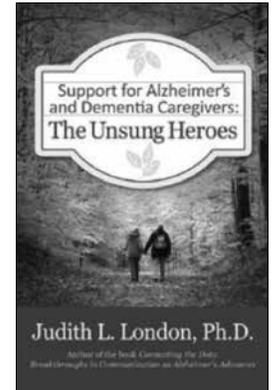
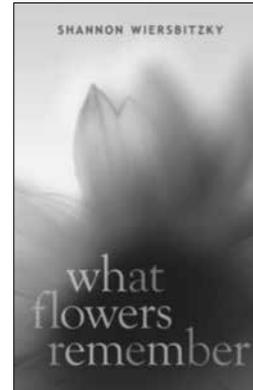
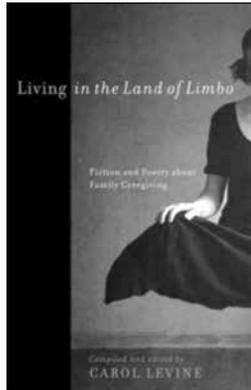
**Lustbader, Wendy, 1993.** *Counting On Kindness: The Dilemmas of Dependency.* Mental health counselor Lustbader presents stories from older persons themselves about the frustrations of being dependent on others. The stories cover a wide range of conditions and people and elicit sensitivity to issues of dependency.

**Matthews, Barbara G. and Blank, Barbara Trainin, 2013.** *What to Do about Mama?: A Guide to Caring for Aging Family Members.* Matthews and Blank offer recommendations and guidance for family caregiving based on their own and others' real-life experiences. The book provides advice to develop realistic goals, expectations, and strategies as a caregiver, particularly for aging parents.

**Wiersbitzky, Shannon, 2014.** *What Flowers Remember* This compassionate novel, for readers aged 11-14, captures the strength of a close-knit community and the tight bonds that can form between the very old and the young. The 13-year-old's frustration, fear and sense of loss will be readily recognizable to others who have experienced dementia in a loved one, and her story may provide some guidance on how to move down the path toward acceptance and letting go.

**Wornell, Douglas, 2013.** *Sexuality and Dementia: Compassionate and Practical Strategies for Dealing with Unexpected or Inappropriate Behaviors.* It is not uncommon for a person with dementia to exhibit inappropriate sexual behavior, which may cause tension for family and professional caregivers. Geriatric neuropsychiatrist Douglas Wornell provides information and practical solutions for coping with these behaviors.

*Bookshelf was edited by Lily Huang, a rising junior at Duke University and a work-study student at the Duke Family Support Program.*



**1 in 8.** That's your chance of developing Alzheimer's disease at age 65.

That risk increases to a **1 in 2** chance at age 85.

There's much that we still need to learn about Alzheimer's disease (AD). If you're a healthy senior, you may be able to contribute to this understanding.

The TOMMORROW study is an important clinical research study now seeking healthy senior participants between the ages of 65 and 83 to help us learn more about the early phase of AD.

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📞 CALL 919-668-0988 OR

🌐 VISIT [WWW.TOMMORROWStudy.COM](http://WWW.TOMMORROWStudy.COM)

If you are selected as a study participant, you will not have to pay for your investigational medication, study visits, or any tests that are part of the study. Transportation assistance may also be available.

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# Online Help



## Alzheimer's Disease and Related Disorders

<http://mag.newsweek.com/2014/04/04/alzheimers-expensive-deadly-growing-wheres-research-money.html> "Alzheimer's Is Expensive, Deadly and Growing. So Where's the Research Money?" A March 2014 Newsweek feature reports that, "Alzheimer's is one of the costliest chronic diseases to the country," yet, "Historically, Alzheimer's research has been grossly underfunded."

[http://www.nia.nih.gov/sites/default/files/the\\_dementias\\_no\\_drop\\_shadow\\_13dec18.pdf](http://www.nia.nih.gov/sites/default/files/the_dementias_no_drop_shadow_13dec18.pdf) The Dementias: Hope Through Research is the newest research update booklet from the NIH that discusses basic information about different types of dementia, risk factors, diagnosis and treatment options, and current areas of research.

[http://alzheimersnswlibrary.blogspot.com.au/2013/10/youre-not-alone-discussing-dementia\\_16.html](http://alzheimersnswlibrary.blogspot.com.au/2013/10/youre-not-alone-discussing-dementia_16.html) You're Not Alone: A playlist of 10 short videos introducing dementia and how to care for people with dementia from Alzheimer's Australia (Oct 2013). Sample titles include: Getting a Diagnosis, Dealing with change, Losing the Dreaming, Looking After Yourself.

<http://geniusofmarian.com/> The Genius of Marian is a National Creative Expression award-winning film about early or young-onset Alzheimer's Disease in a mother and her "struggles to hold onto a sense of self." This website lists public screening dates for the film.

<http://alzpoetry.blogspot.com/> This caregiver award-winning blog features poetry written by people living with Alzheimer's Disease as part of the Alzheimer's Poetry Project.

<http://nccam.nih.gov/health/tips/alzheimers> 5 tips on complementary health practices and dementia and what the science says about ginkgo and omega-3 fatty acids. From the National Center for Complementary and Alternative Medicine in December 2013.

[http://www.alz.org/nyc/in\\_my\\_community\\_22103.asp](http://www.alz.org/nyc/in_my_community_22103.asp) The ADvancing Care newsletter from the NYC Alzheimer's Association is a free quarterly newsletter on care practices for people who work or live in residential care settings. They are brief, practical and care-focused. To receive the newsletter by email, sign up for the mailing list at the link provided. The newsletter can also be read online at this link.

<http://thecallshortfilm.com/> A 3-minute film by David Cooper. A UK radio show asks for call-ins of stories about "How You Met Your Other Half." A husband caregiver calls in and shares his experiences living with and caring for his wife with dementia.

## Caregiving

<http://www.redbookmag.com/health-wellness/advice/facing-my-mothers-dementia> Actress Kimberly Williams-Paisley's personal essay in *Redbook* about loving her mother with dementia. "How I Faced My Mother's Dementia," describes Paisley's struggle to cope with her mother's diagnosis of primary progressive aphasia, a cognitive impairment that involves a progressive loss of language function.

[http://caregiversnewsbasket.blogspot.com/?goback=%2Egde\\_1833888\\_member\\_5829222651213676544#%21](http://caregiversnewsbasket.blogspot.com/?goback=%2Egde_1833888_member_5829222651213676544#%21) A blog listing news and articles of interest for caregivers dealing with Alzheimer's disease and eldercare. It also provides links to numerous other informational resources and videos.

<http://www.newsweek.com/caregivers-alzheimers-can-be-life-sentence-238731> "For Caregivers, Alzheimer's Can Be a Life Sentence," is a March 2014 *Newsweek* feature about the emotional and physical impact of caring for a family member with dementia and, about a unique chorus, The Unforgettables.

<http://www.mountainx.com/article/57277/Who-cares-for-the-caregiver> This article in Mountain Express, an independent newspaper in Asheville, NC, looks at the profound impact that caring for a family member with an incurable or terminal illness has on the caregiver. A description of many of the local resources available in Western NC is also included.

*continued on page 18*

## Online Help *(continued from page 17)*



[http://www.nextavenue.org/article/2014-01/special-series-under-60-and-living-dementia?utm\\_campaign=Feb.13.2014.Newsletter\\_NA&utm\\_medium=email&utm\\_source=Eloqua](http://www.nextavenue.org/article/2014-01/special-series-under-60-and-living-dementia?utm_campaign=Feb.13.2014.Newsletter_NA&utm_medium=email&utm_source=Eloqua) A special series of blogs about a woman diagnosed with FTD at age 50 and her family's experience coping with the challenges of her diagnosis.

[http://www.nextstepincare.org/uploads/File/Guides/Doctor\\_Visits/Doctor\\_Visits.pdf](http://www.nextstepincare.org/uploads/File/Guides/Doctor_Visits/Doctor_Visits.pdf) A brief guide for family caregivers discussing how to manage visits to the doctor. Provides tips and advice for what to do before, during, and after a doctor visit as well as how to navigate conflicts with family members.

[http://www.helpforalzheimersfamilies.com/dementia-support-network/live-chats/?goback=%2Egde\\_1833888\\_member\\_5837185508911915011](http://www.helpforalzheimersfamilies.com/dementia-support-network/live-chats/?goback=%2Egde_1833888_member_5837185508911915011) A website that provides the opportunity to participate in live online chats with dementia experts. Transcripts of past chats are available. See transcripts from chats with David Troxel on Agitation and Aggression.

<http://www.healthinaging.org/> A comprehensive source of information for caregivers from specialists in geriatrics. Provides general information about medical conditions, medications, finding a geriatrics professional, caregiving tips and more for older adults.

[http://sgec.stanford.edu/pdf-word/Dementia%20Novela%20Final\(Web\).pdf](http://sgec.stanford.edu/pdf-word/Dementia%20Novela%20Final(Web).pdf) "Together We Can: Facing Memory Loss as a Family" is a fotonovela from the Stanford Geriatric Education Center on dementia and memory loss targeted towards Latino caregivers. It provides suggestions about how to begin caregiving through the story of a family going through the same situation.

<http://thedementiaqueen.com/> A helpful website that provides information about various types of dementia, including self-care tips, news articles, recent research, and other resources. In particular, see the following posts from 2014: 10 Tips for Managing Hallucinations, Grief and Depression, and The Silent Movie approach.

[http://www.newyorker.com/reporting/2013/05/20/130520fa\\_fact\\_mead](http://www.newyorker.com/reporting/2013/05/20/130520fa_fact_mead) Rebecca Mead's 2013 "A Sense of an Ending" describes the advanced dementia palliative care model used at Beatitudes Campus, a retirement community in Arizona. Beatitudes Campus has become "an incubator for a holistic model of care" with its person-centered approach.

### Planning, Insurance & Long-Term Care

<http://www.consumerfinance.gov/blog/managing-someone-elses-money/> 4 easy-to-understand booklets to help financial caregivers. The Managing Someone Else's Money guides are for agents under powers of attorney, court-appointed guardians, trustees, and government fiduciaries (Social Security representative payees and VA fiduciaries.). The booklets provide a breakdown of financial duties, how to handle scams and exploitation, and where to go for help.

<http://www.cdc.gov/aging/pdf/acp-resources-public.pdf> An Advance Care Planning resource guide from the CDC for families. Includes topics of hospice and palliative care, caregiving, cognitive impairment and legal issues.

[https://www.benefitscheckup.org/esi-home/?utm\\_source=NCOAWeek\\_131210&utm\\_medium=newsletter&utm\\_campaign=NCOAWeek](https://www.benefitscheckup.org/esi-home/?utm_source=NCOAWeek_131210&utm_medium=newsletter&utm_campaign=NCOAWeek) EconomicCheckUp® is a new online tool sponsored by the National Council on Aging for seniors to improve their financial security. It asks a few questions to help older adults learn how to make the most of their money.

<http://longtermcare.gov/costs-how-to-pay/what-is-covered-by-health-disability-insurance/coverage-limits-chart/> This website provides information about long-term care in a straightforward, user-friendly format. The Coverage Limits Chart shows the most common types of insurance and the type of coverage each provides.

### Products & Technology

[http://alzheimersmusicconnect.com/?utm\\_source=AgingCare.com&utm\\_medium=AgingCare.com&utm\\_campaign=AgingCare.com](http://alzheimersmusicconnect.com/?utm_source=AgingCare.com&utm_medium=AgingCare.com&utm_campaign=AgingCare.com) A music product for people with dementia and their caregivers. It utilizes *carefully* selected music to comfort individuals with dementia and provide respite for caregivers.

*Online help was edited by Lily Huang, a rising junior at Duke University and work-study student at the Duke Family Support Program.*